DOCTOR OF PHILOSOPHY

Development and evaluation of an online mindfulness-based intervention for people living with endometriosis and/or adenomyosis

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Development and Evaluation of an Online Mindfulness-Based Intervention for People Living with Endometriosis and/or Adenomyosis

By

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Certificate of Ethical Approval

Applicant:

Clair Dempsey

Project Title:

Systematic Review of Non-pharmacological (psychological)interventions for women experiencing chronic pelvic pain.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

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Glossary

Term	Definition
Adenomyosis	Adenomyosis affects solely the uterus and is often described as a sister condition of endometriosis, due to the similarity in presentation. Adenomyosis affects the ‘normal relationship between the basal endometrial layer (lining of the womb) and the myometrium (middle layer of the womb). The myometrium is disrupted, pockets of endometrial glands and stroma end up within the myometrium.
Chronic pelvic pain	Chronic pelvic pain is any pain in the lower abdomen or pelvis that lasts for more than 6 months.
Dysmenorrhea	Painful periods.
Danazol	An androgen similar to testosterone. A gonadotrophin inhibitor.
Dyspareunia	Pain during/after sex.
Dysuria	Painful urination.
Endo belly	Abdominal swelling experienced by people living with endometriosis and/or adenomyosis.
Endometriosis	Endometriosis is a medical condition where endometrial-like tissue is found outside the uterus, primarily on the pelvic peritoneum, ovaries and rectovaginal septum and in rare cases on the diaphragm, the membranes lining the thorax and enveloping the lungs (pleura) and the membrane enclosing the heart (pericardium). Has been found in every organ.
EHP-30	Endometriosis Health Profile 30. A 30 item measure of quality of life for people living with endometriosis and/or adenomyosis. The five domains are: pain, power and control, emotional wellbeing, social support and self-image
FFMQ	Five Fact Mindfulness Questionnaire. A 36 item questionnaire that measures the five facets of mindfulness: observe, describe, acting with awareness, non-judgement of inner experience and non-reactivity of inner experience.
Fibroids	The most common gynaecological condition. Non-cancerous growths that develop in or around the uterus.
GnRH agonists	Gonadotropin-releasing hormone agonist. A type of medication that affects gonadotropins and sex hormones. Supresses ovarian activity and induces a hypoestrogenic state.

Hysterectomy	A surgical procedure to remove the uterus. Cervix, fallopian tubes and ovaries may also be removed. Can induce surgical menopause.
IBS	Irritable Bowel Syndrome. Common condition that affects the digestive system. Symptoms include: stomach cramps, bloating, diarrhoea and constipation.
Laparoscopy	Can be used for diagnostic purposes or to perform minimally invasive procedures. Surgeon makes one or more small incisions in the abdomen. This allows for insertion of the laparoscope (small tube with a light source and camera), surgical tools and a tube used to pump gas into the abdomen.
Menorrhagia	Heavy periods
Metrorrhagia	Irregular periods
Mindfulness	The awareness that arises from paying attention, on purpose, in the present moment and non-judgementally. Includes the practice of meditation.
Quality of Life (QoL)	The standard of health, comfort and happiness experienced by an individual or group.
Self-Management	Management of or by oneself, the taking of responsibility for one’s own behaviour and wellbeing.

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Abstract: The Development and Evaluation of an 8-week Online Mindfulness-Based Intervention (The Phoenix Course) Designed to Improve the Quality of Life for People Living with Endometriosis and/or Adenomyosis.

Background: Endometriosis and adenomyosis are common health conditions, with symptoms including debilitating chronic pelvic pain, painful, heavy periods, fatigue and painful sex, urination and bowel movements. The average time to diagnosis is 7.5 years. People with these health conditions report that their symptoms impact their quality of life and mental health negatively. The delay in diagnosis, lack of treatment options and challenging encounters with healthcare professionals can also lead to symptoms of anxiety and depression. People living with endometriosis and adenomyosis often spend a lot of time, effort and money on self-managing their symptoms, intending to reduce the impact on their mental health and improve quality of life.

Objective: Follow the Medical Research Council guidelines to develop and evaluate a complex psychological intervention tailored to people living with endometriosis and/or adenomyosis and improve their quality of life.

Design: The Phoenix Course was designed and evaluated by conducting three inter-related studies: a mixed-methods systematic review, a participatory action research needs assessment, and a feasibility randomised controlled trial.

Methods: A mixed-methods systematic review was conducted to identify and review the effectiveness of existing non-pharmacological, non-surgical interventions to improve the quality of life for people living with endometriosis and/or adenomyosis. There were 13 quantitative and 0 qualitative studies included in the review. The needs assessment was conducted using photovoice, a participatory action approach, with a feminist underpinning that uses photography to capture lived experience. Theory of Change was used to develop the intervention on the online Hope platform. This intervention (The Phoenix Course) was an 8-week online mindfulness-based intervention evaluated in a feasibility randomised controlled trial. There were 45 participants in the intervention group and 53 participants in the control group. There were two facilitators in the intervention group (one a mindfulness teacher and one a Hope for the Community facilitator). The primary outcomes were recruitment rates, retention and follow up rates and adherence rates. Secondary outcomes were quality of life (Endometriosis Health Profile-30) and mindfulness (Five-Facet Mindfulness Questionnaire) scores.

Results/Findings: The systematic review found a lack of high-quality research on non-pharmacological, non-surgical intervention for people with endometriosis and/or adenomyosis. It also found that mind-body interventions had the most potential for improving the quality of life for those living with these conditions. The photovoice needs assessment identified psychological needs, unmet needs and coping strategies of people living with endometriosis and/or adenomyosis. The most prominent coping strategy was self-management. This study provided in-depth data that captured the lived experience of people with these conditions. It also produced an output of a photo book. These data were used to tailor the intervention to the needs of this population. The feasibility randomised controlled trial found positive efficacy signals in the primary and secondary outcomes that warrant a further definitive trial.

Conclusion: The results of the three interrelated studies demonstrated a unique contribution, a psychological intervention developed to meet the needs of people living with these conditions that may improve quality of life. The needs assessment also led to an output that provides a compelling perspective of living with endometriosis and adenomyosis. Future research should focus on a further trial of the intervention but also on additional uses of photovoice, including if it can be considered to be a type of intervention as well as being a research method.

Chapter 1 Introduction

This chapter provides an overview of the aim and objectives of the research presented in this thesis. This chapter also outlines the context of the thesis and a brief explanation of the themes within the thesis. The themes include the impact of adenomyosis and endometriosis, strategies employed by both those with the conditions and healthcare professions and why there is a need for a specific psychological intervention that addresses the needs of those with the conditions. This chapter also explores the research context by discussing gender and pain, user involvement in research, and mindfulness interventions in chronic pain populations, including people living with endometriosis. This chapter concludes by describing how the thesis is organised and the content of each chapter.

1.1 Aim and Objectives

The primary aim of this research was to design and evaluate a non-surgical, non-pharmacological intervention that could improve the quality of life for people living with endometriosis and/or adenomyosis. The intervention was developed and evaluated, following the guidance from the Medical Research Council (MRC) (Craig et al., 2019). The objectives of the research discussed in this thesis were guided by the MRC Guidelines and are as follow:

1. To undertake a systematic review in order to identify and evaluate the effectiveness of existing non-surgical, non-pharmacological interventions designed to improve the quality of life for people living with endometriosis and/or adenomyosis.
2. Assessment of the psychological needs and coping strategies of people living with endometriosis and/or adenomyosis to tailor the intervention to the population's needs.
3. Development of an intervention based on the data from the systematic review needs assessment and informed by relevant theory, e.g. Theory of Change.

4. Evaluation of the feasibility of the intervention (The Phoenix Course) using a Randomised Controlled Trial.

1.2 Gender and Pain

Before both endometriosis and adenomyosis can be explored in detail, it is crucial to understand the role that gender plays in both the experience and perception of pain. Consideration should be given to how the construct of gender plays a role in health conditions that are seen as 'women's issues' and the expression and burden of chronic pain. Findings from epidemiological studies suggest that the global burden of visceral pain is significantly higher in females than males (Giamberardino, 2008). Whilst approximately 20% of adults living with chronic pain, women report more severe pain levels and chronic pain than men (Melotti, Fanelli and Sorella, 2019). However, despite experiencing more pain and more severe pain, women are less likely to receive appropriate treatment; they are at risk for undertreatment of their pain (Melotti, Fanelli and Sorella, 2019). Women with unexplained pain are also at risk of mismanagement within primary care and of experiences that negatively influence their treatment compliance, due to gender stereotypes (Clareús and Renström, 2019). Health care professionals may have knowledge gaps when it comes to treating symptoms of pain in women and may also not listen to female patients or consider that their pain is psychological or not real (Braksmajer, 2018, Driscoll et al., 2018).

The next section explains the symptoms of both endometriosis and adenomyosis, one of these symptoms is painful sexual intercourse. Many women have sought medical treatment when they have experienced painful sex (Braksmajer, 2018). However, medical encounters may become a tug of war between healthcare professionals and patients, when patients feel their experiences of illness are not granted legitimacy (Braksmajer, 2018). Women seeking medical treatment for painful sex believe that healthcare professionals would relieve uncertainty about the cause of pain, provide diagnosis and treatment and permit them to avoid sexual activity (Braksmajer, 2018). When a diagnosis is not provided women report feeling that their knowledge of their own bodies was dismissed, and their symptoms were seen as psychological (Braksmajer, 2018). Many women believe that their medical examinations and assessments are influenced by the subjective assumptions reflecting gendered psychopathology, thought to underlie unexplained pain in women (Braksmajer, 2018). Instead, women fight for objective medicalisation of their symptoms, which they see as the opposite of gender bias. (Braksmajer, 2018). It was found that women seek validation from healthcare professionals as evidence of illness rather than their subjective claims of incapacity due to unexplained pain (Braksmajer, 2018).

When women's pain is more likely than men's to be assessed as non-specific, functional or somatoform (NFS), their rehabilitation may be prolonged as valid alternative diagnosis and treatments are not pursued and their negative encounter with healthcare professionals lower the chances of them complying and persevering with treatment (Clareús and Renström, 2019). It has been suggested that external factors such as gender bias and gender-based stereotypes are added to the bio-social-cognitive-psychological models (Clareús and Renström, 2019). This may provide a more inclusive and representative understanding of the higher prevalence of pain in women compared with men (Clareús and Renström, 2019).

There are several ways that gender bias impacts the management of patients in healthcare settings. Severely injured women are less likely to be directed to a trauma centre and women are less likely than men to be admitted to Intensive Care Units and receive life supporting treatment than men and they are more likely to die after a critical illness (Mackey and Diercks, 2018). Gender bias has also been identified in the use of cardiovascular investigation and evidence-based treatment (Mackey and Diercks, 2018). Illnesses that are more common in women are often poorly understood by health care professionals (Driscoll et al (2018). It has been found that healthcare professionals often disregard or disbelieve women's symptoms of pain, these symptoms are often seen as aa mental health problem (Driscoll et al., 2018).

Women may be perceived by others to experience more pain than men and both genders may also underestimate pain in others (Robinson and Wise, 2003). However, it has been found that men showed an even greater underestimation of pain in others, men also based their ratings of pain on their gender role expectations (Robinson and Wise, 2003). It was found that estimates of patients' pain and judgements of their pain expression, were impacted by the characteristics of the observer and of the patient (Schäfer et al, 2016). While trustworthiness had no main effect on pain estimates or judgements but interacted with gender, showing pervasive bias (Schäfer et al, 2016). Women who were considered to be of low trustworthiness were estimated to have less pain and to be more likely to exaggerate it (Schäfer et al, 2016). In this study men were more likely to be recommended analgesics and women to be recommended psychological treatment (Schäfer et al, 2016).

The literature discussed in this section illustrates the context and bias around the perception and experiences of women in pain. Awareness of the reality of gender bias is important both in research and clinical practice, to counteract the bias and to support healthcare professionals in providing more equitable care that is able to meet the needs of all patients (Samulowitz et al., 2018). The concept of 'andronormativity' implies that men and masculinity dominate healthcare to such an extent that women and femininity become invisible (Samulowitz et al., 2018). This concept is apparent when considering the experiences of patients with endometriosis, the delay in diagnosis, how patients are perceived and treated by healthcare professionals and the work women must put it to be taken seriously as a patient living with health conditions that are primarily diagnosed in women or those assigned female at birth.

1.3 Symptoms of Endometriosis

Endometriosis is a medical condition where endometrial-like tissue is found outside the uterus, primarily on the pelvic peritoneum, ovaries and rectovaginal septum and in rare cases on the diaphragm, the membranes lining the thorax and enveloping the lungs (pleura) and the membrane enclosing the heart (pericardium) (Guidice, 2010). It has been estimated that 10% of women worldwide have endometriosis, that's 176 million worldwide and 1.5 million in the UK, similar to the number of women affected by diabetes (Rogers et al., 2009, Horne and Pearson, 2018, Diabetes UK, 2019). It can take an average of 7.5 years from first experiencing symptoms to receiving a diagnosis, and it is estimated that endometriosis costs the UK economy £8.2 billion every year (treatment, loss of work and healthcare costs) (Simoens et al., 2012). Symptoms of endometriosis include pelvic pain, painful periods (dysmenorrhea), heavy periods (menorrhagia), irregular periods (metrorrhagia), pain during or after sex (dyspareunia), infertility, painful bowel movements, painful urination (dysuria), fatigue and painful ovulation (Endometriosis UK, 2019). Pain may be present before or during menstruation, intermittently or constant. Endometriosis has been estimated to cause chronic pelvic pain in women in 30-87% of cases and present in as many as 47% of women struggling with infertility (Chung et al., 2002, Meuleman et al., 2009).

1.4 Symptoms of Adenomyosis

Adenomyosis affects the uterus solely and is often described as a sister condition of endometriosis due to the similarity in presentation. Adenomyosis affects the 'normal relationship between the basal endometrial layer (lining of the womb) and the myometrium (middle layer of the womb). The myometrium is disrupted, pockets of endometrial glands and stroma end up within the myometrium (Hulka et al., 2002). The most common symptoms of adenomyosis are heavy, prolonged periods, severely painful periods, abdominal pressure and bloating (Mayo Clinic, 2019). Abnormal uterine bleeding and painful periods may occur in approximately 62% of those with adenomyosis (Ferenczy, 1998, Bragheto et al., 2007). Chronic pelvic pain has been reported in around 77% of women diagnosed with adenomyosis (Shrestha et al., 2012).

There is an overlap in reported symptoms of endometriosis and adenomyosis. They were considered the same disease until 1925, when Frankl first used 'adenomyosis' to differentiate between a condition occurring inside and outside the womb (Frankl, 1925). It has been estimated that around 27% of women with endometriosis also have adenomyosis (Bazot et al., 2006). In women who underwent a hysterectomy, 20.9%

were found to have adenomyosis (Naftalin et al., 2012). The co-occurrence rises when infertility is an issue, it has been found that in women with endometriosis who are infertile, 70% also had adenomyosis (Kunz et al., 2005). There may be a correlation between a diagnosis of deep infiltrating endometriosis (the most severe) and adenomyosis (DiDonato and Seracchiolo, 2014). Unfortunately, less research appears to have been conducted on adenomyosis on its own, and there aren't as many statistics as possible available regarding the prevalence and financial cost.

1.5 Diagnosis and Management

Endometriosis is only definitively diagnosed by laparoscopy; ultrasound and MRI are unreliable diagnostic methods (Horne and Pearson, 2018). Whilst adenomyosis may be suspected during laparoscopy; historically, it is only diagnosed after a hysterectomy (Tsui et al., 2014). The symptoms of endometriosis and adenomyosis are often similar, as are the methods used to manage the conditions. There are many treatment options available that aim to manage and reduce the range of symptoms. Surgical treatment (laparoscopic ablative or excision techniques, surgical resection, hysterectomy, bilateral oophorectomy) aims to remove to reduce the disease. Pharmacological treatment aims to suppress symptoms such as pain with analgesia (over the counter pain relief or prescriptions such as opioids and anti-inflammatories) or painful and heavy periods with hormonal therapy (combined contraceptive pill, GNRH agonists, IUD and Danazol). Surgery may have risks and significant recovery time. Pharmacological treatments often come with side effects. It is critical to clarify that whilst a hysterectomy may provide relief for adenomyosis; it will not treat endometriosis. Surgeons may use extra either ablation or excision surgical techniques to remove endometriosis. Excision is often chosen over ablation to preserve as much of the ovary and lower the risk of recurrence (Horne and Pearson, 2018). Even if all endometriosis tissue is removed, reoccurrence of symptoms may occur in up to 30% of women within five years (Horne and Pearson, 2018). There is a clear need for those living with chronic pelvic pain to have access to a multidisciplinary team involving medics, pain specialists, physiotherapists, clinical psychologists and sex therapists to maintain a good quality of life (Robb and Mahmood, 2013).

The diagnosis and management of endometriosis and adenomyosis can be a complex journey, challenging for patients and healthcare providers (Grundstrom et al., 2017). As both conditions involve symptoms that appear similar to dysfunctional menstruation, they are often normalised or trivialised by patients themselves, those around them and this is reinforced by healthcare professionals (Culley et al., 2013, Seear, 2009, Grundstrom et al., 2017). If women have always experienced periods as painful from their first period, they may have accepted this as usual. The average delay between onset of symptoms and help-seeking behaviour is 3.8 years (Culley et al., 2013). Women may find it challenging to know when to approach healthcare professionals about their symptoms (Grundstrom et al., 2017). A few factors are contributing to this delay. Women may feel embarrassed or uncomfortable discussing their symptoms; however, societal norms may also play a part. Women may discuss and compare their symptoms with other women, who may normalise their experience and act as a deterrent when expressing their perception of period pain (Denny, 2004a). Once painful periods have been accepted, as usual, they may be seen as something that just needs to be endured, particularly in adolescents (Culley et al., 2013). Women may find it difficult to distinguish between 'normal' periods and symptoms of a medical condition because they may see themselves as 'unlucky' rather than 'unwell'. They may be fearful of disclosing symptoms due to embarrassment and being labelled 'weak' (Cox et al., 2003b, Ballard et al., 2006). Suppose painful periods are considered to be the norm. In that case, it becomes difficult to tell the difference between period pain and a medical condition that causes chronic pelvic pain and painful periods (Horne and Pearson, 2018).

1.6 Delay in Diagnosis

When women decide to approach healthcare professionals, usually their General Practitioner, for advice and help, they often find they have to argue that their symptoms are not typical. Women living with symptoms of endometriosis and or adenomyosis often encounter misdiagnosis, mismanagement, feel like their symptoms are trivialised or ignored (Ballard et al., 2006). There is an average delay in diagnosing endometriosis of 6.7 years and 7.5 years in the UK (Nnoaham et al., 2011, Endometriosis UK, 2019). There are no statistics available for the diagnosis of adenomyosis. The delay is longer in women with more pelvic symptoms such as chronic pelvic pain, painful periods, and painful urination with a higher BMI (Nnoaham et al., 2011). Delays are found to be common at the primary care level and reflect resistance to referral to gynaecologists or other specialists (Culley et al., 2013). Healthcare professionals also contribute to the normalisation of painful periods. Many women are told their symptoms are 'normal', 'in their head' or are diagnosed with other conditions such as irritable bowel syndrome (IBS), fibroids primary dysmenorrhea before finally being diagnosed with endometriosis and/or adenomyosis (Horne and Pearson, 2018). Another factor that may complicate diagnosis from the perspective of healthcare professionals is that symptoms of both conditions may overlap with other illnesses. Although there are recognised symptoms of endometriosis and adenomyosis, it needs to be emphasised that women report a wide variation in the symptoms. For example, women with minimal, superficial endometriosis may experience severe pain. Those with deep infiltrating endometriosis may have a minimal presentation of symptoms, only being diagnosed during investigation for infertility (Whelan, 2007).

Adenomyosis is very difficult to diagnose as hysterectomy is considered the 'gold standard' for diagnosing and treating the condition; many cases are diagnosed by pathological review retrospectively (Tsui et al., 2014). If both conditions are present, it is difficult to tell which condition is responsible for which symptoms.

1.7 Impact on Quality of Life

There are several ways that endometriosis and adenomyosis negatively impact the quality of life of those living with the conditions. Chronic pelvic pain is the most common and debilitating system of the conditions. The Royal College of Obstetricians and Gynaecologists (RCOG) has produced 'Guidelines for Management of Chronic Pelvic

Pain', in which they emphasise the difficulties that women face when living with chronic pelvic pain and the considerable economic and social burden involved. The guidelines highlight that women with chronic pelvic pain often fear their pain will be dismissed as psychological and not seen as a symptom of an underlying condition (RCOG, 2012). The guidelines also discuss delayed diagnosis and the impact this can have on women's lives. This is a complex issue that significantly affects the quality of life of women living with chronic pelvic pain caused by endometriosis and adenomyosis (RCOG, 2012, Horne and Pearson, 2018).

Those living with chronic pelvic pain caused by endometriosis and or adenomyosis suffer emotionally, psychologically, financially and socially. The effect of endometriosis on physical health-related quality of life was found to be substantial, with SF36 scores similar to those reported by women with cancer, the impact was less if women were employed and free from pelvic pain and worse with severe pain and advanced disease (Nnoaham et al., 2011). Symptoms of endometriosis, particularly chronic pelvic pain, negatively affect daily life and physical functioning, 16-61% of women experience difficulties with mobility, daily activities and self-care, 23-71% reported that symptoms made it difficult to take care of household activities and negatively impacted their relationships, childcare, energy and vitality and sport and exercise (Culley et al., 2013).

1.8 Women's Experience of Healthcare Professionals and Settings

Women with these conditions often feel upset, angry, depressed, uncertain, weak, powerless, helpless, defeated, disappointed, frustrated, exhausted, and a burden on others (Morardi et al., 2014). Women often feel they are dependent on the skill and knowledge of healthcare professionals; it has been reported that healthcare professionals lack a basic understanding of endometriosis (Grundstorm et al., 2017). The relationship between patients and healthcare professionals can significantly impact patients' quality of life and how they view their symptoms. The experience of women with endometriosis of encounters with healthcare professionals has been referred to as 'double edged', as women report either destructive (ignorance, exposure and disbelief) or constructive (feeling acknowledged and confirmed, boosting their self-esteem) encounters (Grundstorm et al., 2017). The destructive encounters involved women struggling with exposing the most private parts of their lives to healthcare professionals. Women felt that they were disbelieved, exaggerating or imagining their symptoms and had low pain thresholds (Grundstorm et al., 2017).

It is not surprising that women often report tense or difficult relationships with healthcare professionals due to delay in diagnosis or misdiagnosis. Delayed diagnosis could have severe ramifications to health as well as leading to feelings of frustration. Prolonged delays with painful symptoms can worsen the prognosis for fertility (Matsuzaki et al., 2006). It is not surprising that women feel angry at the delay, have complicated relationships with healthcare providers, and often feel vindicated when they reach a diagnosis. Their persistence pays off (Denny, 2004a, Denny and Mann, 2008). The prolonged time to get a diagnosis has led to women working to educate themselves to advocate for their health needs when they do engage with health care professionals. Self-advocacy applies to fighting for diagnosis and treatment to reduce symptoms, maintain fertility, and improve and maintain quality of life (Whelan, 2007). Healthcare professionals appear to find it difficult to diagnose endometriosis and adenomyosis. The way healthcare professionals describe and discuss endometriosis in medical literature often undermines the accounts provided by patients. Women with endometriosis are often described as nervous, irrational women who exaggerate symptoms (Whelan, 1997, 2003). There appears to be a divide between symptoms reported by patients (patient experience) and clinical signs (medical observations); pain symptoms are subjective and difficult to measure from a medical point of view (Whelan, 2007). The severity of pain symptoms may not correlate with the observable extent of the condition. Patient and health care professionals accounts of endometriosis may contradict one another (Whelan, 2007). The subjectivity of the patients' experience may be contrasted by a lack of objective confirmation, which may lead to others, including healthcare professionals, to doubt the patient's reality of the experience (Whelan, 2007).

1.9 Recurrence of Symptoms and Long-Term Management

Once women have realised that their pain is not normal, they then have to seek help from healthcare professionals. Seeking help from healthcare professionals often involves patients having to advocate for a diagnosis and appropriate treatment. From the patient's perspective, this process of seeking help, diagnosis, and treatment can be experienced as 'double-edged'. For example, diagnosis and excision surgery could reduce symptoms and no need for further hormonal treatment or pain relief. However, patients may be advised to have a hysterectomy with medication, side effects and additional health concerns. As previously mentioned, appropriate treatment may take the form of diagnostic laparoscopic surgery, including ablation or excision of endometriosis tissue/cysts, pain relief and hormonal therapy. There is no cure for endometriosis, whilst a hysterectomy may cure adenomyosis. There are also no drugs designed to treat these conditions specifically. Hormonal therapy means patients are prescribed medication intended to fake pregnancy or menopause, to mask/reduce symptoms, particularly prolonged, painful and heavy periods.

Treatment for endometriosis and adenomyosis can positively and negatively impact a woman's quality of life. Surgery may involve the removal of cysts or lesions, which may reduce symptoms and preserve fertility but may also include the removal of organs such as ovaries, fallopian tubes or uterus. Hormones may relieve symptoms and have side effects such as weight gain or depression and aren't an option if pregnancy is a goal. Pain relief may include over the counter medicine such as paracetamol and ibuprofen but may also include prescriptions for opioid-based medication. Opioid based medication also comes with side effects such as constipation, drowsiness and, if long term, risk of dependence or addiction. Women may feel dissatisfied with their body image due to weight gain, scars from surgery, pallor due to heavy bleeding and anaemia (Moradi et al., 2014). Suppose the women have undergone surgically induced menopause and the resulting changes. In that case, they may also avoid going out in public when feeling unwell or low in mood and reassess their attractiveness criteria (Pearce et al., 2014).

Unfortunately, women have been offered hysterectomies to stop the symptoms of endometriosis, which is often unsuccessful unless adenomyosis is also involved. Recurrence of endometriosis post-hysterectomy is as high as 62% in advanced stages of endometriosis in which ovaries are conserved (Rizk et al., 2014). There are cases when the uterus and ovaries have been removed, and endometriosis tissue has been left behind and is responsible for persistent symptoms. For many years, this was standard practice, as it was incorrectly believed that endometriosis tissue would atrophy in the absence of estrogenic stimulation (Sampson's theory) (Rizk et al., 2014). There is a lower recurrence rate with complete removal of all endometriosis tissue at the time of hysterectomy (Rizk et al., 2014).

1.10 Painful Symptoms and Psychological Impact

The picture painted above illustrates the challenges those living with physical symptoms of endometriosis and adenomyosis face and the healthcare professionals who provide them with care. Painful symptoms, delayed diagnosis, painful surgery, fear of the future, side effects and fertility concerns all have a psychological impact on those living with the conditions. Diagnosis and treatment do not always mean the end of a painful journey but the beginning of a new one. The psychosocial consequences of endometriosis have been listed as: reduced health-related quality of life, impaired educational achievement and professional activity, perturbed body perception/female identity, difficulties in partnership, realising the wish for children and further social contact, limited performance of leisure activities, disturbances of role performance/physical functioning, diminished self-esteem, sexual disorders, reduced control over life, limited perspectives for the future, psychosomatic and psychiatric symptoms: depression, aggressiveness, fear and or anxiety (Guidice, Johannes, Healy, 2012). Emotional wellbeing can be drastically impacted; emotional distress may be a key feature of living with endometriosis and feelings of hopelessness, isolation, worthlessness, depression, and suicide ideation (Culley et al., 2013). Even after medical and surgical intervention, women may still suffer from pelvic pain, indicating the need for a different approach than what is currently offered to patients. This approach that would integrate the medical, psychosocial, and sexual elements of healthcare and engage with patients in a collaborative journey towards self-management may be what is needed (Engeler et al., 2013).

It should be clarified that the above paragraphs mainly refer to literature discussing endometriosis only. There is very little literature on adenomyosis, and the term 'endometriosis' often refers to both endometriosis and adenomyosis, as the symptoms are similar. However, the symptoms are similar the treatment may not be.

1.11 Expert Patients

So how do women navigate the physical and emotional burdens that come with living with these conditions? Women have become 'expert patients' and use the internet to educate and help themselves. This work has been described as a 'third shift' performed in addition to paid and unpaid work (Seear, 2009b). Becoming an expert patient with endometriosis can reduce and add to existing stress (Rimke, 2000). Women come together and are inspired to become experts in their illness in the face of the uncertainty they experience (Seear, 2009b). While women work to research their conditions and symptoms and alleviate their suffering, medical and surgical management of the conditions is not entirely satisfying. Women may have to go through multiple treatments when trying to reduce symptoms, including several hormonal treatments, fertility treatments and, for most, at least one surgical intervention. Despite this, most women with endometriosis are still not symptom-free (De Graff et al., 2013). It has been recommended that to improve the quality of life for these women, medical care should also address the emotional, sexual, and social impact of the disease (De Graff et al., 2013).

1.12 Self-Management and the Need for More Comprehensive Support

Women often turn to self-management strategies to manage the physical symptoms and psychological impact of endometriosis and adenomyosis. Living with chronic pain may cause chronic stress, leading to inflammation, more pain and depression (Bertero et al., 2019). Healthcare professionals and patients desire a biopsychosocial approach to endometriosis diagnosis and management; this approach should combine the physiological, psychological, social, sexual, and spiritual (Bertero et al., 2019). The patients want to be seen as more than a 'biomedical defect object'; however, many physicians have explained that they cannot adopt a biopsychosocial perspective on their own and suggested the involvement of other physicians to form a multidisciplinary team (Bertero et al., 2019). This finding supports the treatment and care suggestions made by NICE (2017) guidelines. They state that women with endometriosis can have significant physical, sexual, psychological, and social impact and may have complex needs and recommend that women have access to a multidisciplinary team for treatment. The NICE (2017) guidelines also that healthcare professionals should inform patients of local support groups, online forums, and national charities and how to access them. The guidelines also state that research should aim to provide evidence-based options to support self-management of endometriosis (NICE, 2017).

Self-management plays an essential role in managing symptoms of endometriosis and adenomyosis and attempting to limit the impact of symptoms on everyday life, including emotional wellbeing and mental health. An online survey in Australia asked 484 patients with endometriosis about their self-management strategies (Armour et al., 2019). Self-management strategies used include heat (70%), rest (68%) and meditation or breathing exercises (47%). The women also reported using negative strategies with associated adverse events such as alcohol/hangover (538%), exercise/increased pain (34%), heat/burns (16%). The authors concluded that effective self-management strategies and lifestyle changes can play an essential role in managing symptoms and may 'empower' patients to take more control over their health and provide an effective add-on to their current treatment. They also stressed that patients with endometriosis have unique needs and self-management practices need to be considered in light of the potential for flare-ups (Armour et al., 2019). This study highlights the need to assess adverse events of any intervention or self-management strategy, as even helpful strategies such as heat can also have adverse events/effects (burns). NICE (2017) added an update to their guidelines in 2019, stating that there was a lack of high-quality research on the effectiveness of lifestyle interventions for endometriosis, such as diet or exercise and other non-medical treatments in reducing pain fatigue and other symptoms. The guidelines also state that supporting self-management is 'critical' to improving the quality of life for those living with endometriosis and adenomyosis.

Comprehensive self-management courses, both face to face and online, have shown benefits to people living with chronic health conditions, including chronic pain (Mehlsen et al., 2015, Wilson et al., 2015, Riva et al., 2014; Nicholas et al., 2012). Benefits have included reductions in pain, physical disability, pain self-efficacy, pain intensity, pain interference, pain catastrophising and depression and anxiety and alter patients' feelings of empowerment and help prevent medication misuse (Mehlsen et al., 2015, Wilson et al., 2015, Riva et al., 2014, Nicholas et al., 2012). Web-based chronic pain management programs have advantages, including inexpensive to scale to provide services to more extensive and diverse populations, conveniently accessible about the clock and allow a tailored experience to specific symptoms or needs (Nevedal et al., 2013).

A self-management approach where patients are informed and supported by healthcare professionals can improve outcomes and reducing healthcare costs (Lorig and Holman, 2003, Bodenheimer et al., 2002). The components and objectives of self-management interventions might differ depending on the conditions and symptoms being address. Still, the critical feature is increasing patients' ability to deal with the day to day impacts of their condition to maintain a satisfactory quality of life (Barlow et al., 2002). However, self-management interventions are not straightforward; they are not a 'one size fits all' solution like pharmacological or surgical options for treating endometriosis and adenomyosis (Trappenburg et al., 2013). Complex interventions are defined as interventions with several interacting components with several dimensions of complexity (Craig et al., 2019). The complexities could be related to the range of possible outcomes, variability in the target population or the number of elements in the intervention itself (Craig et al., 2019).

1.13 Clinical Relevance

The previous section outlines the context that led to the development of the intervention that addresses the needs of those living with endometriosis and adenomyosis. There is a need for a psychological intervention in conjunction with surgical and pharmacological treatments. This section will provide further context by outlining the clinical relevance by using recommendations made in clinical guidelines.

The RCOG's guidelines are not the only set of guidelines published on endometriosis; NICE released their first set of guidelines on endometriosis in 2017, titled 'Endometriosis: diagnosis and management'. Both Endometriosis UK and the RCOG also provide links to the European Society of Human Reproductive and Embryology (ESHRE), published in 2013. The ESHRE guideline replaced the RCOG's 'Green-top guidelines N0. 24 (October 2006), minor revisions (October 2008): The investigation and management of endometriosis'.

The ESHRE guidelines are clinical guidelines that advise on the best practice for caring for those with endometriosis and suspected endometriosis. Recommendations on diagnosis, symptoms predictive of endometriosis, treatments (including non-pharmacological), surgery, and medically assisted reproduction are included. The primary target users of these guidelines are secondary and tertiary healthcare professionals.

The ESHRE guidelines provide insight into why diagnosis is often delayed; it is acknowledged that women suffering from pelvic pain are prescribed analgesics and hormonal medication without a definitive laparoscopic diagnosis. There are two explanations given: the first is the invasive nature of the laparoscopic procedure, and the second is the ease of prescribing hormonal contraceptives. The guidelines acknowledge that prescribing oral contraceptives in adolescents with pelvic pain without a definitive diagnosis might contribute to the 'well-known delay in diagnosing the disease' (ESHRE, 2013). In the section addressing the empirical treatment, the guidelines give the following recommendations: *'The Guideline Development Group (GDG) recommends clinicians to counsel women with symptoms presumed to be due to endometriosis thoroughly and to empirically treat them with adequate analgesia, combined hormonal contraceptives or progestagens'* (ESHRE, 2013). When discussing surgery as a treatment for endometriosis-associated pain, the guidelines state, *'When endometriosis is identified at laparoscopy, clinicians are recommended to surgically treat endometriosis, as this is effective for reducing endometriosis-associated pain'* (ESHRE, 2013). Prescription of hormonal therapies are not recommended pre-operatively but are post-operatively (ESHRE, 2013).

The ESHRE guidelines also discuss non-medical management strategies for the treatment of endometriosis-associated pain. The team behind the guidelines carried out literature searches investigating neuromodulation, nerve blocks, transcutaneous electoral nerve stimulation (TENS), acupuncture, behavioural therapies, nutritional supplements, expert patient programmes, recreational drugs, reflexology, homoeopathy, psychological treatment, TCM, herbal medicine, sports and exercise. The Guideline Development Group reached the following good practice point:

'The GDG does not recommend the use of nutritional supplements, complementary or alternative medicine in the treatment of endometriosis-associated pain because the potential benefits and/or harms are unclear. However, the GDG acknowledges that some women who seek complementary and alternative medicine may feel benefit from this' (EHSRE, 2013).

The guidelines encourage research into the role of complementary and alternative medicine for the treatment of endometriosis-associated pain and infertility, the psychological impact of endometriosis and how this should be addressed, patient-centred care, couple centred interventions and interventions to improve quality of life. In summary, these guidelines do not discuss the psychological impact of endometriosis or make any recommendations for this aspect of care. They discuss the use of hormonal therapy, surgery and analgesia for the reduction of pain. However, hormonal treatments are not helpful for those whose goal is pregnancy. The guidelines also recommend the use of hormonal therapy and analgesics for suspected endometriosis before a surgical diagnosis has been made, adding to the delay in diagnosis and potential progression of endometriosis and its symptoms. These guidelines provide a glimpse into how decision making is informed and what little evidence is available to healthcare professionals making decisions about what treatment should be offered to patients. Unfortunately, these are used by the Royal College of Obstetricians and Gynaecologists.

In comparison, the NICE guidelines, published in 2017, were written for women with suspected or confirmed endometriosis, their families and carers, and healthcare professionals, commissioners and providers. These guidelines are very much patient-centred, including a section on considering the whole person rather than just a set of symptoms. The guidelines recommend assessing each individual's needs, considering their circumstances, symptoms, priorities, desire for pregnancy, aspects of daily living, work and study, cultural backgrounds, and physical, psychosocial, and emotional needs. The guidelines recommend that women receive information about their diagnosis, symptoms and signs, treatment options, and available support, including support groups and online forums.

The NICE guidelines recommend that a 'clinical network be set up, consisting of GPs, practise nurses, school nurses, sexual health services, gynaecology services and specialised endometriosis centres. Specialised endometriosis centres should provide coordinated care and have transparent processes for diagnosis and treatment, as delays for diagnosis and treatment can result in deterioration of quality of life and progression of the disease (NICE, 2017).

These guidelines not only acknowledge delayed diagnosis and the factors that feed into this, but they also discuss the tension between healthcare professionals and patients. The guidelines state:

'Patient self-help groups emphasise that healthcare professionals often do not recognise the importance of symptoms or consider endometriosis a possibility; in addition, patients can delay seeking help because of a perception that pelvic pain is normal. Delays of 4 to 10 years can occur between first reporting symptoms and confirming the diagnosis. Many patients report that the delay in diagnosis leads to increased personal suffering, prolonged ill-health. It also makes the disease more difficult to treat' (NICE, 2017).

These guidelines demonstrate that patients' perspective matters, unlike the previous guidelines that acknowledge the same issues yet recommend treatment without a surgically confirmed diagnosis.

Quality of life is an important factor that is considered throughout the NICE guidelines. Included in the recommendations for future research are questions that should be considered:

'pain management programmes – are they a clinically and cost-effective intervention? Is laparoscopic treatment of peritoneal endometriosis effective for managing endometriosis-related pain? Are specialist lifestyle interventions effective, compared with no specialist lifestyle intervention for women with endometriosis? And what information and support interventions are effective to help women with endometriosis deal with their symptoms and improve their quality of life?' (NICE, 2017).

Both sets of guidelines encourage research and development of interventions that aim to improve the quality of life of those living with endometriosis. Early diagnosis by laparoscopy, appropriate hormonal treatment, and pain relief are needed, in conjunction with psychological interventions that aim to listen, validate experiences, and improve quality of life overall.

A systematic review of two international and five international sets of guidelines on diagnosing and managing endometriosis was conducted. Included in the results were publications up until February 2016. Therefore, the NICE guidelines were not included. The ESHRE guidelines were evaluated as the highest quality set of guidelines. There was substantial variation between the supporting evidence used in the individual guidelines to make recommendations. Forty-two recommendations were not supported by research evidence. The authors of the review recommended that future guidelines be developed used high-quality methods in consultation with key stakeholders, including patients, to guarantee that the recommendations can inform clinical practice and put an end to unwarranted, unjustified variations in clinical practice (Hirsch et al. 2017). It appears that NICE have used just this approach to develop their guidelines.

The development of a psychological intervention designed to help improve the quality of life of those living with the painful symptoms of endometriosis and adenomyosis needs to be built on a solid evidence base that includes empirical findings and input directly from those the intervention is designed for. Only then will the intervention be fit for purpose from the perspective of both healthcare professionals and patients with the conditions.

1.14 Chronic Pelvic Pain and Mindfulness

Mindfulness-based interventions have been shown as an effective self-management option for people living with chronic health conditions. Mindfulness-Based Stress Reduction is an 8-week course originally developed and facilitated by Jon Kabat-Zinn at the Stress Reduction Clinic at the University of Massachusetts Medical Centre in 1979

(Kabat-Zinn, 1982, 2013). It was designed to treat patients who had not responded to tradition treatment for their chronic health conditions and had ongoing poor health (Kabat-Zinn, 2013). The 8-week course provides mindfulness meditation training, in 2-3 sessions and often includes a day long intensive or silent retreat day at the end of the course. MBSR courses include group discussion, known as inquiry and attendees are encouraged to be curious, aware, non-judgmental, and accepting of their experiences of their health conditions and everyday life.

There are a few published studies that investigated the use of mindfulness as an intervention for women living with endometriosis. A pilot study investigating an MBSR course intervention for chronic pelvic pain found improvement in quality of life and ability to manage pain (Fox et al., 2008). This pilot study was also a clinical treatment, and no control group was used. However, they also found that 4 weeks of mediation was not enough to cause an improvement, all 8 weeks of the course had to be completed to see an improvement in scores. They encouraged further research into using mindfulness as an intervention for women with CPP, as it is safe to use and is reasonable in cost. Another study also used a modified version of the MBSR 8-week course for women with endometriosis, the results reported a complex pattern but positive effects on pain level, improvement in physical health and quality of life but no improvement in sexual function or mental health (Kold et al., 2012). This study also didn't use a control group, nor did they use a measure of mindfulness skills or traits. In a follow up to this study the authors found that 12 months after the intervention there were lasting significant improvements in pain, control and powerlessness, emotional wellbeing, and social support. Between the 12 months and 6 year follow up there were further improvements but these were not found to be statistically significant (Hansen et al., 2016). A recent systematic review of psychological mind-body interventions for endometriosis, including yoga, mindfulness, relaxation, CBT with physical therapy, Chinese medicine with psychotherapy and biofeedback. (Evans et al., 2019) The results of this review found that psychological mind-body interventions for endometriosis appear promising for endometriosis-related pain, anxiety and depressive symptoms, stress, and fatigue. All the above studies recommend further research, more thorough research using active control groups to investigate where mindfulness-based interventions can be of benefit to those living with endometriosis and adenomyosis by improving quality of life.

The Phoenix course is an 8-week, online mindfulness-based self-management course designed in consultation with women living with endometriosis and adenomyosis. It was designed following the Medical Research Council’s guidelines for developing complex interventions (Craig et al., 2019). The main aim of the intervention is to reduce the psychological suffering that is associated with living with endometriosis and adenomyosis. This is an online course, that can be used by participants in the comfort of their own home. Participants can access the course using mobile phones, tablets, laptop or desktop computers.

1.15 Methodological Approach

A mixed-methods approach was used to conduct the research presented and discussed in this thesis. Taking a mixed methods approach to research has it emerged as a ‘third paradigm’ for social research (Denscombe, 2008). This ‘third paradigm’ has led to the development of ideas and practices that are considered credible and distinctive, that demonstrate the approach as a viable alternative to quantitative and qualitative paradigms (Denscombe, 2008). The first study in this PhD project was a mixed methods systematic review, conducted to examine the existing interventions and participants experiences of them. The systematic review investigated: What non-surgical, non-pharmacological interventions are effective at improving quality of life for women with chronic pelvic pain, and what are the experiences of women attending them? The systematic review indicated that mindfulness had the potential to the helpful for people living with endometriosis and/or adenomyosis. Another of the main findings of the systematic review was that there was a lack of qualitative research that looked at the participant or patients experience of nonsurgical, non-pharmacological interventions. The Medical Research Councils guideline on intervention development also encourages the implementation of user involvement in the development and evaluation of complex intervention (Craig et al., 2019).

A mixed-methods approach can have the capacity to intersect with other approaches such as participatory action research, by adding a sound methodological foundation and producing an integrated approach that has the potential to address complex problems (Ivankova and Wingo, 2018). The literature on the interactions between female patients, including those with endometriosis and healthcare professionals is discussed earlier in this chapter. The overall findings indicate that patients may feel that their symptoms aren't taken seriously, symptoms may be blamed on a psychological or emotional root cause or patients may be misdiagnosed. There is also an imbalance of power between patients and healthcare professionals. Therefore, it was decided that a Participatory Action Research approach would be taken when conducting the needs assessment that would help tailor the intervention. Photovoice was chosen as the research method, which is a form of participatory action research (Latz, 2017). It has been defined as: 'a process by which people can identify, represent and enhance their community through a specific photographic technique' (Wang and Burris, 1997). Participatory action research differs from more conventional research in three main ways: shared ownership of research, community-orientated understanding of social problems and propensity for community action (Kemmis and Taggart, 2005).

Participatory action researchers conduct research with participants and not on participants (Latz, 2017). The needs assessment investigated the psychological needs and coping strategies of people living with endometriosis and/or adenomyosis. The needs assessment study was vital in identifying needs, in order to tailor the intervention for the population. Combining mixed methods with action research can enhance the process of translating research findings into practice and may strengthen the study potential by combining qualitative stakeholder perspectives with evidence-based data driven quantitative outcomes (Ivankova and Wingo, 2018). It has been argued that developing an intervention that is driven by data and includes contextual details, increases the chances for better transferability of successful results to other contexts, practices and communities (Ivankova and Wingo, 2018). The active involvement of participants that the intervention will be tailored towards, helps to generate a sense of ownership an empowerment among these stakeholders and provides the basis for optimising intervention outcomes (Ivankova and Wingo, 2018).

The systematic review identified that mindfulness had the potential of being an effective intervention that would improve quality of life by address the psychological and emotional burden that those living with endometriosis and/or adenomyosis face. The needs assessment identified both adaptive and maladaptive coping strategies, needs and unmet needs. Due to the number of unmet needs the women in this study had used several self-management techniques to manage their symptoms and try to improve and maintain their quality of life. A number of these coping strategies were incorporated into The Phoenix Course.

Developing and evaluating an intervention built on a systematic and comprehensive assessment of the problems, enhanced by mixed methods research and in collaboration with participants belonging to the targeted population can help to highlight critical areas for targeted action and intervention (Ivankova and Wingo, 2018). This approach to intervention development can also help to identify solutions that are meaningful and acceptable to those affected by the issue, in this case, endometriosis, adenomyosis and the suffering caused by these conditions (Ivankova and Wingo, 2018). The final study was a randomised controlled feasibility study of The Phoenix Course, this was also designed as a mixed methods study. This study aimed to explore the feasibility of conducting a randomised controlled trial, testing the study design and the functioning of an online mindfulness-based intervention designed to improve the quality of life of people living with endometriosis and/or adenomyosis. The feasibility study examined participant engagement rates, completion rates, estimated sample size for a larger trial, participant feedback on taking part in the trial and of receiving the intervention.

1.16 Conclusion

The main body of this thesis explores the development and evaluation of The Phoenix Course, an 8 week online mindfulness-based intervention, which has been designed to improve the quality of life for people living with endometriosis and/or adenomyosis. The thesis is comprised of three main studies: a mixed method systematic review, a needs assessment conducting using photovoice; a participatory action research method and a feasibility trial of the intervention.

The following section outlines the further chapters of this thesis. This Introduction chapter has outlined the themes addressed within the research conducted for this thesis. It has also outlined the patients need for a tailored psychological intervention explicitly designed for people living with endometriosis and/or adenomyosis. Section 1.12 briefly describes the following chapters, their aims and their purpose within this thesis.

1.17 Thesis Structure

Chapter 2 Methodology

Chapter 2 presents and discusses the methodology and methods chosen and used to conduct the three research studies contained within this thesis. This chapter outlines how the Medical Research Guidelines (Craig et al., 2019) on developing and evaluating a complex intervention were incorporated into the research design. The rationale behind the choices made in the research design and alternative philosophies and research designs are discussed. The researcher's positionality is clarified, and the implications of this are discussed.

Chapter 3 Mixed Methods Systematic Review

Chapter 3 presents the results of the mixed-methods systematic review. The research question was: What non-surgical, non-pharmacological interventions are effective at improving the quality of life for women with chronic pelvic pain, and what are the experiences of women attending them? This chapter presents the search strategy, provides examples of search terms, study selection, quality assessment, data extraction, risk of bias, results, the papers identified, limitations of the review, discussion and conclusion. This chapter also explains how the findings of this review contributed to the development of the intervention.

Chapter 4 Needs Assessment

Chapter 4 presents the results of the needs assessment. The research question was: What are the psychological needs and coping strategies of people living with endometriosis and/or adenomyosis? This chapter discusses the rationale behind choosing a Participatory Action Research Approach. It also describes the method, findings, discussion, limitations and concludes with the needs and coping strategies identified and how they were used to tailor the intervention.

Chapter 5 Intervention Development and Feasibility Trial

Chapter 5 provides further information on how the intervention was developed, the theory that informed the development of the intervention and the details and results of the feasibility study. The intervention that was developed was an 8-week online mindfulness self-management intervention called The Phoenix Course. There were 98 participants recruited who were assigned to either the intervention group or the waitlist control group. This chapter provides details on the intervention and the feasibility study, including the method, results, limitation, discussion and conclusion. This chapter also contains recommendations for future research.

Chapter 6 Discussion

As this first chapter introduces the aims and objectives of the research contained in this thesis, this final chapter discusses how the aims and objectives of the research were met. This introduction chapter also provides context for the research contained within this thesis, the final discussion chapter explores the context surrounding the findings of the research and the unique contribution that the research findings make to this field of research. Future research, clinical relevance and recommendations are also discussed.

Chapter 2 Methodology

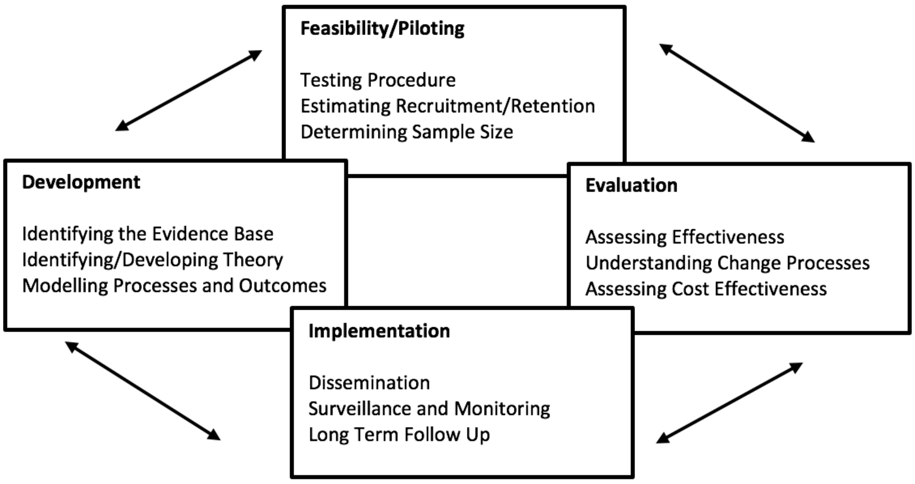
2.1 Overview

Chapter one (Chapter 1 Introduction) introduced the research area and a brief overview of each chapter to come. It also described the complexities contributing to the poor quality of life experienced by those living with endometriosis and/or adenomyosis. The purpose of this chapter is to explain the research methods chosen to implement the Medical Research Council's guidelines on the development of a complex intervention (Craig et al., 2019). It also provides the rationale for taking a feminist approach to mixed methods research, including considerations of positionality when conducting 'insider research'. This chapter also introduces the research methods used in developing and evaluating a complex intervention designed to improve the quality of life for people living with endometriosis and/or adenomyosis.

2.2 Research Aim, Research Questions, Objectives and Design

This thesis presents the research process undertaken to develop and evaluate a complex intervention designed to improve the quality of life of people living with endometriosis. The Medical Research Council has provided guidelines on developing and evaluating various interventions, including psychological-based intervention (Craig et al., 2019). There were three stages undertaken during the development process of the intervention. Each of these stages had a different research question, aims, objectives and design. Below is a diagram showing the process recommended by the Medical Research Council to develop and evaluate a complex intervention.

Figure 2.1 The process recommended by the Medical Research Council for developing and evaluating a complex intervention (Craig et al., 2019).



2.3 Aim

To develop and evaluate an 8-week online mindfulness-based intervention designed to improve the quality of life for people living with endometriosis and/or adenomyosis.

2.4 Research Questions

Systematic Review

What non-surgical, non-pharmacological interventions are effective at improving quality of life for people living with endometriosis and/or adenomyosis? What are the experiences of people attending them?

Needs Assessment

What are the psychological needs and coping strategies of people living with endometriosis and/or adenomyosis?

Feasibility Study

Is The Phoenix Course a feasible and acceptable mindfulness-based intervention for people living with endometriosis and/or adenomyosis?

2.5 Objectives

2.5.1 Development

- To identify the evidence base by systematically reviewing existing non-pharmacological, non-surgical interventions for effectiveness. This step was used to determine what type of intervention(s) could improve the quality of life for those living with endometriosis and adenomyosis.

- To identify/develop theory, this refers to the needs assessment and the theory identified that would enable the development of the complex intervention. The needs assessment was conducted to tailor the intervention to the needs of the target population and identify any coping strategies that could be incorporated. The theory identified as helpful in developing the intervention was Theory of Change (De Silva et al., 2014).

2.5.2 Evaluation

- To test the procedure by conducting a feasibility study of the complex intervention developed using Theory of change and tailored to the needs of people living with endometriosis and/or adenomyosis. This included examining the recruitment, retention and engagement rates. Participant feedback was also considered valuable and essential regarding recommendations for future research.

2.6 Rationale for Taking a Feminist Approach to Conducting Research

A feminist approach to research is not just about the gender of the researcher and the participants in the study. Feminist methodologies attempt to address and reduce gender bias in research and find ways to capture women's voices consistent with feminist ideals (Campbell and Wasco, 2000). A review on gendered norms around pain, and pain treatment, found that gendered norms are reflected in healthcare, and medical treatment of chronic pain is affected by gender bias (Samulowitz et al., 2018). The review also found a lack of knowledge about how gender bias manifests in pain treatment (Samulowitz et al., 2018). Chapter 1 discussed patients experience of living with endometriosis and adenomyosis and how women feel that they are not being listened to. They often have their pain normalised, and the delay in diagnosis significantly impacts their lives. Therefore, it made sense that the research was conducted using a methodology that would emphasise women's voices and attempt to meet their needs by developing an intervention.

Research conducted in New Zealand investigating if gendered matters in healthcare settings found that women are treated poorly in these settings, which has a detrimental impact on their health outcomes, including receiving a correct diagnosis (Thompson and Blake, 2020). The factors contributing to women being poorly treated in healthcare settings include female bodies being excluded from medical research (Thompson and Blake, 2020). This means that little is known about how illnesses present in female bodies or how they affect women and that symptoms and conditions in men are considered the default textbook examples (Thompson and Blake, 2020). As a result, women may face delayed diagnosis or misdiagnosis and report feeling they are not taken seriously in healthcare settings (Thompson and Blake, 2020).

In the UK, gender bias has been investigated with the NHS. Gender bias was seen as wide-reaching and deep-seated within medical schools, the NHS and society as a whole (Brown et al., 2020). This research explored medical students perceptions and experiences of gender bias within medical education in the NHS. The findings showed that women medical students were often assumed to be nurses by patients because of their gender and constantly introduced or referred to as ‘Miss’ instead of ‘Doctor’. Another example of gender bias was that whilst male changing rooms were attached to theatres, female changing rooms were connected to wards. The findings showed that despite progress regarding overt gender discrimination, the implicit bias persists, with existing positive action inadequate in promoting the advancement of women (Brown et al., 2020). However, the researchers also found that men were reluctant for increased positive action as it may disadvantage them (Brown et al., 2020).

The existence of gender bias within healthcare systems, and experienced by healthcare professionals and patients, is not a problem on the individual level but at a systemic level. The roots of gender bias in clinical work may also be found at a systemic level, in healthcare organisation, routines or distorted content in established medical knowledge (Hamberg, 2008). There is evidence that women are not offered the same treatment as men and are less likely to receive more advanced diagnostic and treatments (Hamberg, 2008). This occurs in health conditions that can affect both men and women, such as cardiovascular conditions. A review of cardiovascular care in the NHS showed that South Asian populations had higher access, Black populations lower and that women and older aged patients are consistently associated with inequality in cardiovascular care (Asthana et al., 2016). Women were found to delay help-seeking for longer than men and were less likely to undergo detailed risk factor assessment for cardiovascular disease, even when presenting with identical symptoms (Asthana et al., 2016). The authors also found that while gender differences in prescribing were mixed, evidence of gender inequity in specialist interventions was solid and consistent (Asthana et al., 2016). The authors highlight the need to improve access and quality of care for women at all healthcare system levels (Asthana et al., 2016).

The research findings illustrate that women may experience gender bias and discrimination when they try to access healthcare. However, this barrier increases when women attempt to get diagnosed with and treatment for health conditions that are typically seen as only affecting women or those assigned female at birth. Women report different experiences to men regarding pain, chronic pain and discussing treatment options with healthcare professionals (Pryma, 2017, Hoffman and Tarzian, 2001). Women often have their pain diagnosed as having a psychological cause, and that compared to men, women have more pain, it is more acceptable for women to be in pain, and more women are diagnosed with chronic pain (Samulowitz et al., 2018).

Research examining the language clinicians use to construct medicine and women with endometriosis and whether they endorsed or challenged associated historical discourses (Young et al., 2018). This study found that medicine was largely supported as being the authoritative knowledge of the body and as providing answers and 'doing something' to the body (Young et al., 2018). Women with endometriosis were seen by clinicians as reproductive bodies and placed within the hysterical discourse, particularly when discussing difficult patients (Young et al., 2018). Whilst some clinicians found women's experiential knowledge of their condition useful, others excluded this knowledge completely. Again, the bias found in this research was not due to the practice of individual clinicians but produced by the medical culture and the patriarchal society (Young et al., 2018). The authors conclude: *'Women are entitled to healthcare that is fundamentally based on them as a whole person rather than reproductive bodies with hysterical minds'* (Young et al., 2018).

From a patient perspective, women were often wary of doctors' social status and power to reduce their wellbeing through medical labels they did not identify with or by inhibiting their access to care (Young et al., 2020). The women in this study navigated knowledge and power within the medical encounter related to their endometriosis, balancing their lived experience and expertise with doctors' clinical expertise (Young et al., 2020). The findings demonstrate the need for medical education to equip medical professionals with the skills to acknowledge women's knowledge of their bodies, symptoms and medical conditions (Young et al., 2020). The diagnostic process for endometriosis typically takes 5-10 years, indicating that healthcare professionals need higher 'suspicion' for this condition (Huntington and Gilmour, 2005). Women have also reported no formal long-term pain management to follow up after diagnosis and treatment, meaning women seek out information on their own to help them manage their pain (Huntington and Gilmour, 2009). Women with endometriosis report feeling disbelieved that they were exaggerating or imagining their symptoms and were told they had low pain thresholds (Grundström et al., 2017). Women with endometriosis may live with debilitating pain, fears over their fertility, and worry about navigating the healthcare system. This can take a toll on mental health (Morardi et al., 2014, Culley et al., 2013, APPG on Endometriosis, 2020).

There is evidence of gender bias existing within the healthcare system that negatively impacts women when they seek diagnosis, treatment and how they are treated by healthcare professionals. Women are still seen as having 'hysterical minds' (Young et al., 2019), and their physical symptoms are viewed as psychological. Women with endometriosis experience this gender bias as delay in diagnosis, no long term follow up after diagnosis and report medical professionals not being educated on their condition (Grundström et al., 2017). Women with endometriosis may face being seen as a ‘reproductive body’ (Young et al., 2017). This can also affect the treatment they are offered, balancing pain relief with desire for children.

Therefore, it seemed appropriate to take a feminist approach to designing and conducting the research studies discussed within this thesis. To develop an intervention that could meet the psychological needs of people living with endometriosis and/or adenomyosis patients, voices and experiences needed to be recognised and included in the research. A feminist approach was chosen as feminist methodologies attempt to address and reduce gender bias in research and find ways to capture women’s voices consistent with feminist ideals (Campbell and Wasco, 2000).

2.7 A Feminist Approach to Mixed Methods

A mixed-methods approach was taken to conduct the research discussed within this thesis. A range of research questions and issues had to be answered and considered whilst developing a complex intervention for a specific health condition that is diagnosed mainly in women and those assigned female at birth. Deciding on using a mixed-methods approach allows for flexibility that enables the researcher to be responsive to various issues and opens up a range of choices for research methods (Dures et al., 2010). Philosophy drives the methodology of an approach; it underpins all aspects of the research process, including aims, methods, results, and data analysis (Creswell, 2018). Mixed methods researchers value collecting data using a range of methods whilst appreciating that they are situated within an epistemological framework that has shaped the nature of the research question and the interpretation of the results (Dures et al., 2010).

There once was understanding in research that quantitative and qualitative approaches were opposing and incompatible paradigms used to study the social worlds (Dures et al., 2010). Research paradigms and methods are no longer viewed in such concrete, black and white terms. A research paradigm is ‘the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed’ (Kuhn 1962). Each research approach is underpinned by vastly different assumptions about the nature of reality (ontology) and ways of knowing and understanding (epistemology) (Dures et al., 2010).

The scientific paradigm is underpinned by positivism (Scotland, 2012). Its ontology assumes a rational, external world, existing independently of the researcher. This world is understood through scientific and technical progress. The scientific paradigm's epistemology seeks to reveal the working of generalisable causal laws and to present statistically verifiable facts about the world. This approach to research is quantitative, numbers-based and aims to provide models, explanations, predictions, identify empirical patterns and stereotypes (Scotland, 2012). This approach is often considered to be objective, explanatory and universal. Quantitative research methods test objective theories by examining the relationship among variables (Creswell and Creswell, 2018). Examples of quantitative research designs are experimental, nonexperimental such as surveys and longitudinal studies. Quantitative research studies are valuable and useful due to large sample sizes and reliance on objective, measurable data. In healthcare, randomised controlled trials are used to test interventions, including medicines, vaccines, surgical techniques, psychological interventions, public health interventions, and many others.

The interpretative paradigm's ontology is that reality is 'socially constructed'; reality does not exist independently of the researcher and the researched (Scotland, 2012). The epistemology of this approach places value on beliefs, perceptions, values, emotions and feelings. This paradigm aims for an empathic, interpretative understanding of human behaviour, contrasting with the scientific paradigm, which takes a more objective stance. Interpretative research methods attempt to see the world from the perspectives of those being researched, the participants. Unlike the scientific paradigm, this paradigm is based on interpreting texts, such as analysing transcripts of qualitative interviews and including ethnography (Creswell, 2018). This paradigm aims to interpret the meanings participants place on social phenomena to understand their lifeworld's, beliefs, and behaviour. This research approach is considered to be subjective, idiographic, inductive, qualitative and interpretative. This approach to research is valuable in the social sciences and health psychology, where a deep understanding of human behaviour is required. This approach is used by researchers aiming to study beliefs, perceptions, emotion-rich events and experiences. This type of research isn't generalisable as it concentrates on collecting rich data from a few participants. Whereas the scientific paradigm encourages a large number of participants, collecting numerical data, usually based on scales and measurements.

The third paradigm is the critical theory paradigm, which has led to various methodologies that attempt to go beyond observable behaviour and challenges taken-for-granted assumptions about the world and how it can be studied (Scotland, 2012). The ontology of this paradigm emphasises the importance of emergent properties, apparently hidden properties such as relations of power, exploitation and control, and unsettling conventional boundaries, for example, between researcher and researched (Scotland, 2012). The epistemology of this paradigm emphasises theory and critique and on the emancipation of the disempowered, with researchers recognising that no research is value-free (Scotland, 2012). Features of approaches that fall under this paradigm include an emphasis on relationships, rather than people and things in themselves, they are inherently political and critical of established orthodoxies, and these approaches focus on conflicts, inequalities and contractions in societies and economies (Scotland 2012). Unlike both the scientific and interpretative paradigms, the overall purpose of methods that fall under the critical theory paradigm is to change the world, not just explain or interpret it (Grant and Giddlings, 2002).

Examples of the approaches under this paradigm include structuralism, poststructuralism, critical realism, feminism, Marxism, post-colonialism and post-modernism. These approaches use a range of methods and data sources, including official statistics, surveys, document analysis, media analysis, interviews and participatory research techniques. Critical methodologies include critical discourse analysis, critical ethnography, action research and ideology critique (Scotland, 2012). Critical methods generate qualitative data in focus groups, open-ended questionnaires, and other methods (Scotland, 2012). Critical research methodologies advocate for dialogical relations of equality between researchers and participants and create an agenda for change or reform (Scotland, 2012).

An alternative approach to research is to employ both qualitative and quantitative research methods, to mix methods whilst conducting research. This paradigm is called the pragmatic paradigm. Pragmatism is not committed to just one system of reality, allowing researchers to draw on both quantitative and qualitative assumptions (Mackenzie and Knipe, 2006). Instead of focusing on methods, researchers emphasise the research problem and the research question and use all approaches available to understand the problem (Creswell and Cresswell,2018). Pragmatism means individual researchers can choose from a wide range of appropriate methods to meet their research work's needs and purposes (Creswell, 2018). The philosophy of pragmatism is often linked with mixed methods approaches to research (Johnson and Onwuegbuzie, 2004). Pragmatic researchers agree that research always occurs in social, historical, political contexts (Creswell and Creswell, 2018. Researchers taking a pragmatic approach will use mixed methods and turn a theoretical lens on their methodology, for example, taking an action research approach or being influenced by feminist theory (Creswell and Creswell, 2018). Mixed methods researchers have to outline the need for mixing methods, providing a rationale for why quantitative and qualitative data need to be mixed in the first place (Creswell and Creswell 2018).

There is no single feminist approach to research methods or methodology, and n distinctive and separate feminist research ‘method’, which can be advocated for and straightforwardly applied (Sampson et al., 2008). The feminist contribution to the discussion of research methods was to initially advocate for the use of qualitative research methods, to amplify the voices and experiences of women (Sampson et al., 2008). However, other feminists took the position that there was a need for quantitative research studies within feminist methodology (Kelly et al., 1994). Feminist researchers recognise that various methodological techniques are needed to help them understand women’s lives (Campbell and Wasco, 2000). Feminist research can take the form of qualitative research, quantitative research or mixed methods but they do all have in common is how the research is conducted. Feminist researchers in the social sciences have a vital concern with reflexivity, consideration of the power within research relationships, and the protection of those participating in research (Sampson et al., 2008).

It has been argued that whilst any research method can be conducted from a feminist perspective, any research method can also be misused in sexist ways (Peplau and Conrad, 1989). No research method comes with a feminist guarantee; researchers have to make an effort to reduce gender bias and be sceptical of all research methods (Peplau and Conrad, 1989). Campbell and Wasco (2000) describe the four primary features of feminist research:

1. Expanding methodologies to include both quantitative and qualitative methods.
2. Connecting women for group-level data collection.
3. Reducing the hierarchical relationship between researchers and their participants to facilitate trust and disclosure.
4. Recognising and reflecting upon the emotionality of women's lives.

The overarching goal of feminist research is to identify how oppression may impact women's lives and empower women to tell their stories by providing a respectful and egalitarian research environment (Campbell and Wasco, 2000). This requires multiple methodologies and has resulted in feminist scholars creating alternative research approaches, for example, feminist participatory action research (Campbell and Wasco, 2000).

The research studies contained within this thesis were conducted with the awareness of the gender bias within healthcare and the knowledge that women had expressed being dismissed or misdiagnosed. The introduction chapter provides information and background on the experience of those living with endometriosis and adenomyosis. This knowledge led to the conclusion that neither the advantages of qualitative nor quantitative research would be sufficient to address the work needed to develop a complex intervention. Therefore, when the research process was being planned, work went into identifying research questions and methods that met the needs of the research, including and amplifying women's voices and led to thorough testing of the intervention.

2.8 Positionality

A researcher's background may influence their interpretation. Researchers' position themselves within their research to acknowledge how their interpretations are influenced by their personal, cultural and historical experiences (Creswell and Creswell 2018). My position as a researcher within the research discussed in this thesis is affected by several factors. I'm a feminist 'insider' researcher, and whilst I used a participatory action research approach for one study, I also used more traditional quantitative research designs for conducting a systematic review and a randomised controlled feasibility trial. My research approach can be considered a feminist pragmatic approach. I used the most appropriate method to answer the research questions. I value the voices and experiences of women in my research but also value quantitative methods for testing hypotheses and examining the relationship among variables.

Throughout this PhD research project, there have been times when I identified with being more of a patient than a postgraduate researcher and vice versa. However, for the majority of the studentship, I managed both identities at the same time. Towards the end of the project, I effectively ‘came out’ within the university setting; not only was I a disabled researcher, but those around me became aware that I had lived experience of my research topic. Whilst I agree with Gillberg (2020) that there is no such thing as unbiased research as that would entail knowledge being produced in a cultural, historical and political vacuum, identifying as insider research means consideration should be given to offset any of my personal experiences. Coming out as disabled is different from coming out as LGBTQ, but there are similar issues with discrimination and disability (Sheldon, 2017). There are many practical barriers for disabled people who are also researchers (Sheldon, 2017). One such barrier is the assumption of bias, but there are many other physical barriers that I have experienced as a disabled person in academia. My disability is invisible most of the time, so I often have to disclose that I am disabled when accessing accessibility options at the university and beyond. I also struggled with the lack of reasonable adjustments and performing at the same level under the same conditions as abled researchers. This helped me consider accessibility issues for the participants in my research. I also felt compelled to engage with the university to help reduce barriers for myself and other disabled researchers.

Feminist and disability studies highlight the risks of empirical detachment from the research process, arguing that researchers must reflexively locate themselves in the research process, reflecting on their influence and positionality (Longhurst, 2011). In particular, there may be unconscious biases, and whilst I may not be aware of them, others will pick up on them. Attempting to locate oneself with one’s research and exploring the concept of positionality has been a critical strategy for many feminists in challenging patriarchal objective approaches to knowledge production (Maxey, 1999). Therefore, whilst conducting the different stages of this research, I put strategies designed to add balance into my research approach. I found using mixed methods helped to inform these strategies. For example, I audio recorded the qualitative needs assessment to reflect on the questions I asked the co-researchers and allow me to carry out a secondary analysis of the data. For the feasibility study, I used randomisation and had the guidance of a second facilitator whilst running the intervention. I also kept a reflexive journal throughout my studentship, which I used to record concerns, list open-ended questions to ask co-researchers and record my emotional responses to the qualitative data.

There were also ethical considerations to conducting this research from an insider perspective. As a woman who lives with endometriosis and adenomyosis, I belong to several social media support groups, some of which are closed to outsiders. As a member of these groups, I had to agree with several rules before joining the group. These groups had rules against selling products or promoting businesses and products; they often allowed research study recruitment adverts. I decided not to advertise in these groups because I used them as a patient, not a research student. I felt uncomfortable 'outing' myself within these groups and did not want to include my identity as a researcher within these online spaces. I felt this would be verging unethical behaviour. As a member of these online groups, I experienced researchers lying to get access to the group, taking advantage of the lack of research into endometriosis and hoping that they could collect data via surveys before a moderator questioned their presence in these closed areas groups.

2.9 Ethical Considerations

The attempts by the authors of ethics guidelines to address the potential for harm and abuse of power in research has inadvertently re-categorised some populations as vulnerable (Gustafson and Brunger, 2014). These 'vulnerable' populations are seen as disadvantaged and in need of protection rather than as potential partners in research about their communities (Gustafson and Brunger, 2014).

The ethics committee of Coventry University expressed concerns over the use of photographs in the photovoice study. Initially, the ethics reviewers misunderstood the research method and were concerned about researchers photographing participants. Once this was re-explained, the reviewers were concerned over the lack of confidentiality for participants and that their medical conditions would be 'exposed'. The consent process was re-explained, and that participants got to decide if they included photographs of themselves and if they were to be displayed publicly. There seemed to be little consideration of the participant information sheet and consent forms included in the ethics submission. These documents showed that consent was sought from participants twice in the process, they were also allowed to withdraw their data, and anyone they took photographs of was required to sign a consent form. The participant information sheet advertised for people diagnosed with endometriosis and/or adenomyosis over 18 and explained the nature of the research method and study. It was assumed that this information would reassure ethics reviewers that informed consent was taken seriously and that participants would have the capacity to decide for themselves if they wanted to include themselves in their images. Two participants decided not to include images of their faces, but everyone wanted to use their first names.

2.10 A Compassionate Perspective on Conducting Research

The outcome of the research presented within this thesis was an online 8-week mindfulness-based self-management course. One of the main components of these types of interventions is compassion and, in particular, self-compassion. I qualified as an accredited mindfulness teacher in 2017. I had begun practising mindfulness a few years earlier as an approach to pain management. I regularly practise meditation and mindfulness, and self-compassion has been essential for managing my health whilst studying full-time. It made sense that I take a compassionate approach to my work. It would accumulate with the development and evaluation of a mindfulness-based intervention designed to meet the psychological needs of people living with endometriosis and adenomyosis.

It is possible to research from a compassionate perspective, but three crucial elements need to be included: ethnography, aesthetics and emotionality (Hansen and Trank, 2016). These elements allow the opportunity to experiment with theoretical frameworks that can lead to the alleviation of suffering in the immediate research context and new theoretical insights (Hansen and Trank, 2016). As a researcher with lived experience of my research topic, a compassionate approach to answering the research questions stemmed from the pragmatic paradigm. I wanted to alleviate the suffering of the participants and co-researchers involved in the studies of this research project. Yet, I had to maintain an appropriate distance from those I was researching with and for. While distance should be kept for analysis, for compassionate research, it must be accompanied by ‘closeness’ in observation and engagement with participants and emotions, including the researcher’s (Hansen and Trank, 2016).

As the research studies discussed within this thesis were not a part of a larger research project, I was the primary researcher in all of the studies. I developed the intervention, with guidance, I facilitated the intervention, I collected and analysed the data. All strict procedures were followed, such as randomisation. I did have a lot of contact with the participants. However, a second facilitator in the intervention group was an experienced online self-management course facilitator. The limitations of this study are discussed in more detail in chapter 5 and included in chapter 6, the discussion chapter. However, as this chapter discusses researcher bias, it is important also to mention allegiance bias. Allegiance bias is a researcher’s preference for a particular treatment (Munder et al., 2011). It has been suggested that researcher allegiance bias may impact outcome differences (Luborsky et al., 1975).

It has been claimed that researcher allegiance bias may be responsible for mindfulness-based interventions outperforming active control groups but not evidence-based treatments in psychiatric conditions (Goldberg and Tucker, 2020). Researcher allegiance bias was associated with larger effects and a significant moderator of between-group effect sizes (Goldberg and Tucker, 2020). Whilst I am an accredited mindfulness teacher, I was supervised by a supervisor who was also a mindfulness teacher and one who was not. In the final year of my PhD, another supervisor joined the team, a clinical and health psychologist who is critical of mindfulness interventions and experienced in intervention development. To be transparent about the research process, this is discussed in more detail in chapter 5.

2.11 A Mixed Methods Systematic Review

The systematic review examined existing non-pharmacological, non-surgical interventions for improving the quality of life of people living with endometriosis and adenomyosis. The rationale for choosing mixed methods was that it was important to identify existing interventions and quantify how effective they were, but the patient experience was also necessary to consider.

2.12 A Participatory Action Research Needs Assessment

Feminist action research (FAR) is a conceptual and methodological research framework that is primarily about exploring and pursuing opportunities for social justice (Reid, 2004). This approach belongs to the critical theory paradigm. Feminist action research is a conceptual and methodological framework that attempts to address these needs and limitations and to place the study of women’s health in a broader social justice agenda (Reid, 2004). Feminist action research strategies attempt to be inclusive, participatory, collaborative and to clarify women’s experiences (Reid, 2004). Whilst qualitative research methodologies are often critiqued as being subjective, and the results are not generalisable, participatory research has increasingly been seen as a valuable and scientifically sound approach (Decker et al., 2010).

A slogan that Charlton first used (1998) that became popular in the disability rights movement is ‘Nothing About Us Without Us’ (Sheldon, 2017). This refers to the inclusion of the disabled when decisions are being made that may affect them. It has been suggested that people with disabilities researching disability is the epitome of participatory action research (Sheldon, 2017).

Photovoice is a method where participants are considered to be co-researchers. They collect data in the form of photographs with captions in response to a research question (Wang and Burris, 1997). This method was chosen to give an in-depth look at the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis.

2.13 Use of Theory of Change in Intervention Development

The Medical Research Council has produced guidelines for developing, evaluating, and implementing complex interventions (Craig et al., 2008, Craig et al., 2019). The guidelines provide researchers with guidance on choosing appropriate methods and the development-evaluation-implementation process. When developing an intervention, the guidelines ask researchers to consider questions like: *Are you clear about what you are trying to do: what outcome you are aiming for, and how you will bring about change? Does your intervention have a coherent theoretical basis? Have you used this theory systematically to develop the intervention? Can you describe the intervention fully, so that it can be implemented properly for the purposes of your evaluation, and replicated by others?* The guidelines ask further questions and emphasise the importance of the work that goes into developing an intervention before the evaluation stage. However, what the guidelines don't include are examples of theories that provide the theoretical basis for developing interventions.

When developing complex interventions that aim to be effective, substantial and scalable, researchers need to understand not just if the intervention works but also how and why an intervention has a particular effect, including which parts of a complex intervention have the most significant impact on outcomes (De Silva et al., 2014). De Silva et al. (2014) have proposed a theory-driven approach to the design and evaluation of complex intervention by adapting the integrating the Theory of Change (ToC) into the MRC framework. This is presented and discussed in more detail in Chapter 5, intervention development and feasibility trial.

A program theory is an explicit theory of how an intervention contributes to a chain of intermediate results and finally to the intended or observed outcomes (Funnell and Rogers, 2011). Program theory has two components: a theory of change and a theory of action. Theory of change is about the central processes that lead to change for individuals, groups, or communities, e.g., psychological, social, physical, and economic processes (Funnell and Rogers, 2011). Although it may contain psychological or social processes, ToC is not a sociological or psychological theory but a pragmatic framework that describes how the intervention affects change (De Silva, 2014). A strong ToC is powered by reliable and robust theories that provide a clear explanation of why change takes place. Theory of Change has a flexible format that clearly describes the pathways through which the outcomes work to achieve the desired impact (De Silva et al., 2014). ToC allows for multiple pathways, levels, and feedback loops that reflect how complex interventions achieve their impact (De Silva et al., 2014). Theory of change incorporates an evidence base for each strand that feeds into the long-term outcome. This allows researchers to understand which components of the intervention have been successful or unsuccessful and how the components of the intervention have contributed to the change in outcomes (Funnell and Rogers, 2011).

2.14 Conclusion

This chapter has explored how a methodology was used to follow the guidance provided by the Medical Research Council on the development of complex interventions (Craig et al., 2019). A mixed-methods approach was taken in the research process of developing and evaluating an 8-week mindfulness-based self-management intervention. This chapter has introduced the three studies conducted as part of this PhD project and the methods chosen to conduct the research. This chapter has also discussed researcher positionality and bias and how a feminist worldview and compassionate perspective led to the design and execution of the research methods of each study. Chapter 3 presents the mixed-methods systematic review. Chapter 4 presents the needs assessment. Chapter 5 presents the feasibility study, including details on the intervention. The last two chapters are the discussion and conclusion chapters.

Chapter 3 Systematic Review

3.1 Overview

This chapter discusses the first step of the intervention development process: the systematic review. This mixed-method systematic review was conducted to investigate the effectiveness of existing non-surgical, non-pharmacological interventions that aimed to improve the quality of life of people living with endometriosis and adenomyosis. The systematic review findings impacted the choice of methods for the needs assessment and the main components of the intervention itself.

3.2 Background

As mentioned in the introduction chapter of this thesis, there are many options available that aim to manage the symptoms of adenomyosis and endometriosis. Surgical treatment aims to remove or reduce the disease. Pharmacological treatment aims to suppress symptoms such as pain with analgesia or dysmenorrhea with hormonal therapy. Diagnostic laparoscopy is the 'gold standard' method of diagnosing women who experience chronic pelvic pain symptoms. Laparoscopic surgery identifies endometriosis, adhesions, dilated pelvic veins and ovarian pathology but not adenomyosis. Surgical excision of endometriosic lesions during laparoscopy is the gold standard for treating endometriosis. Historically adenomyosis is confirmed after a hysterectomy. Medical management includes analgesia, COCP and hysterectomy. It is crucial that those that experience chronic pelvic pain can access a multidisciplinary team involving pain specialists, physiotherapists, clinical psychologists and possibly sex therapists. The aim of multidisciplinary management should be to identify appropriate treatment, aid self-management, and improve quality of life. (Robb and Mahmood, 2013, Rogers and Weston, 2012).

Although these health conditions have physical symptoms, they also have a psychological impact. Women living with endometriosis have reported experiencing feeling upset, angry, depressed, uncertain, weak, powerless, hopeless, defeated, disappointed, frustrated, exhausted, and a burden to others (Moradi et al., 2014). Qualitative research methods such as interviews and focus groups have been used to examine and explore the emotional and psychological impact of living with chronic pelvic pain. One qualitative study found that once diagnosed, pelvic pain tends to be treated with a range of medical options without a long-term pain management plan (Huntington and Gilmour, 2005). Treating the whole person, mind and body, not just physical symptoms, may be helpful when treating the complexity of symptoms that can occur with a condition like endometriosis Huntington and Gilmour, 2005).

3.3 Existing Systematic Reviews: Where does this review fit?

There have been both qualitative and quantitative systematic reviews conducting within this area of research. The findings of these reviews were considered when this review was designed in 2017. The research question was developed so that the results could inform intervention development. However, it was recognised that it would be beneficial to conduct a systematic review to fill a gap in research published in this area.

A systematic review was conducted to determine the extent of endometriosis and its treatment had on health-related quality of life (Shuang-Zheng et al., 2012). While studies of medical treatment, surgical treatment and complementary treatment (dietary therapy, acupuncture, progressive muscular relaxation and Chinese herbal medicine) were included in this review, studies investigating psychological therapies and physiotherapy were not included. The review concluded that endometriosis impairs health-related quality of life, and this impairment can be partially and temporarily managed with hormonal therapy and conservative surgery (Shuang-Zheng et al., 2012). The authors' conclusions support the European Society of Human Reproduction and Embryology (ESHRE) Guidelines (Kennedy et al., 2005) that state multidisciplinary strategy involving a pain clinic and counselling should be implemented in the management of Endometriosis (Shuang-Zheng et al., 2012).

In 2012, a systematic review was published to evaluate the effectiveness of psychological therapies in reducing chronic pelvic pain. This review included only RCTs, excluding other quantitative studies and all qualitative studies. There was not enough evidence available when including only RCTs in the search strategy to conclude the effectiveness of psychological interventions for reducing chronic pelvic pain. This review did not prioritise the psychological impact of living with chronic pain, instead focused on the physical symptom of pain. The search for evidence to be included in this review ended began with the inception of the databases to 2010 (Champaneria et al., 2012).

The two systematic reviews above were considered when this systematic review was designed. The goal was not to duplicate previous studies but to make a unique contribution to this area of research. Therefore, it was decided that all non-surgical, non-pharmacological interventions should be included in the search strategy. Shuang-Zheng et al. (2012) didn't include psychological therapies and physiotherapy, so this review included these. Champaneria et al. (2012) focused on the physical symptoms of pain and whether interventions reduced or improved pain symptoms. While this is an important aspect when considering the effectiveness of interventions, it is also possible to improve quality of life while living with chronic pain. Endometriosis and adenomyosis are lifelong conditions; even with surgery, painful symptoms can return. It is crucial that people with these conditions are offered treatment that does more than just reduce or improve pain symptoms.

This systematic review intended to create a link between these two reviews and identify existing non-surgical, non-pharmacological interventions that may be effective at improving quality of life. The findings of this review were used to inform the development of a complex intervention, as guided by the Medical Research Council guidelines on the development and evaluation of complex interventions (Craig et al., 2019). The Medical Research Council advises that the first step of identifying the evidence base when developing an intervention is carrying out a systematic review (Craig et al., 2019).

This systematic review provided a sound starting point for understanding what interventions were helpful to people living with painful symptoms and reduced quality of life. The Discussion section of this chapter outlines how the results of this review influenced the components chosen to be included in the intervention. The Discussion section also highlights the importance of user involvement in the development of the intervention. This chapter concludes with a section on how the systematic review findings were included in the intervention., as well as recommendations for future research in this area.

The review questions were: What non-surgical, non-pharmacological interventions are effective at improving the quality of life for people with endometriosis and/or adenomyosis? What are participants experiences of non-surgical, non-pharmacological interventions?

3.4 Method

The protocol for this systematic review was registered on PROSPERO; the ID is CRD42017067081.

3.4.1 Search Strategy

In January 2017, ethical approval was granted for the mixed-method systematic review to begin. Each member of the supervisory team made contributions and suggestions to the search strategy. A copy of one of the search strategies used is provided in the Appendices (Appendix I – Systematic Review Search Strategy). Once an agreement was reached, the first search strategies were run in December 2017. Electronic databases (MEDLINE, CINAHL, PsycINFO, Cochrane Library) were systematically searched for peer-reviewed studies, written in the English language, including grey literature to reduce publication bias, from the inception of each database to April 2017. A forward citation search was compiled from the included studies, and reference lists were checked for any relevant papers. Relevant journal articles were also manually checked to ensure no relevant articles were missed. Below is a table (Table 3.1) showing examples of the search terms used. The search terms included combinations consisting of MeSH subheadings, text and word variations for the search terms. Both American English and UK English terms were used, for example, behavior and behaviour. The main terms were searched for in title and abstracts and in main headings or keyword searches. A comprehensive database, using Endnote, was kept, importing full text pdfs from each database searched and the studies obtained from the additional sources. Logs and dates of each search were kept so the searches could be rerun and updated at a later stage if needed.

Table 3.1 Examples of Search Terms

Search Terms (MEDLINE, CINAHL, PsycINFO, Cochrane Library)		
Diagnosis/symptoms	**Quality of Life**	**Interventions**
Endometriosis	Quality of life	Pain Management
Adenomyosis	Resilience, psychological	Pain Clinics
Chronic pelvic pain	Activities of daily living	Behaviour Sciences
Persistent pelvic pain	Pain measurement	Behaviour Medicine
Infertility, female	Attitude to health	Cognitive Therapy
Recurrent pelvic pain	Quality-adjusted life years	Behaviour Therapy
Infertility	Personal satisfaction	Psychological Techniques
Dysmenorrhea	Happiness	Relaxation Therapy
Painful menstruation	Mental health	Psychodynamic Therapy
	Health-related quality of life	Counselling
	Well-being	Person-Centred Therapy
	Wellness	Psychotherapy
	QoL	Psychotherapy, group
	HRQoL	Self-help groups
	Mental well-being	Self-Management
	Catastrophising	Social Support
	Pain scores	Support Groups
	Pain assessment	Social Media
	Health behaviour	Mobile applications
	Optimism	Physiotherapy
	Distress	Mindfulness
	Self-esteem	Mind-Body Therapies
		Meditation
		Acceptance and Commitment Therapy
		Yoga
		Medicine, Chinese Traditional
		Acupuncture
		Massage

3.4.2 Study Selection

All Titles and Abstracts were screened independently by two reviewers, Clair Dempsey and Laura Allen, a PhD student (CD and LA), to identify potentially relevant manuscripts. Before the screening began, a practice file was set up, with 100 records. Laura Allen was provided with a copy of the review protocol, and the criteria were discussed in detail before practice screening commenced. This exercise aimed to make sure both screeners agreed and were applying the criteria in the same way. Practice screening was attempted twice before satisfaction was achieved, and screening of the records began. Disagreements were resolved by discussion and explanation of the decision. Two screeners (CD and LA) screened full-text versions of these included studies to assess eligibility for inclusion in the review. All studies selected for the review had to be available in full-text manuscript format.

The two reviewers (CD and LA) independently assessed that the studies met the following PICOS-based inclusion criteria (University of York, Centre for Reviews and Dissemination, 2009):

1. Participants will be women with a confirmed diagnosis of adenomyosis or endometriosis who experience chronic pelvic pain as a symptom.
2. Interventions will be non-surgical, non-pharmacological, including quantitative and qualitative papers that feedback on the intervention/RCT.
3. All control types will be included (e.g., passive and active controls).
4. Quality of life must be an outcome of the study.
5. All settings will be included in the review.

If any study did not meet the above criteria, it was excluded from the review. The two reviewers (CD and LA) systematically applied the exclusion criteria (Table 3.2) to assess the eligibility of studies to be included in the review. The results were then brought to the larger research team.

Table 3.2 – Exclusion Criteria Process

	Exclusion Criteria
1	Exclude if it is not written in English
2	Exclude if it does not include human participants
3	Exclude if it does not include participants who are women
4	Exclude if not about chronic pelvic pain caused by adenomyosis or endometriosis)
5	Exclude if the focus is solely on medical, surgical or pharmacological interventions
6	Exclude if quality of life is not included as an outcome (as defined in the introduction)
7	Exclude if the manuscript is a conference abstract, thesis, protocol or summary of other reviews
8	Exclude if the participants are the same in a previous related study unless separate qualitative and quantitative studies.
9	Exclude if the quantitative or qualitative paper is not about an intervention
10	Exclude if cannot extract data from other data that is not relevant to the review question (e.g., cannot extract chronic pelvic pain in women from men or cannot extract chronic pelvic pain caused by adenomyosis or endometriosis from other types of pelvic pain)

3.4.3 Quality Assessment

Once full manuscripts were located and those not meeting eligibility criteria had been excluded, they were appraised for methodological quality using the Mixed Methods Appraisal Tool (MMAT) – Version 2011 (Pluye et al., 2011). This tool allowed for an overall quality score for each study and a descriptive summary, including qualitative, quantitative and mixed methods. The two reviewers carried out the appraisal independently (CD and LA) and then discussed it with the larger research team. Although the searches identified no qualitative studies in 2017, this appraisal tool is still appropriate for quantitative or qualitative reviews.

The MMAT allows researchers to grade the quality of studies by assigning them a score out of four. The MMAT enables researchers to determine the methodological quality of studies based on the type of study, e.g., qualitative, quantitative randomised controlled trials, quantitative nonrandomised, quantitative descriptive and mixed methods. After answering the screening questions, the studies are assessed by responding yes, no or don't know. For example, if a study is a quantitative randomised controlled trial, the questions are: 1. Is there a clear description of the randomisation? 2. Is there a clear description of the allocation concealment? 3. Are there complete outcome data (80% or above? And 4. Is there low withdrawal/dropout (below 20%)? Each Yes answer gives a score of 1. The scores are calculated to produce a percentage.

3.4.4 Data Extraction

Data were extracted from each of the studies included in the review by one reviewer (CD) and checked for accuracy by the second reviewer (LA). Where necessary, the study's authors were contacted for clarification by email if there was any information required not written about in the published article. There were no disagreements at this stage of the review. General data were extracted, including author, year, journal, study design and setting. Table 3.3 below outlines what PICOS data were extracted from the quantitative papers (University of York, Centre for Reviews and Dissemination, 2009).

Table 3.3. PICOS

Population	Age, diagnosis, symptoms, no. of participants, attendance/compliance to intervention, details of current or previous treatment
Intervention	Type, duration, frequency of intervention, elements of the intervention, qualification of facilitator, the content of the intervention
Comparator	Type and description
Outcomes	What outcomes were included in the study, and how were they measured. Must include quality of life. Themes, analysis, significance, discussion of results.
Study Design	Type of study, aims, understanding of conditions, conclusions, recommendations

Once the data extraction tables were complete, it became clear that the amount of missing data meant a meta-analysis could be not performed as there were too many gaps in the data presented in the studies. Table 3.4 (Appendix II Data Extraction) shows the data extracted from the studies and the gaps in the data presented in the studies. There tended to be a pattern with missing data; it happened when quality of life was a secondary outcome measure in a study. It also occurred because some studies only presented the significant scores of the outcome measures, which meant there was no data to input into a Review Manager to conduct the meta-analysis. Therefore, a critical narrative approach was taken to the discussion of the results of the review. This approach allowed for a full investigation of the review's findings, including the gaps in methodological issues and the lack of qualitative studies retrieved using the search strategy outlined above. This approach also allowed for achieving an understanding of which types of interventions had the potential to improve quality of life and could indicate what form the intervention should take.

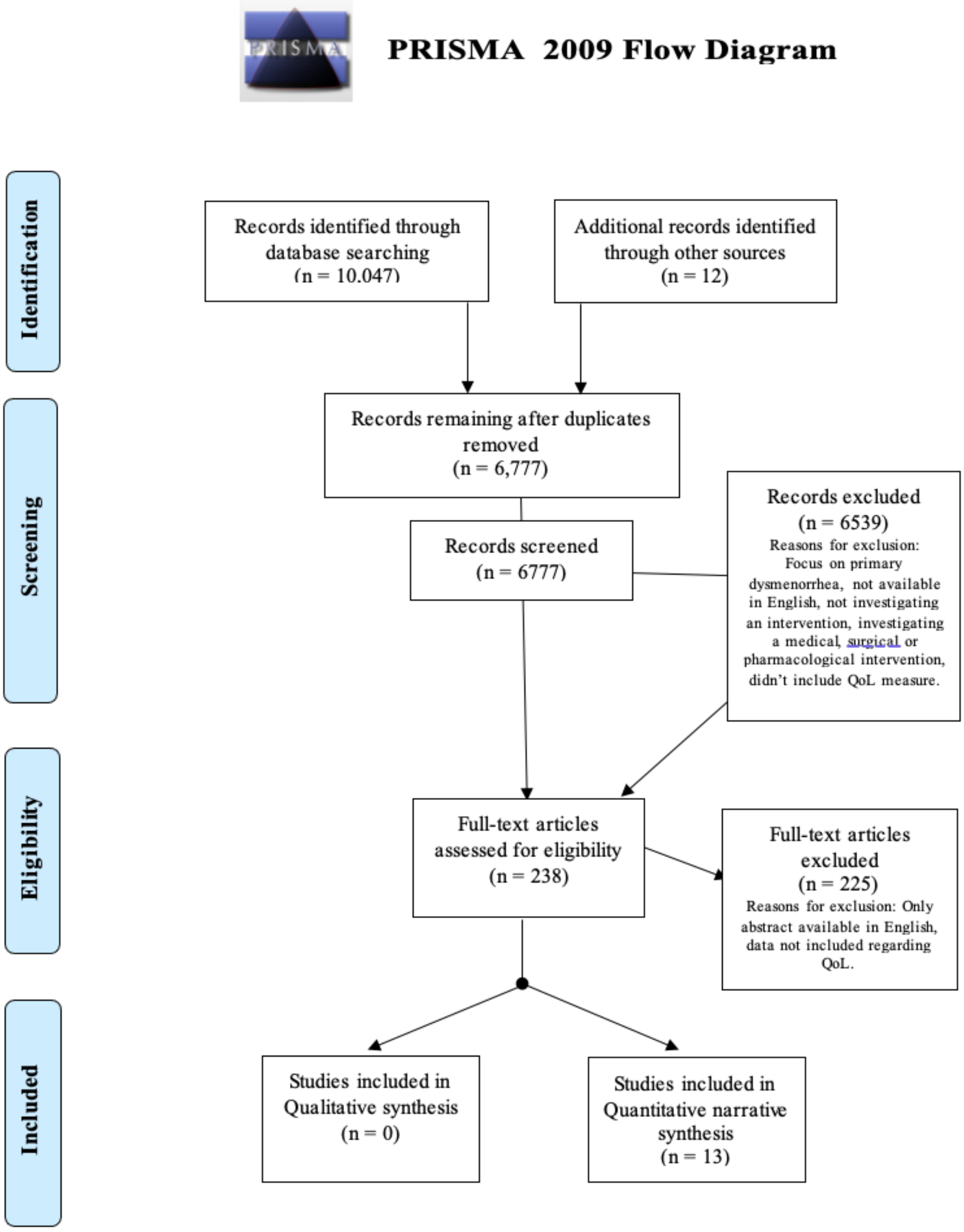
3.4.5 Risk of Bias

The risk of bias was assessed using The Cochrane Collaboration's tool. This tool assessed: selection bias, performance bias, detection bias, attribution bias, reporting bias and other biases. This tool was vital when gaining a deeper understanding of the results presented in the studies and the conclusions the authors drew from the results they chose to give. For example, some authors presented all the data, including non-significant scores, which provided context when the discussion and conclusion sections were considered. However, some studies only included partial data, sometimes not reporting the scores themselves, making it difficult to determine if the authors' conclusions were convincing.

3.5 Results

The database searches were run in December 2017 and resulted in a total of 10,047 studies. A further 12 studies were identified via hand searching the reference lists of the studies initial retrieved. There were 6777 studies remaining after duplicates were removed. There were 6539 studies further excluded after applying the inclusion criteria. The Full-text search returned 238 full-text papers, which were then screened. After screening full-text articles, 225 were excluded; the reasons are outlined below in the PRISMA flow diagram (Figure 3.1). There were no qualitative studies included in this mixed methods review and 13 quantitative studies. These results are discussed below.

Figure 3.1 PRISMA Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

3.6 Characteristics of Papers

Although the review's focus was narrow, the search terms included a variety of interventions from varying disciplines. Table 3.5 shows the variety of interventions included in this review, from the UK, USA, Canada, Denmark, Germany and Brazil. It should be noted that two papers were the pilot study and follow up of the same intervention, using the same sample.

3.7 Study Characteristics

There are 13 papers included in this review, all published between 2008 and 2017. Four of the articles were published in 2017, perhaps indicating a recent increase in research into endometriosis and how it can be managed (Ahn et al., 2009, Allaire et al., 2017, Beissner et al., 2017, Meissner et al., 2016, De Sousa et al., 2016, Flower et al., 2011, Goncalves et al., 2017, Hansen et al., 2017, Kold et al., 2012, Mira et al., 2015, Petrelluzzi et al., 2012 and Teixeira et al., 2017 and Wayne et al., 2008). Five of the articles presented research that was conducted in Brazil (De Sousa et al., 2016, Goncalves et al., 2017, Mira et al., 2015, Petrelluzzi et al., 2012 and Teixeira et al., 2017), two in the USA (Ahn et al., 2009 and Wayne et al., 2008), two in Denmark (Hansen et al., 2017 and Kold et al., 2012), one in Canada (Allaire et al., 2017), one in Germany (Beissner et al., 2017 and Meissner et al., 2016) (one study, two published articles) and one in the UK. (Flower et al., 2011). Most of the articles are from high-income countries with developed healthcare systems. Most of the studies recruited participants from hospitals or clinics (12), and one study used adverts placed in newspapers and online. Table 3.5 presents the study characteristic is included in the Appendices (Appendix III Table 3.5 Study Characteristics)

3.8 Types of Interventions

Many of the interventions studied included a mind-body aspect, where participants were taught techniques that link the sensations of the body with the thoughts and feelings of the mind. The interventions included Japanese-style acupuncture, a combination of psychotherapy and somatosensory stimulation, acupuncture, Chinese Herbal Medicine, Yoga, Mindfulness-based intervention pilot and follow up, TENS, physical therapy and psychological therapy, interdisciplinary treatment and homoeopathy (Ahn et al., 2009, Allaire et al., 2017, Beissner et al., 2017, Meissner et al., 2016, Flower et al., 2011, Goncalves et al., 2017, Hansen et al., 2017, Kold et al., 2012, Mira et al., 2015, Petrelluzzi et al., 2012 and Teixeira et al., 2017 and Wayne et al., 2008).

Table 3.6. Intervention details and components

Study	Specific Components of Intervention
Ahn et al., 2009	• Sixteen acupuncture treatments. 2 per week for eight weeks. • Treatments were administered by a total of 7 licensed acupuncturists with specific training in Japanese style. • The active acupuncture treatment was a manualised approach to pelvic pain based on the Japanese-style acupuncture developed by Shina and Chase, and Manaka. • Treatment elements included: needling 8-12 points to activate and balance Extraordinary and Divergent acupuncture channels, burning moxibustion (warming herb) on both back shu acupuncture points using the Hibiki-7 device.
Allaire et al., 2017	• Interdisciplinary interventions. • Patients were given the choice of minimally invasive surgery, medical management (hormonal, pain adjuvants, trigger point injections) and or a pain program (pain education workshop, physiotherapy and counselling). • Treatments individualised to each patient. • Pain Education Workshop – validation of patients experiences and discussion of the multifactorial contributors to chronic pelvic pain. Information was also provided on the neurophysiology of pain as an output of the nervous system, e.g., that pain can persist in the central nervous system even after 'tissue' peripheral factors' have been addressed. • The physiotherapy component of the pain program involved calming breathing techniques, addressing fear of movement, helpful postural and movement patterns, pacing and grading activity, and exercises to relax identified overactive muscle groups, often including abdominal obliques, rectus abdominus, hip abductors, deep hip rotators and pelvic floor muscles. Manual therapy to address hep and sacroiliac joint asymmetries were performed as needed. • If needed, dietary, behavioural and postural modifications for bladder/bowel function were given. • Counselling in the pain program included mindfulness-based meditation, breathing, guided visualisation, body scans and progressive muscle relaxation. Patients were also taught cognitive behavioural therapy strategies to learn how the identification and modification of thoughts and beliefs could affect emotions. • Patients were directed to appropriate community resources and community mental health referrals as required.
Beissner et al., 2017 Meissner et al., 2016	• Integrative psychotherapy combining elements from hypnotherapy, mindfulness-based psychotherapy, cognitive behavioural therapy and problem-solving therapy. • Strong emphasis on the joint involvement of mind and body in the therapeutic process. • Employed diagnostic concepts and stimulation methods from traditional Chinese medicine. • The minimum number of treatments was four, but most patients received more. • One on one treatments lasted 60 minutes.
De Sousa et al.,	• Five sessions of acupuncture, during which 19 Dong Bang needles were inserted. First, two needles were inserted at the lower angle of the scapula, two fingers apart from the 7th thoracic vertebra. • The women were placed in the supine position to insert needles sequentially. • After 20 minutes, the needles were withdrawn. • The therapy was performed once a week at an interval of 6-8 days. Sessions lasted 40 minutes.

Flower et al., 2011	• 16 weeks • Women in the active group received individualised herbal formulations of between 10 and 15 hers selected from the Chinese Materia medica, with a daily dosage amounting to between 150g and 250g. • A month's supply of herbs was soaked in 9 litres of water for 40 minutes and then cooked for 1 hour using pressurised herb cooking machines commonly used in Chinese hospitals. • Herbs were dispensed as individual dosages of 180 ml in sealed plastic packets
Goncalves et al., 2011	• Hatha Yoga • 2-hour sessions, twice a week for eight weeks • Sessions conducted under the guidance of the same qualified Yoga instructor • Participants joined the practice at any time and left after eight weeks. • Sessions consisted of 30 minutes of conversation and interaction among participants, 10 minutes of initial physical and psychological relaxation with pranayama's, intonation of mantras and body awareness. This was followed by 60 minutes of asanas, 10 minutes of physical and psychological relaxation exercises that included meditation, breathing techniques, and chanted mantras; in the final 10 minutes, the women commented on the session and organised the room where the class took place.
Hansen et al., 2017 Kold et al., 2012	• Mindfulness-based psychological intervention • Body scan, sensory training, breathing techniques, music and bio-feedback support. • Psycho-education and group dialogue • Individual session – themes were adapted to the individual client's personal goals and challenges. • Follow up
Mira et al., 2015	• Intervention 1 Transcutaneous Electrical Nerve Stimulation (TENS) • Acupuncture-like TENS, frequency 8Hz, pulse duration ~250 us and VIF (variation in intensity and frequency of 1ms). The intensity was adjusted according to the women (strong but comfortable) without any motor stimulation. Application site: sacral region (S3-S4). • A dual-channel TENS unit was used, equipped with four rubber electrodes (~5cm x 3cm) and neutral aqueous gel lubricant, attached to the skin with adhesive tape crossed in an X pattern. 30-minute sessions once a week for eight weeks. • Intervention 2 Self-applied TENS. • Frequency 85Hz, pulse duration ~75 us. The intensity was adjustable with three options: 10, 20, 30 mA. • Participants were instructed to choose the intensity that was 'strong but comfortable'. • Application site: sacral region S3-S4. The correct placement of the device was initially explained and demonstrated on the patient during evaluation, and the researcher dispelled doubts. • Sessions were twice a day, 20 minutes per application, setting 12 hours between applications. • A return visit was scheduled after four weeks of treatment for follow-up of the device's use. • A final reassessment was carried out after eight weeks.
Petrelluzzi et al., 2012	• Physical therapy and psychological intervention • Ten sessions, once a week. Each session lasted two and a half hours.

	• The sessions were held in a comfortable room with relaxing ambient music. • In the first hour, the patients received physical therapy, including lumbar repositioning, body awareness training, breathing exercises (focusing on rhythm, frequency, depth, the volume of inspired air and respiratory rehabilitation), stretching exercises targeting the muscles that were shortened by the patient preference for specific pain-relieving positions, active free exercise aimed at maintaining or increasing the amplitude of joint movement, dissociation of pelvic from the scapular waist, exercises directed to the pelvic region, perineal muscle strength, massage, self-massage, TENS, relaxation techniques and instructions related to activities of daily living. • The remainder of each session included a psychological intervention, based on the concepts of cognitive behavioural therapy, applied in discussions of the following issues: endometriosis, pain, stress, family and social relationships and sexuality. Behavioural and cognitive techniques taught patients to cope with the disease and the accompanying pain through games that led them to contemplate their health problems. Educational materials were also used to instruct the patients regarding their symptoms, feelings and thoughts.
Teixeira et al., 2017	• Homoeopathy • Potentized estrogen was prepared from 17-beta-estradiol valerate in compliance with the Brazilian Homeopathic Pharmacopeia. The first three steps consisted of serial grinding of 17 beta-oestradiol mixed with lactose, followed by dilution 1:100 (each dilution agitated 100 times) until reaching potencies 12cH, 18cH and 24cH. The medication was delivered as drops (30% hydro-alcoholic solution) in 30-ml vials, including a dropper. • Each participant allocated to the active treatment group (verum) was scheduled to receive a vial of potentised 17-beat-estradiol. After initial assessment and delivery of the first vial of homoeopathic medication (potency 12cH) or on visit 1, the participants were evaluated by the physician-investigator every eight weeks during the study (24 weeks). On visits 2 and 3, participants were given new vials of homoeopathic medicine. • The Control group were given placebo vials.
Wayne et al., 2008	• A Japanese style of acupuncture. Sixteen treatments were administered over eight weeks. • The Control group were given sham acupuncture treatment.

3.9 Types of Studies

All studies were published between 2008 and 2017. All of the studies were quantitative. The only study that did not use a control group was the Kold et al. (2012) mindfulness-based intervention and the follow up (Hansen et al., 2017). Below Table 3.7 shows the MMAT Score that measured bias in the methodology and reporting in the studies. Table 3.4 (Appendix II Data Extraction) provides more details on the specific concerns regarding bias in the studies.

Table 3.7. Quality Assessment

Authors	Intervention type	MMAT Score
1. Ahn et al., 2009	Acupuncture	¾ (75%)
2. Allaire et al., 2017	Interdisciplinary	¾ (75%)
3. Beissner et al. 2017	Combination of psychotherapy and somatosensory stimulation	2/4 (50%)
4. de Sousa et al., 2016	Acupuncture	4/4 (100%)
5. Flower et al., 2011	Chinese Herbal Medicine	2/4 (50%)
6. Goncalves et al., 2011	Yoga	4/4 (100%
7. Hansen et al., 2017	Mindfulness follow up	4/4(100%)
8. Kold et al., 2012	Mindfulness pilot	4/4 (100%)
9. Meissner et al., 2016	Psychotherapy with Somatosensory Stimulation for Endometriosis-Associated Pain	2/4 (50%)
10. Mira et al., 2015	TENS	¾ (75%)
11. Petrelluzzi et al., 2012	Physical and psychological therapy	¾ (75%)
12. Teixeira et al., 2017	Homoeopathy	¾ (75%)
13. Wayne et al., 2008	Japanese-style acupuncture	¼ (25%)

3.10 Types of Outcome Measures

The 13 studies included in this review all measured quality of life. However, this wasn't the only measure used in the studies; Table 3.6 (Appendix II) lists all the measures used in each study. As the review question was interested in improving quality of life, this review focuses on the results of quality of life measures.

The Endometriosis Health Profile 30 was used nine times as a quality of life measure (Ahn et al., 2009, Allaire et al., 2017, De Sousa et al., 2016, Flower et al., 2011, Goncalves et al., 2017, Hansen et al., 2017, Kold et al., 2012, Mira et al., 2015 and Wayne et al., 2008). The Short Form-36 was used four times (Hansen et al., 2017, Kold et al., 2012, Petrelluzzi et al., 2012 and Teixeira et al., 2017). The Short Form-12 was used twice (Beissner et al.,2017, Meissner et al., 2016), and the Paediatric Quality of Life Inventory was used twice (Ahn et al., 2009 and Wayne et al., 2008) (Ware et al., 1993, Ware et al., 1996, Jones et al., 2001, Varni et al., 2002).

3.11 Synthesis of Results

3.11.1 Findings and Considerations

This systematic review details thirteen papers for inclusion. Although this was a mixed methods review, unfortunately, only quantitative studies were returned in the searches. The sample sizes in the included studies varied: the smallest study had 10 participants (Kold et al., 2012, Hansen et al., 2017), while the largest study included 296 participants (Allaire et al., 2017).

All of the studies reported positive outcomes. However, not all the quality of life scores were statistically significant, although some studies report clinically important improvements. Only one study and follow up used a quality of life measure as a primary outcome measure (Kold et al., 2012, Hansen et al., 2017). Pain was the primary outcome measure for five studies (Petrelluzzi et al., 2012, Allaire et al., 2017; Mira et al., 2015; Flower et al., 2011; Ahn et al., 2009). Four studies used quality of life measures and pain scores as a primary outcome measure (Wayne et al., 2008, Teixeira et al., 2017, Goncalves et al., 2017, de Souse et al., 2016). One study's primary outcome measures were brain connectivity of the hippocampus and pain (Beissner et al., 2017, Meissner et al., 2016)

Most of the interventions studied could be considered mind-body interventions, where physical symptoms and the emotional impact of these symptoms are addressed. However, there were three exceptions: homoeopathy, Chinese Herbal Medicine and TENS (Teixeira et al., 2017, Flower et al., 2011 and Mira et al., 2015). Two studies did not have a control group (Allaire et al., 2017, Kold et al., 2012, Hansen et al., 2017). More details on the intervention summaries and components are presented in Tables 3.4 and 3.5.

3.12 Synthesis of Quantitative Findings

The evidence on effectiveness is limited. Even though many of the studies used the same outcome measures, it was still not possible to conduct a meta-analysis due to the amount of missing data. Table 3.4 contains all the data extracted from the studies, with blank columns/rows indicating missing data. There are different reasons given for the missing data, the main one being that quality of life was often a secondary measure (Ahn et al., 2009; Allaire et al., 2017; Beissner et al., 2017; Meissner et al., 2016). However, in some studies, baseline scores were not reported, only post intervention scores (Flower et al., 2011), one study reported 'ns' (non-significant) instead of the scores (Kold et al., 2012), and one study did not report all the post intervention scores (Teixeira et al., 2017). Due to incomplete datasets, the use of Cohen's d and CI's was not possible. When attempting to analyse the results of the thirteen studies, it was vital to bear in mind methodological issues and the risk of bias.

There are some studies included in this review that raised concerns about methodological quality and risk of bias. Wayne et al. (2008) stated that their results showed that Japanese-style acupuncture could be an effective, safe and well-tolerated therapy for endometriosis-associated pain. Whilst this study's quality of life measures showed improvements in scores post-intervention, they were not statistically significant. The methodological assessment showed no details on the randomisation process, blinding of acupuncture was impossible, and the dropout rate was 22%. The risk of bias tool showed it was unclear how much detection bias and performance bias impacted the study.

Flower et al. (2011) did not report baseline scores for the EHP-30; therefore, the risk of bias assessment showed that this study had a high risk of attrition bias. There were missing data, and the researcher-practitioner was inexperienced and blamed for missing data. This study was at low risk of selection bias and performance and reporting bias. There was also a dropout rate of 22.5%, and the control group was suspended. While the authors are clear about the substantial limitations of the study itself, they are not as transparent with how they have reported the data. They report clinically important changes, and it is impossible to determine this as the baseline data is missing. The authors state that both groups showed improvements in all domains of the EHP, except in the social support domain for the placebo group. They also found that the active group showed a clinically large change while, in the placebo group, this was the case for control, emotional well-being and self-image. The authors also state that the placebo decoction may have had a therapeutic effect, which could explain the improvement in scores on the EHP-30. This study had major limitations, and clear conclusions cannot be drawn from the results.

Another study with low methodological quality and bias risk is the Jing-Well acupuncture study (Ahn et al., 2009). This study used quality of life as a secondary measure and did not include all the EHP-30 and Paediatric Quality of Life Inventory data. There were technical issues with the Hibiki-7 device used. The authors presented simple statistics and stated that *'it is possible that more complex, even nonlinear measures would better reflect clinical outcomes*' (Ahn et al., 2009). This study didn't state how participants were randomised and had a high dropout rate of 22%. The study's overall results, including the primary measures, are not presented in a way that makes it easy to draw conclusions from the results.

One of the studies included in this review investigated the effect of homoeopathic treatment (potentised estrogen) on endometriosis-associated pain (Teixeira et al., 2017). This study was found to have low methodological quality and to be at high risk of bias. The randomisation and blinding were described, and the dropout rate was low at 18%. However, there was missing data, the post intervention scores for the intervention and the placebo groups. It is unclear how the data were analysed. The data presented in graphs were not clearly labelled. There were 23 participants in the intervention group and 27 participants in the placebo group. The authors conclude that the use of potentised estrogen had significant improvement of all the outcomes measured, including quality of life. However, the data presented does not support this claim. The authors state no improvements in the placebo group's scores, but the post intervention scores are not given. The authors also reported adverse event related withdrawal on one patient from the intervention group, drug-related adverse events in four participants in the intervention group and eleven participants in the placebo group.

Petrelluzzi et al. (2012) investigated the combination of physical therapy and psychological therapy. This study had a low risk of bias; however, it did have methodological concerns, a low response rate of 57%. The SF-36 was used to measure the quality of life; there were only two statistically significant improvements: physical functioning and vitality subscales. This study didn't report scores that weren't statistically significant, used 'not sig' instead. This study had a small sample size of 30; 26 completed the ten weeks of treatment. However, the study showed reductions in perceived stress, normalising salivary cortisol and a slight effect on pain intensity. Allaire et al. (2017) investigated the impact of interdisciplinary treatment on chronic pelvic pain. This study had a low risk of bias; however, they had no control group due to the nature of the setting. The study had strict exclusion criteria, meaning 75% were excluded from taking part. They did have the largest number of participants of studies included in this review, 296. They did not report all the EHP-30 subscale scores as this was a secondary measure. The authors state: *'For the secondary outcomes, there was a significant improvement in functional quality of life (EHP-30 pain subscale)'* (Allaire et al., 2017). There was a significant reduction in participants with a physician or emergency visit in the last three months. The authors concluded that even if their pain improves, patients may still suffer from psychological concerns such as catastrophising, helplessness, depression, and anxiety. The authors recommend that psychological treatment be included in all treatments for chronic pelvic pain/endometriosis. This study did not present all the EHP-30 data.

One of the studies investigated the effectiveness of using psychotherapy with somatosensory stimulation for endometriosis-associated pain (Beissner et al., 2017, Meissner et al., 2016). The two papers provide a straightforward approach to the study and how the data were presented. The primary outcome of this study was looking at the functional connectivity of the hippocampus by using an MRI scanner. The secondary outcomes were quality of life, anxiety, depression and trait anxiety and stress. The authors used the SF-12 to measure quality of life. They presented two subscales, physical health, and mental health. To better understand the pre and post scores of the intervention and the control group, it was necessary to also look at the data in the Meissner et al. (2016) paper, as this paper presents mean changes. The Beissner (2017) paper provide methodological detail but only includes baseline scores for two subscales for the intervention and control group. This study is of low risk of bias; however, it does appear to have methodological issues, which are only understood by reading both papers. For example, the waitlist control group was only used for three months, and then those participants also received treatment, making it impossible to compare the follow-ups. All participants scores were included in the follow-ups. The authors did have success with their primary outcome measures, stating they found remarkable reductions in pain, anxiety and depressive symptoms. There does appear to be a statistically significant mean change in SF-12 physical health and mental health at the three months mark when the intervention mean change is compared with the control group mean change. The authors do acknowledge that this is a major limitation in the secondary outcome measurement.

Some studies had both a low risk of bias and no major methodological concerns. Goncalves et al. (2011) had no methodological issues (No missing data, zero dropouts, precise randomisation sequence) and low risk of bias. The authors were transparent about limitations and conservative when making conclusions and recommendations regarding using yoga as an intervention to improve pain and quality of life. Although the mindfulness-based intervention did not use a control group, they had zero dropout rates in the pilot and follow-up study. However, their sample size was small, and they reported 'ns' instead of providing scores. The authors were clear on the study's limitations and made conservative conclusions and recommendations (Kold et al., 2012, Hansen et al., 2017). The TENS intervention study was of high methodological quality and low risk of bias, with zero dropout rate. However, the authors report that it wasn't possible to blind participants and personnel. The authors also declare statistically significant results on the EHP-30 quality of life measure. Acupuncture-like TENS and self-applied TENS may be effective as a complementary treatment for chronic pelvic pain and deep dyspareunia in women with endometriosis (Mira et al., 2015).

De Sousa et al. (2016) investigated the effects of acupuncture on chronic pelvic pain and quality of life in women with endometriosis. This study had high methodological quality and a low risk of bias. Randomisation and allocation sequence is clearly presented, and there was a low dropout rate of 9.7%. This study used a control group and gave all the scores on the EHP-30 for both groups. Although they had a small sample size, the authors found statistically significant improvements in several EHP-30 subscales (work, sexual relationship, relationship with doctors, and relationship with treatment). Participants also reported a reduction in pain. The authors state: *'Data from this study demonstrated that improved quality of life was associated with decreased pain intensity during the five weeks of treatment. However, it is* *still not possible to confirm whether the reduction in pain led to improved quality of life or the converse'* (De Sousa et al., 2016).

3.13 Updated searches (November 2020)

The searches of databases were rerun in November 2020, almost three years since the initial searches were run. The same databases were used, and the same search strategies were used. The time period was limited to 2017-2021. There were 4,023 results returned from the searches after duplicates (985) were removed; there were 3038 results to be screened by title and abstract. After the titles and abstracts were screened, 23 studies were identified, and the full text of the articles were screened. Reasons for excluding results in the title and abstract screening were similar to the 2017 process: article was not available in English, participants didn't have endometriosis or adenomyosis, the study didn't use a quality of life measure, the intervention wasn't non-pharmacological or non-surgical.

After the full-text screening of 23 studies, two articles were considered relevant to this systematic review. The interventions included self-care counselling (Farshi et al., 2020) and Guided Self-Determination (Munch Simonsen, 2019).

The study on self-care counselling was a randomised controlled trial that aimed to determine the effects of self-care counselling on depression and anxiety and quality of life among participants with endometriosis. Self-care counselling focuses on an individual's ability to perform self-care and identify the individual’s needs. It is conducted in a series of group sessions. There were 38 participants in the intervention group and 38 participants in the control group. The SF-36 was used to measure quality of life. The authors did not report all the item scores for the SF-36. They did provide scores for the physical health composite and the mental health composite. The results showed that both scores for the SF-36 subscales were statistically significant. Limitations include missing data and not discussing the positive impact of group sessions on improving quality of life (Farshi et al., 2020).

The study on Guided-Self Determination aimed to assess if it was a feasible intervention for participants with endometriosis and if it supports self-management. This study used the EHP-

30 to measure quality of life and conducted a qualitative evaluation using semi-structured telephone interviews and focus group interviews, which were analysed using thematic analysis. There were 10 participants. The authors report that the EHP-30 scores improved at two weeks, and the EHP-30 scores showed improvement still after one year. The four themes identified were: feeling alone with the disease, establishing a meaningful relationship with healthcare professionals in traditional hospital settings, person-specific knowledge facilitated new behaviours and accepting a chronic condition – the beginning of a process. Whilst the scores for the EHP-30 were provided, those scores were not statistically analysed. The authors did provide figures showing the change in individual scores from baseline to 2 weeks and the one year follow up. The authors are cautious in the conclusion stating that Guided Self-Determination supported participants with endometriosis develop self-management skills concerning their condition and its symptoms. They encourage future investigation using a randomised controlled trial.

These articles were not included with the results from 2017 as those were used to inform the other stages of interventions: the needs assessment and the intervention itself. However, it is positive that qualitative studies have started to be returned as search results when this wasn't the case in 2017.

3.14 Adenomyosis

'Adenomyosis' was included in the search strategy and synonyms for painful, heavy periods. Whilst' primary dysmenorrhea' came up often in the results, adenomyosis did not. The first chapter of this thesis describes adenomyosis and its symptoms. However, the published literature excludes adenomyosis completely in intervention research or includes it under an umbrella term of 'endometriosis'. It could also be that a definitive diagnosis can't be made unless a hysterectomy has been performed and histological testing has shown adenomyosis was present in the uterus, so many younger women may not know they have it, or it may be suspected but not confirmed. Women can have adenomyosis alone, even though it is more commonly found with endometriosis. It should be noted that the symptoms do differ as well as the treatment.

3.15 Discussion

This mixed methods systematic review aimed to answer this research question: What non-surgical, non-pharmacological interventions are effective at improving quality of life for women with chronic pelvic pain, and what are the experiences of women attending them?

This review has included thirteen quantitative and zero qualitative papers. The interventions reviewed included: acupuncture, interdisciplinary treatment, a combination of psychotherapy and somatosensory stimulation, Chinese herbal medicine, yoga, mindfulness-based intervention, psychotherapy with somatosensory stimulation, TENS, physical therapy and psychological therapy, homoeopathy and Japanese-style acupuncture (Ahn et al., 2009, Allaire et al., 2017, Beissner et al., 2017, Meissner et al., 2016, de Sousa et al., 2016, Flower et al., 2011, Goncalves et al., 2017, Hansen et al., 2017, Kold et al., 2012, Mira et al., 2015, Petrelluzzi et al., 2012 and Teixeira et al., 2017 and Wayne et al., 2008). Each study attempted to evaluate the effectiveness of the intervention at improving the quality of life of women living with endometriosis and/or adenomyosis. Due to the variety of interventions and methodological quality issues, it is challenging to determine which interventions are more effective than others at improving quality of life.

The findings of two systematic reviews published in 2012 found that symptoms may be managed with hormonal therapy and surgery. However, a multidisciplinary approach to care is needed, and psychological interventions may be effective, but further research was needed (Shuang-Zheng et al., 2012, Champaneria et al., 2012). This systematic review supports the findings of these reviews; a multidisciplinary approach is required to provide adequate treatment that can improve quality of life. However, the need for published studies with higher methodological quality and a low risk of bias is just as essential. There is a need for appropriately powered studies with larger sample sizes.

This systematic review was conducted in 2017; section 3.13 discusses two identified articles when the search strategies were rerun in 2020. However, there have also been two systematic reviews published in 2019. One systematic review investigated psychological and mind-body interventions for pain and associated outcomes in people with endometriosis

(Evans et al., 2019). A second systematic review looked at the use of psychological interventions for endometriosis-related symptoms. It aimed to determine the effectiveness of these interventions at reducing pain and the psychological impact of endometriosis (Van Niekeik et al., 2019). The authors of these reviews found: a lack of high-quality research, mind-body interventions have the potential to be useful for people living with endometriosis, physical interventions, including physiotherapy, could be helpful for endometriosis pain, and mindfulness-based interventions had been associated with improvements of quality of life (Evans et al., 2019, Van Niekeik et al., 2019). This systematic review supports the findings of these reviews and has novel findings. It looked at a wider variety of interventions with one specific outcome, quality of life. Some papers overlap in all three reviews, but they all make their individual recommendations.

One of the main findings of this review was that many of the existing interventions that aim to improve the quality of life for people with endometriosis and/or adenomyosis contain elements of both mind and body therapy. Researchers have suggested that those who experience chronic pelvic pain are provided with access to a multidisciplinary team, including pain specialists, physiotherapy, psychologist and sex therapists, and GPs and surgeons (Robb and Mahmood, 2013, Rogers and Weston, 2012). This appears to be the most acceptable form of treatment, as patients have reported suffering psychological and physical symptoms (Moradi et al., 2014). The symptoms of endometriosis are complex and affect the whole person, body and mind (Huntington and Gilmour, 2005). Any intervention that aims to successfully improve the quality of life for those living with endometriosis and adenomyosis would have to include components that address physical symptoms and psychological suffering.

Another important finding of this review was the lack of published research on the patient experience of non-surgical, non-pharmacological interventions designed to improve the quality of life. There is a need for more user involvement in evaluating patients' experience of these types of interventions. The patient voice appears to be missing in this area of evaluation of interventions. There were no qualitative studies identified in this review when the searches were run in 2017.

The Medical Research Council advises that the first step of intervention development is identifying the evidence base by conducting a systematic review (Craig et al., 2019). The findings of this review were used to inform the following stages of intervention development. The findings informed the decisions made regarding the needs assessment and components of the intervention of this review. Due to the lack of qualitative studies identified in this review, it was decided that the needs assessment should be a qualitative study. The existing evidence suggests that a mind-body intervention has the most potential for improving the quality of life for people living with endometriosis and adenomyosis. These two findings are further discussed in the next section.

3.16 Implications

This systematic review implied that the next stage of intervention development, the needs assessment, should be a qualitative study. The Medical Research Council encourages researchers to consider what kind of user involvement could be implemented when developing interventions (Craig et al., 2019). The MRC advises that appropriate users should be involved at all stages of the complex intervention's development process and outcome analysis. This will likely result in better, more relevant science and a higher chance of producing implementable data (Craig et al., 2019). The MRC also advises that qualitative research can provide valuable insights into processes of change and can be a good way of involving users in developing an intervention (Craig et al., 2019).

The findings of the review, combined with the advice from the Medical Research Council, led to the choice of photovoice as a method for the needs assessment. Photovoice is a type of participatory action research (Latz, 2017). It is a process by which people can identify, represent and enhance their community through a specific photographic technique (Wang and Burris, 1997). This participatory research method aims to share the power between the researchers and the participants, who are given the role of co-researchers. The method places importance on the participant/co-researchers voices and experiences. Due to the gap in qualitative research identified by this review, the needs assessment would also aim to identify coping strategies that could also be incorporated into the intervention development process.

The main implication of the findings of this review was that the intervention needed to be psychological, with a mind-body component. Acupuncture was investigated in three studies in this review; the studies had varied methodological quality and results (Ahn et al., 2009, de Sousa et al., 2016, Wayne et al., 2008). However, this type of intervention lacks the 'mind' aspect of mind-body approaches. Yoga and mindfulness had been rated high on the MMAT (Goncalves et al., 2011, Kold et al., 2012, Hansen et al., 2017). The interdisciplinary approach and the combination of physical therapy and psychological therapy also had the potential for improving quality of life (Allaire et al., 2017, Petrelluzzi et al., 2012).

Mindfulness was chosen because this intervention has a mind-body component already contained within the intervention. It was also decided to include information on the link between the mind and body, pacing and a physiotherapy component. There would also be a session on mindful movement and diaphragmatic breathing. Chapter 5 discusses in more detail the building of the evidence base for the mindfulness intervention, where mindfulness interventions were evaluated, as well as the other components.

3.17 Limitations

There were a few limitations in this review, the main one being a lack of meta-analysis. The protocol for this review planned to include both meta-analysis and meta-ethnography of qualitative studies; however, it wasn't possible to have these in the review. The poor quality of reporting results in some studies meant there were a lot of missing data. There were also no qualitative studies included in the 2017 searches. This could be due to a lack of qualitative studies published in this area; however, it could also reflect how the research question was worded, including the word 'effectiveness', a term used primarily in quantitative studies. It may have been more helpful to separate the research into two, one looking for qualitative and one for quantitative studies. However, in the 2020 search, two of the articles were qualitative studies.

3.18 Conclusion

Endometriosis and adenomyosis are lifelong medical conditions with painful symptoms that can have a negative impact on quality of life. The most commonly prescribed treatments for these conditions are hormonal therapy, pain relief and minimally invasive surgery. Due to the nature of these conditions, pain can reoccur or change throughout a person's life. There is a need for non-surgical, non-pharmacological interventions to be adjutant therapies to provide patients with multidisciplinary care. There is a lack of high-quality research into which non-pharmacological, non-surgical interventions are most effective at improving quality of life. There is also a need for increased user involvement in qualitative research studies into the patient experience of these types of interventions.

This review found that mind-body interventions have the most potential to improve the quality of life for people living with endometriosis. This finding led to the identifying mindfulness, with a component of body awareness, pacing and physiotherapy as the complex intervention that was developed. The Phoenix Course then became an online 8-week mindfulness-based intervention, that was tailored to the psychological needs of people living with endometriosis and/or adenomyosis. User involvement in the intervention development process took the form of a participatory action research needs assessment; this is discussed in more detail in chapter 4. This needs assessment also helped identify further components to be incorporated into the intervention, as well as providing the psychological needs that the intervention had to address to improve quality of life.

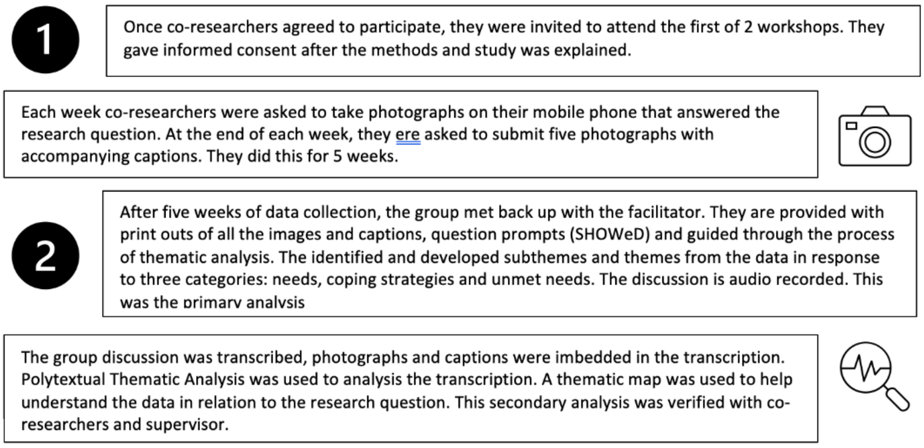
Chapter 4 Needs Assessment

4.1 Overview

The previous chapter discussed the findings of a systematic review of the evidence base. This chapter discusses the next stage of the intervention development process described in the MRC guidelines on developing complex interventions (Craig et al., 2019). Before the intervention was created, the needs of the target population needed to be better understood. While the evidence base shows that endometriosis and/or adenomyosis substantially negatively impacts quality of life, a better understanding was needed of specific needs. The components of the intervention had to be tied to particular needs. This chapter discusses the needs assessment, the photovoice research method and the findings of this study.

Figure 4.1 illustrates a simplified process of this photovoice study; each step is discussed in depth in this chapter.

Figure 4.1 What are the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis: A photovoice study.



Once co-researchers agreed to participate, they were invited to attend the first of 2 workshops. They gave informed consent after the methods and study was explained.

Each week co-researchers were asked to take photographs on their mobile phone that answered the research question. At the end of each week, they ere asked to submit five photographs with accompanying captions. They did this for 5 weeks.

After five weeks of data collection, the group met back up with the facilitator. They are provided with print outs of all the images and captions, question prompts (SHOWeD) and guided through the process of thematic analysis. The identified and developed subthemes and themes from the data in response to three categories: needs, coping strategies and unmet needs. The discussion is audio recorded. This was the primary analysis

The group discussion was transcribed, photographs and captions were imbedded in the transcription. Polytextual Thematic Analysis was used to analysis the transcription. A thematic map was used to help understand the data in relation to the research question. This secondary analysis was verified with co-researchers and supervisor.

4.2 Background

Chapter 1 discusses that previous studies have shown how the symptoms of endometriosis and adenomyosis can negatively impact the quality of life. The studies referenced in this chapter make a compelling case for the need to provide more high-quality interventions. Still, they do not identify and explore the everyday needs of this population. As with many chronic pelvic pain conditions, the difficulties of living with endometriosis and adenomyosis are complex, often intertwined, and challenging to untangle. Endometriosis is an ‘invisible illness’, meaning it’s not easy to objectively see the symptoms (Donaghue and Siegel, 1992).

People living with the most debilitating symptoms of endometriosis and adenomyosis may appear perfectly healthy, fit, and young. However, privately, they may be struggling with difficulties such as poor sleep, which has been reported in as much as 80% of women with chronic pelvic pain (Cosar et al., 2014). The painful impact of the symptoms of endometriosis is associated with an elevated likelihood of developing depression and anxiety among all ages of those diagnosed. It has been reported that 80% of women with endometriosis also showed symptoms of depression and anxiety, 30% had symptoms of severe depression, and 60% had symptoms of major anxiety (Sepulcri and de Amaral, 2009). Compared with healthy controls, it has been found that people with endometriosis have a higher prevalence of depressive and anxiety disorders (Cavaggioni et al., 2014). A longitudinal study of 10,439 women with endometriosis and the same number of control participants showed that people with endometriosis had a high incidence of developing major depression and depressive disorder and anxiety disorders (Chen et al., 2016).

The substantial impact of living with the painful symptoms of these conditions on mental health and quality of life may not be visible to others. People living with endometriosis may face the complex combination of living years with painful symptoms before receiving diagnosis and treatment, feeling ignored or not believed by healthcare professionals, interruption of everyday activities, difficulty with sexual and intimate relationships, uncertainty about fertility and the future, disruption in education and the workplace (Culley et al., 2013, Aerts et al., 2018). The painful symptoms may negatively impact mental health; however, the psychological suffering may also lead to increased pain symptoms and worse treatment outcomes (Aerts et al., 2018). When examining the needs of this population, it may be challenging to separate the physical from the psychological. The research question was focused on the psychological, but previous research has shown that both the psychological and the physical needs are interconnected (Guidice, Johannes, Healy, 2012, Culley et al., 2013).

User involvement in intervention development is encouraged by the MRC (Craig et al., 2019). The co-researchers in this study were aware that the purpose of the study was to examine psychological needs that could be addressed by a psychological intervention. Issues could have arisen by making assumptions based on published research findings and excluding the patient perspective. As the systematic review showed (Chapter 3), no qualitative studies investigated the patient experience of non-pharmacological, non-surgical interventions. This needs assessment allowed for the inclusion of the patient voice when developing the intervention. The APPG on Endometriosis was collecting data for their inquiry while the data for the needs assessment was being collected, showing that there was a demand for a more comprehensive understanding of the needs of this population.

People living with endometriosis and/or adenomyosis often turn to patient communities and self-help groups when their needs are unmet (Whelan, 2007, Horne and Pearson, 2018). Patients have found that they have had to educate themselves to advocate for themselves and obtain the diagnosis and treatment they need to reduce their symptoms, maintain their fertility, and increase their quality of life to lessen the impact of their condition (Whelan, 2017). The work carried out by women to reduce the effects of their condition has been described as a ‘third shift’, performed in addition to women’s paid and unpaid work (Seear, 2009b). This ‘third shift’ is a double-edged sword. It may be necessary to discover more about the condition and manage symptoms. Still, it can also be time-consuming and contribute to the stress and psychological suffering already being experienced. When needs are not being met, this ‘third shift’ may be vital in developing self-management strategies and getting access to treatment. However, patients already live with a painful chronic illness, working in and/or outside the home and putting in a ‘third shift’ has the same impact as working another job. Being proactive in managing their own health needs can be seen as patients empowering themselves and taking control of an otherwise difficult and emotionally demoralising situation. However, it has been suggested that if the role of self-care becomes a vital component, a possible consequence is that those who do not do everything they can for their health can be seen as ‘irresponsible citizens’ (Rimke, 2000).

There is a middle ground for managing chronic health conditions that can help both patients and healthcare professionals. A self-management approach where patients are informed and supported by healthcare professionals can improve outcomes and reduce healthcare costs (Lorig and Holman, 2003, Bodenheimer et al., 2002). The components and objectives of self-management interventions might differ depending on the conditions and symptoms being addressed, but the critical feature if the aim of increasing patients’ ability to deal with the day to day impacts of their condition to maintain a satisfactory quality of life (Barlow et al., 2002). However, self-management interventions are not straightforward; they are not a ‘one size fits all’ solution like pharmacological or surgical options for treating endometriosis and adenomyosis (Trappenburg et al., 2013). Complex interventions are defined as interventions with several interacting components with several dimensions of complexity (Craig et al., 2019). The complexities could be related to the range of possible outcomes, variability in the target population or the number of elements in the intervention itself (Craig et al., 2019). There is a lack of empirical evidence around what should be considered essential components of a self-management intervention, and the extent and direction effect size varies across different target populations (Trappenburg et al., 2013). More research is needed to try and establish the most effective design of dynamic self-management interventions, where content, mode and intensity can be tailored to the characteristics, preferences and values of individual patients (Trappenburg et al., 2013).

Understanding the needs of people is vital when attempting to provide them with an intervention of any kind. Maslow’s hierarchy of needs explains the different levels of needs that all humans have, starting with the basic physiological needs that need to be met for humans to have the motivation to work towards self-actualisation. (Maslow, 1943, 1954). This theory would provide insight into what happens when endometriosis and adenomyosis interfere with the basic needs or add additional needs that have to be met that healthy people may not have.

The objective of the overall PhD research was to develop an intervention to improve the quality of life of people living with endometriosis and/or adenomyosis. The systematic review findings showed that mindfulness has the potential to help people living with these conditions. However, the published literature on the impact of endometriosis and adenomyosis on quality of life has shown that many complex factors together and separately can lead to poor quality of life. To tailor a complex intervention, people living with the condition's psychological needs and coping strategies have to be explored more deeply. People living with endometriosis and/or adenomyosis have already been shown to put effort into understanding and managing their conditions and share this information within their community. It, therefore, makes sense to involve patients to help identify the psychological needs and coping strategies so that the complex intervention can be tailored to their specific needs. As mindfulness was identified in the systematic review findings, it could be suggested that any 8-week mindfulness intervention could be used. However, any intervention targeted at this population must acknowledge the complexity of the conditions and the psychological impact.

Several qualitative research methods could have been chosen to conduct a needs assessment. Focus groups, interviews or surveys could have been used to gather data that would help to tailor the intervention. These methods would have worked; however, it was essential to collect data on needs and coping strategies and encourage participants' deep reflection about their experiences in the study. There was concern that asking participants specific questions at one timeline would lead to data that did not fully capture their experiences. It was important that the data showed the underlying psychological impact and emotional reaction. Photovoice was chosen over other qualitative research methods for several reasons. 1. Endometriosis and adenomyosis are invisible conditions, and patients report feeling dismissed when they attend medical appointments despite painful symptoms, 2. Patients with endometriosis often seek support from others with the same symptoms or conditions. The second workshop focused on group discussion, with the co-researchers working collaboratively with both the intervention and final presentation of the photovoice study as goals. 3. Reflection on data was an essential requirement in the needs assessment. 4. Group discussion had to be purposeful, focused on talking about the images and captions to inform the psychological intervention. Rather than a general discussion sharing experiences of the conditions, the underlying psychological needs and coping strategies had to be identified. This was a requirement because it would be the findings would be incorporated into the intervention.

This photovoice study is reported following the Standards for Reporting Qualitative Research (SQRQ); these standards have been followed and documented to provide transparency in all aspects of the study and the method used (O'Brien et al., 2014).

4.3 Aims and Research Question

This study aimed to conduct a needs assessment to inform the development of a complex psychological intervention for people living with endometriosis and/or adenomyosis. The findings of this study would be used to tailor components of the intervention.

The research question was: 'What are the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis?

4.4 Methods

4.4.1 Qualitative Approach and Research Paradigm

Many qualitative research methods were considered, such as semi-structured interviews and focus groups. However, there was concern that these methods would lead to similar findings as the studies discussed in the introduction chapter or identify much larger needs than a psychological intervention could target, such as a cure for endometriosis/adenomyosis, new pharmacological treatments or suggestions for changes to the NHS. All these needs would be valid but could not be addressed by a psychological intervention. This study's participants needed to engage in reflection, which led to participant diaries or writing exercises being considered. The final decision about using photovoice over other qualitative methods was due to the invisible nature of the conditions being studied and the inclusion of the participants' own words alongside images. The data would be collected over five weeks from the same participants, allowing for reflection on both the images and captions chosen each week. The reflection by participants happened week by week but also during the second workshop.

Chapter 1 Introduction outlines the literature on gender bias in healthcare, particularly when it comes to women experiencing pain related to menstruation. It seemed appropriate to choose a method that had a participatory action research approach underpinned by feminist theory. Two women developed the photovoice method to collect data on the invisible aspects of community and society, e.g. homeless women and women living with HIV (Wang and Burris, 1997, 1999).

Photovoice is a form of participatory action research (Latz, 2017). It has been defined as ‘a process by which people can identify, represent and enhance their community through a specific photographic technique’ (Wang and Burris, 1997). Participatory action research differs from more conventional research in three main ways: shared ownership of research, community-orientated understanding of social problems and propensity for community action (Kemmis and Taggart, 2005). Participants are often referred to as co-researchers and involved in many aspects of the research process, even identifying the research question (Latz, 2017). Participatory action researchers conduct research with participants and not on participants (Latz, 2017). Shared power is the cornerstone of this approach (Latz, 2017). In this photovoice study, participants will be viewed as co-researchers as they are heavily involved in the data collection, data analysis and what form the outcome will take. The sharing of power and working collaboratively with a population who have reported being disbelieved, dismissed and ignored made photovoice an appealing choice as a research method.

Photovoice has been used as a tool to examine people’s lived experience, impact on quality of life and what could be done to improve the lives of those living with a range of long-term conditions (Wheeler and Early, 2018, Williams, Sheffield and Knibb, 2016, Mosarel and Sanders, 2010, Burles and Thomas, 2012, Bukowski and Buetow, 2011 and Wiersma, 2011). Photovoice can be a helpful research method as it can make the invisible aspect of long term conditions visible to others. Photovoice is a flexible research method that can be altered to fit diverse partnerships, community contexts, participant characteristics and research or intervention interests. The most robust photovoice projects are those with the highest rates of participation. These projects produce important outcomes to improve community health, including enhanced community involvement in action and advocacy, enriched public health research, and individual empowerment (Catalani and Minkler, 2010). Conducting a needs assessment using photovoice allows participants to describe their needs and provide a visual image of that need, enabling them to communicate that part of their lives to others (Wang and Burris, 1997). Photovoice has three main goals: 1) to enable people to record and reflect their community's strengths and concerns, 2) to promote critical dialogue and knowledge about important issues through large and small discussions of photographs and 3) to reach policymakers (Wang and Burris, 1997).

Although the philosophy underpinning photovoice as a research method is compatible with the study's aims, there are risks involved in any photovoice project. For example, the way this method was used in this study relied on a group of people to meet twice and can only work as a method if most people attend both workshops. As mentioned above, the most robust photovoice projects are those with the highest rates of participation. Issues with attendance or engagement with the method could lead to a weaker project. Also, as discussed above, there was no guarantee that the co-researchers would not identify the more significant needs of those living with endometriosis/adenomyosis.

There were two other concerns about using this method: 1. making sure the collaboration and action components were present in the research process and 2. ensuring that data analysis was both collaborative, with a high level of participation but also thorough. If these elements weren't present in the research process, it could be argued that it was a qualitative photo-elicitation study and not a photovoice study (Liebenberg, 2018).

4.4.2 Researcher Characteristics and Reflexivity

During the recruitment stage of this study, potential co-researchers were told that the facilitator and researcher had also been diagnosed with endometriosis, adenomyosis and fibroids. This was disclosed so that co-researchers could understand both the motivation behind the condition and that they didn't need to educate the researcher about the symptoms of their conditions. It was also hoped that this disclosure would indicate to the co-researchers that the facilitator and researcher belonged to the same community as them.

McFarlane and Hansen (cited in Kindon, Pain and Kesby, 2008) have written about how their experiences of being disabled women informed their research with disabled people. They disclosed their disabilities to participants to illustrate their politics and positionality in their research. They wanted to show that they were not using other people's struggles but that they had also experienced these struggles. They tried to set the scene and dissolve any appearance of hierarchy within the research; they continued to try to do this throughout the study. As a result, the participants in the study felt actively engaged in the project, which told the story of disabled women's lives and were able to effect change beyond their own circumstances. I wanted to inform the co-researchers that I had lived experience and academic knowledge of the researched conditions by disclosing my diagnoses. I tried to reduce the barriers in communication during the research process that may have arisen if the co-researchers felt the need to educate me about their symptoms or their conditions. There is further discussion on insider researcher in Chapter 2 Methodology.

4.4.3 Context

This photovoice study was conducted at Coventry University, with participants from the West Midlands (Coventry, Birmingham and Leamington Spa) and Cardiff. All of the participants were NHS patients, and some had sought private treatment or advice. The experiences captured by participants reflect the treatment they have received in the Midlands and Cardiff and further afield, such as Surrey or London. The participants reflected on recent experiences and historical experiences and accumulated knowledge of attempting to access care and treatment for endometriosis and adenomyosis from the onset of symptoms.

4.4.4 Sampling Strategy

Once the Coventry University ethics committee had approved (ref: 86194), a digital recruitment advert was produced. It was shared on social media platforms such as Twitter, Facebook and Instagram. Popular hashtags were paired with the recruitment advert to help encourage sharing by social media users. It was shared by academics at Coventry University and by support group members of Endometriosis UK online Facebook groups for Birmingham and the West Midlands. Potential co-researchers were invited to email if they were interested in coming to the workshops. Several email responses were received, and were contacted to arrange a screening phone call. Two participants were met in person, two participants could not attend the first workshop, so phone calls were arranged. A copy of the participant information sheet (Appendix IV Needs Assessment Participant Information Sheet) and the recruitment advert (Appendix V Needs Assessment Recruitment Advert) are included in the appendices.

To encourage in-depth conversation, it is recommended that the photovoice group has 7-9 participants (Wang, 1999). There were 7 participants recruited for this study. However, one person did not show up on the first workshop day due to ill health. Below are the inclusion criteria that were included in the recruitment advert and participant information sheets.

4.4.5 Inclusion Criteria

- Participants of this study should have a formal diagnosis of adenomyosis and/or endometriosis, including post-menopausal women.
- Able to read, write and speak English.
- Available to attend two workshops in Coventry.
- Have a mobile phone capable of taking and sending photographs

Five of the co-researchers were from the West Midlands and one from Cardiff, Wales. All co-researchers had a diagnosis of endometriosis, one had a confirmed diagnosis of adenomyosis, and two co-researchers reported having hysterectomies due to their condition. The women in this study were aged between 26 and 46 years old. None of the women in this study has had children. One woman was self-employed, one woman had been signed off work for long term illness due to her condition and recent hysterectomy, two women were full-time students, and two were in full-time employment.

4.4.6 Ethical Issues Pertaining to Human Subjects

When designing the study, it became clear that this participatory action research study would have different ethical considerations than a purely qualitative study. As the co-researchers would have a more active role in the research process than participants in a traditional qualitative or quantitative study, the ethics form and documents had to reflect this. There were two participant information sheets, one for the coresearchers to read before they signed their informed consent forms and one for the coresearcher to use for any third party they took an identifiable photograph of. There were three consent forms. One for the coresearchers to sign to participate in the study, one for them to use with third parties they took identifiable photographs of and a release form where the co-researchers gave consent to use their images and captions in publications, exhibitions etc. The General Data Protection Regulation (GDPR) came into effect in May 2019, just as the ethics form for this study was being prepared. The ethics committee raised concern over the use of photography in a research study, particularly as the data collected would be personal and sensitive. They asked if it was necessary to include photographs of people and, particularly, people's faces. A response was written, explaining due to the participatory nature of the study, it would be up to the coresearcher if they wanted to include images of themselves, their real names and how much they revealed about their medical conditions.

The ethics committee and the Office of Information Security also provided advice about the appropriate storage of digital images. These digital photographs were only accessible to the research team and stored on Coventry University's secure SharePoint online storage facility. For example, any printed materials signed consent forms were kept in a secure, locked locker on the fourth floor of the Richard Crossman building in Coventry University. The photographs were kept in online folders with participant ID numbers on them, and each one was numbered from 1-25 to show which order they were submitted in to avoid confusion. Physical copies of the photographs were printed for workshop two, these were also stored in the secure locker. Signed consent forms were scanned and saved digitally, and the paper copies were shredded. The ethics committee approved the study after these reassurances (P86194).

4.4.7 Data Collection Methods

The recruitment data collection period occurred over the Summer of 2019. Two workshops were held in the Centre of Intelligent Healthcare, the fourth floor of the Richard Crossman building at Coventry University. This venue was chosen as it's close to public transport links, car parks and has lift access, with bathrooms nearby. Both workshops were held on a Sunday, as this day fit the availability of the co-researchers. This also meant that privacy and a quiet environment could be provided to aid confidential discussion. The second workshop was audio recorded to aid with data analysis.

4.4.7.1 Workshop 1

The purpose of workshop 1 was to explain the study in detail to the coresearchers (including use of the third party participant information sheet and consent form), give them their research packs, provide training on the method and allow them to ask questions or raise any questions. The research pack contained copies of the third party participant information sheet and consent forms for the co-researchers to use, a printout of the slides from the presentation, information about the steps of the research process and a notebook and pen. There was also a copy of the information about data security from the Office of Information Security about password protecting Word documents. The coresearchers talked about the definition of the word 'need' and were shown different examples of photovoice projects. A copy of the presentation for Workshop 1 (Appendix VI Workshop 1 Presentation) is included in the appendices.

4.4.7.2 Workshop 2

Once data collection was finished, the coresearchers attended a second workshop. This workshop lasted from 10 am to 4.30 pm, with breaks throughout the day. Lunch, snacks and drinks were provided for the workshop. Again, the coresearchers were given a folder, this time with printed and numbered copies of their images and captions. There was another presentation explaining the schedule for the day and the process of data analysis. A large piece of paper was pinned to the back of the door, where ideas for the final presentation could be written down: pens and large sheets of paper were on the table in the room. Also on the table were two sets of stickers. Red stickers for any images the coresearchers did not want to be included in the study, the final presentation or both. Gold stars were provided for any image that the coresearchers felt were particularly meaningful and had to be included in the final presentation. A copy of the presentation from Workshop 2 (Appendix VII Workshop 2 Presentation is included in the appendices.

Wang and Burris have provided a procedure of eight steps when using the photovoice method (Wang and Burris, 1999). This procedure, as followed in this study, is outlined below.

4.4.7.3 Procedure

Step One: Identification

This step involved identifying the topic to be researched and the research question. It also involved identifying policymakers, those who could be made aware of, have a hand in or be an advisor to the group of coresearchers. For this study, the co-researchers were tasked with deciding what format the final presentation would take and who they would like to invite to the final presentation. The co-researchers were given until the second workshop to think about ideas for the final presentation; they were shown examples of final presentations from other photovoice projects. It was important that the co-researchers felt a sense of ownership and responsibility for the project and involving them in decision making was a way of doing this.

This study was part of the needs assessment stage of intervention development; the research question was already decided upon before workshop 1. However, during the first workshop, time was spent discussing the co-researchers interpretation of the word ‘needs’ and differentiating between physical and psychological needs. Different definitions of needs were also discussed. The facilitator's role here was to encourage the co-researchers to have confidence in using their own interpretation of the research question and that there was no right or wrong answer. The co-researchers were also asked to think about if they wanted to use their real names, be anonymous or use a pseudonym. All the co-researchers chose to use their real names.

Step Two: Invitation

Before the study began, the co-researchers were asked to read the participant information and sign the consent form. The co-researchers were informed of the nature of the study, the commitment required from them as co-researchers, including dates, ties and place of workshops, time and effort involved in data collection and analysis, how their data will be stored and processed and how the findings will be used. The co-researchers were given time to ask questions before signing the consent form and throughout the research process. They were informed that participation was voluntary and that they may leave the study at any time without giving a reason.

Step Three: Education

As described above in section 4.4.7.1 Workshop 1, the purpose of the first workshop in the research process was to educate the co-researchers on the method of photovoice and all of the practical responsibilities of the co-researchers in the research process. The first workshop lasted two hours and included a presentation with information about the study and a group discussion, which had time for questions and any concerns. The ethical considerations of the study were discussed in detail, and the co-researchers were encouraged to send emails if they had questions during the research process.

Step Four: Documentation

The co-researchers were instructed to take as many photographs using their mobile phones each week for five weeks. At the end of each week, they had to choose five images, put them in a word document, add a caption for each image, add the agreed password to the document, and email it to the facilitator. The facilitator would download the documents on a

Sunday afternoon, securely save the document, and delete the email. There were times when the documents containing the images and captions were delayed due to other commitments and illness; the co-researchers were reassured that they should prioritise their commitments and health and send the documents when able. During the first week of data collection, all of the co-researchers sought reassurance from the facilitator that they had answered the research question correctly, and they were given reassurance that they had.

Step Five: Narration

The photographs taken and emailed by the co-researchers in response to the research question were not considered data by themselves. Without the captions, it would not be possible to view the image and understand the context and meaning behind the image. Without the captions, the images would be meaningless and could be misinterpreted. The addition of the images means interpretation by the viewer is minimalised, and viewers can see through the co-researchers eyes. In previous studies, when disposable cameras have been used, the narration stage is often later than taking the photographs, happening after the film has been developed. The use of mobile phones allowed captions to be applied directly to the images as they were submitted each week.

Step Six: Ideation

This step relates to the data analysis stage of the research process. This step takes place during workshop 2. The facilitator's responsibility is to 'give voice' or 'make space' for the co-researchers to interpret and analyse the images and captions they have produced (Latz, 2017). At this stage, the facilitator's role is to facilitate the process, support the co-researchers, and keep in mind that the images and captions produced should always show the co-researchers gaze, something the facilitator/researcher can never fully experience or understand completely (Latz, 2017). Even though the facilitator/researcher in this study does live with the same conditions as the co-researchers, there can be variation in symptoms and experience. Therefore, it cannot be assumed that the facilitator/researcher has the same understanding of the conditions as the co-researchers. This step is discussed in further detail in the Data Analysis section below.

Figure 4.4 is a photograph taken of the co-researchers during the second workshop. All the co-researchers consented to this picture being taken and shared.

Figure 4.4. Co-researchers during thematic analysis in the second workshop.

Steps Seven and Eight: Presentation and Confirmation

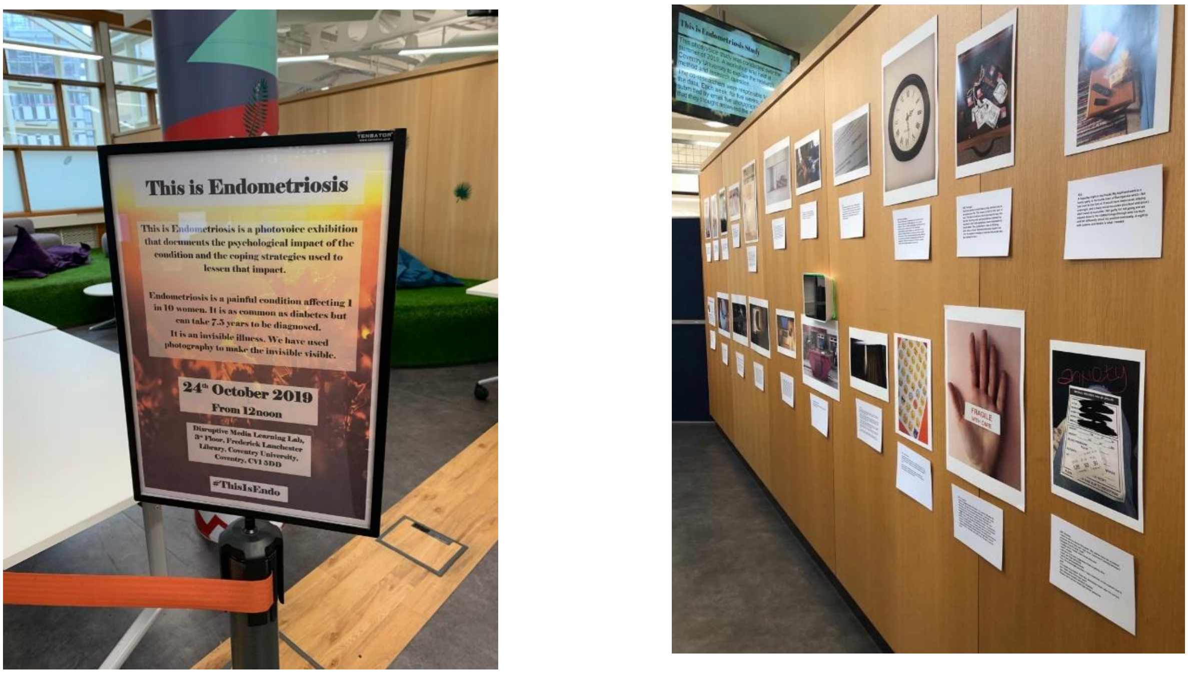
During the first workshop, the co-researchers were asked to think about what they would format they would like the final presentation to take. They were shown examples of a photography exhibition, website, short film but were asked to suggest their own ideas.

During the second workshop, the co-researchers decided upon a photography exhibition and brainstormed a title. The facilitator/researcher had reassured them that while they would get to determine if any images and captions were not included, they also got a say in which images they felt should be included in the exhibition. One co-researcher indicated an image she wanted to exclude from being publicly displayed related to her employment. The co-researchers decided they trusted the facilitator/researcher to choose the images to be displayed. They were given a cool-off period in case they changed their mind.

The group were also asked if they would like to write individual profiles or comments for the exhibition, as one of the examples shown in workshop 1 had done. The co-researchers discussed this and explained that they had worked as a collective and small community and wanted the exhibition to show this. They wanted the exhibition to tell the story of the needs and coping strategies of the 'Endo Community'. They did not want the images to be grouped by individuals but by the themes identified in the data. The co-researchers were also asked to email a list of people they wanted to invite. The facilitator/researcher's responsibility was to create the adverts for the exhibition and contact people to be invited. The co-researchers could also invite people; adverts were printed and sent to the co-researchers so they could give them to people and advertise in their local area. Adverts were also placed around Coventry city centre and the university. It was also advertised online using social media. The co-researchers also shared the adverts online and in in-person support groups.

The final presentation of the study results took the form of a photography exhibition, held on 24th October 2019. The co-researchers had agreed on the title of 'This is Endometriosis' for the exhibition. There were 143 images, and the captions totalled over 13,000 words. They were organised into themes to tell the story of what it's like to live with endometriosis. They were organised into symptoms, everyday life, gratitude, emotional burden and mental health impact. Four co-researchers were able to attend and invited their friends and family members. The Endometriosis UK support group from Leamington Spa attended to offer support and information; many of the members of their group attended along with their family members. Academics, researchers and students from the Centre for Intelligent Healthcare, the faculty of Health and Life Sciences, Coventry University were in attendance. A local CIC, Hope For The Community, provided support and displayed their gratitude wall, where attendees could share what they were grateful for. Attendees were asked to complete a postcard exercise, where they had to complete the sentence: 'Endometriosis is . . .' on the back of a postcard. The purpose of this exercise was to see if the exhibition impacted the attendees and see if the 'action' part of PAR had been achieved. The responses showed that the attendees were split into two groups: those living with endometriosis and those who were not but who know someone with the condition and saw the opportunity to learn more. The photography exhibition was then turned into a photo book (Living with Endometriosis).

Figure 4.5 and 4.6. The photography exhibition 'This is Endometriosis'.



This is Endometriosis

This is Endometriosis is a photovoice exhibition that documents the psychological impact of the condition and the coping strategies used to lessen that impact.

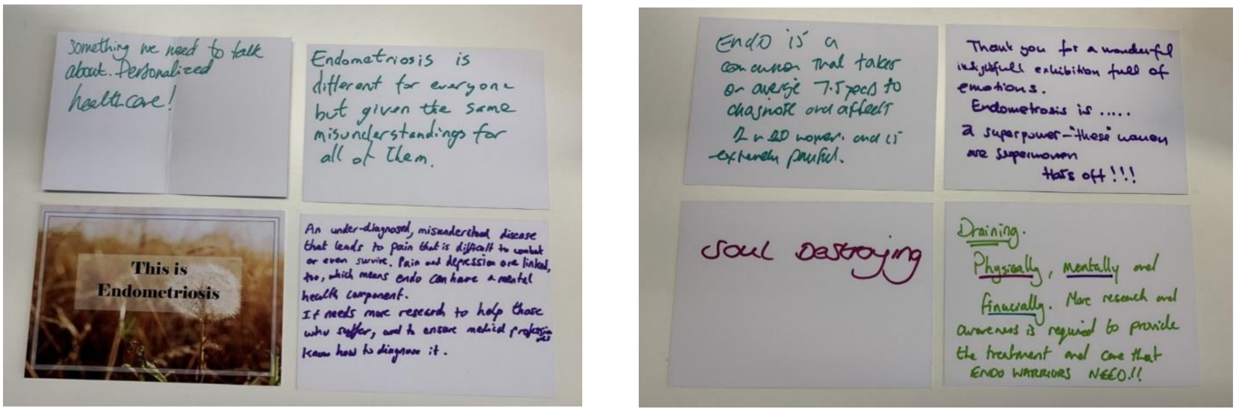
Endometriosis is a painful condition affecting 1 in 10 women. It is as common as diabetes but can take 7.5 years to be diagnosed.
It is an invisible illness. We have used photography to make the invisible visible.

24th October 2019
From 12noon

Disruptive Media Learning Lab,
3rd Floor, Frederick Lanchester
Library, Coventry University,
Coventry, CV1 5DD

#ThisIsEndo

Figure 4.7 and 4.8 Some of the postcards completed by attendees of the 'This is Endometriosis' photography exhibition.



Something we need to talk about. Personalized healthcare!

Endometriosis is different for everyone but given the same misunderstandings for all of them.

This is Endometriosis

An under-diagnosed, misunderstood disease that leads to pain that is difficult to combat or even survive. Pain and depression are linked, too, which means endo can have a mental health component.
It needs more research to help those who suffer, and to ensure medical professionals know how to diagnose it.

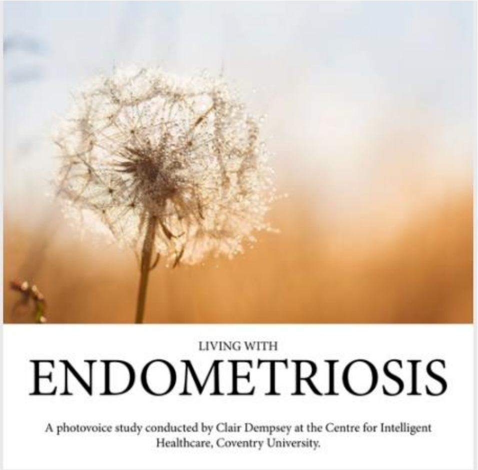
Endo is a condition that takes on average 7.5 years to diagnose and affects 1 in 10 women. and is extremely painful.

Thank you for a wonderful insightfull exhibition full of emotions.
Endometrosis is .....
a superpower - "these" women are superwomen
hats off!!!

Soul Destroying

Draining.
Physically, mentally and financially. More research and awareness is required to provide the treatment and care that ENDO WARRIORS NEED!!

Figure 4.9 Cover image and QR code for Living with Endometriosis digital photo book



LIVING WITH

ENDOMETRIOSIS

A photovoice study conducted by Clair Dempsey at the Centre for Intelligent Healthcare, Coventry University.

4.4.8 Data Collection Instruments and Technologies

The eight-step procedure provided by Wang and Burris (1999) was followed throughout the study. Participants used their mobile phones to take and send photographs to the facilitator. The images and captions were stored securely on a SharePoint folder, accessed only by the facilitator and supervisor, Professor Andy Turner. A PowerPoint presentation was given in both workshops to explain the nature of each workshop and the goal of each workshop. Two audio recorders were used to capture the discussion in the second workshop. One recorder was used as a backup in case of technology or battery failure. There were question prompts placed on the table in the second workshop, but these weren’t used. Each participant was provided with a colour copy of the images and captions submitted via email to the study. Each image had an identifiable number written next to it to aid discussion and later analysis. As shown in Figure 5.4, large pieces of paper were used to write down subthemes and themes and photograph numbers.

4.4.9 Units of Study

There were six participants in this study. Combined, the co-researchers submitted 143 images to this study, each with a caption. The captions combined totalled over 13,000 words. The co-researchers, guided by the facilitator, conducted the primary analysis followed by a secondary analysis of the discussion transcript recorded in workshop 2, with the images and captions placed within the transcript, where a co-researcher spoke the identifiable number of the image.

4.4.10 Data Processing

The primary data analysis was done in the second workshop. Each co-researcher was given a folder containing their images and captions. Each image was also numbered in the order they were submitted by email. The co-researchers were numbered 1-6, and the images/captions were number 1-25. Each image/caption had three numbers written beside it. The facilitator/researcher also had a copy of all of the images/captions with numbers. Section 4.3.5 provides details about what happened in the second workshop. The data analysis process was explained in a presentation, and the SHOWeD technique (Shaffer, 1983) was described, and print outs provided to the co-researchers in case they needed prompts to guide the discussion. These weren't used on the day. The goal and process of polytextual thematic analysis were explained (Gleeson, 2011). The purpose of the numbering was explained as well. As the second workshop was audio recorded, for the secondary analysis, instead of holding up the image/caption while talking about it, the co-researchers would need to read out the number written on the image/caption. Before the data analysis started, there was a group discussion on the meaning of 'need' and 'coping strategy'.

Initially, the plan was first to identify needs, followed by coping strategies developed in response to the needs. However, during the practice exercise, where the co-researchers first discussed an image in pairs, it became clear that the needs and coping strategies were entangled, and the most straightforward way to discuss them were together. Large pieces of paper were placed on the table, along with pens, notepaper and stickers. The facilitator/researcher was responsible for making notes on the large sheets of paper about the subthemes, themes, needs and coping strategies. This was enabled by using the audio recorder, as the facilitator/researcher didn't have to keep notes on the discussion.

Before the primary analysis began, a co-researcher raised the point that from looking back through her images, it was clear to her that there were 'needs', 'coping strategies' and 'unmet needs'. The group discussed this, and the others agreed and decided that 'unmet needs' had to be added to the categories. The rationale for this was that everyone has needs, whether they have a long term health condition or not. However, endometriosis and adenomyosis can often prevent these basic needs from being met. They also discussed how gaps in healthcare resulted in them having 'unmet needs' that should be taken care of by the healthcare system. When these 'unmet needs' occur, the co-researchers often have to develop coping strategies to limit the impact these have on their quality of life.

4.4.11 Data Analysis

The goal and procedure of thematic analysis (Braun and Clarke, 2006) were explained to participants in the presentation given at the beginning of the second workshop. The question prompts on the table of the second workshop were SHOWeD (Shaffer, 1983). These prompts are:

1. What do you **S**ee here?
2. What is really **H**appening here?
3. How does this relate to **O**ur lives?
4. **W**hy does this situation, concern or strength **e**xist?
5. What can we **D**o about it?

The SHOWeD prompts were discussed at the beginning of the second workshop, and printouts were on the table. These prompts weren't overtly used in the analysis. However, they were helpful in the initial discussion of identifying and developing themes and subthemes. This discussion led to the decision to include 'unmet needs' as a category.

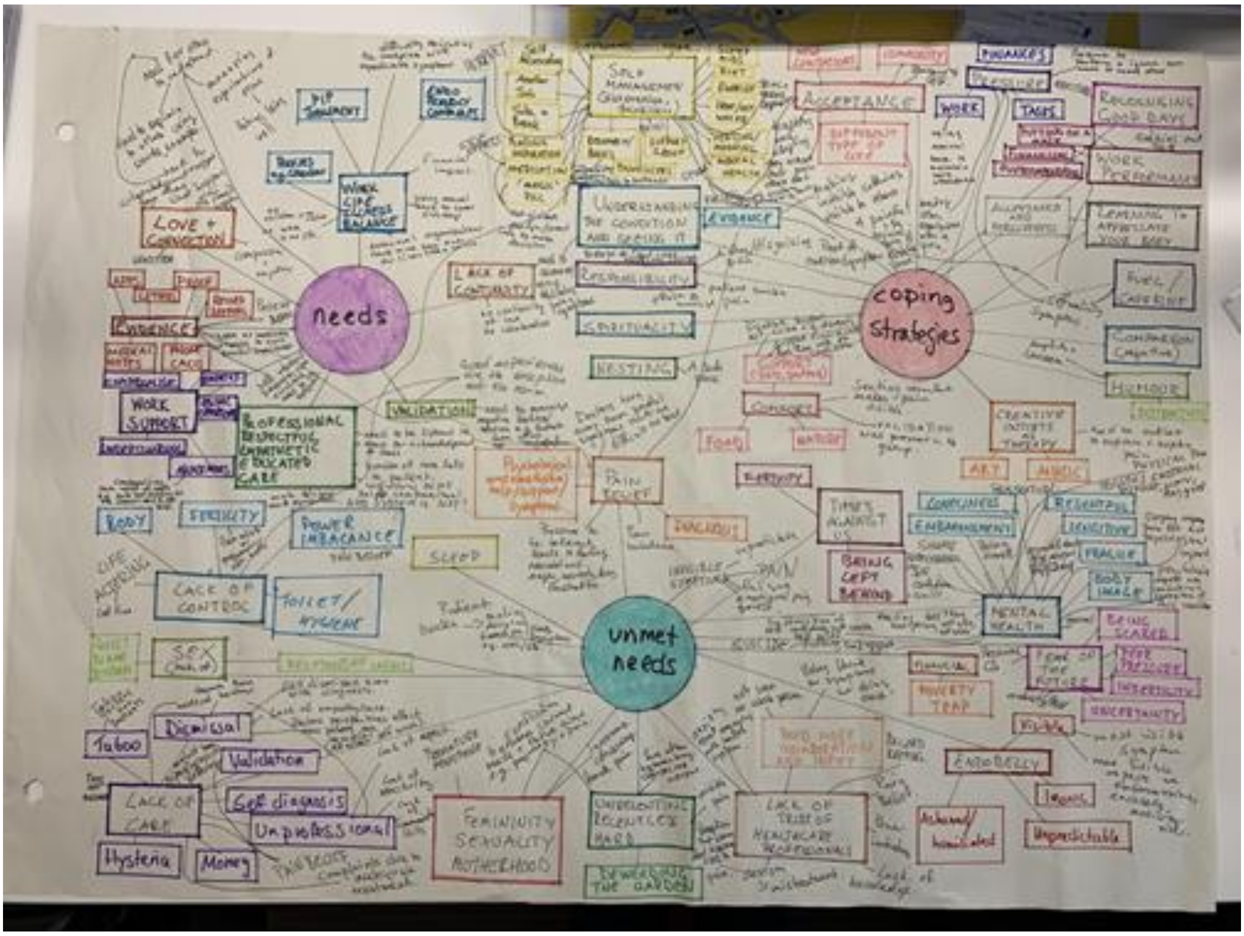
Large pieces of paper were placed on the table, along with pens, notepaper and stickers. The facilitator/researcher was responsible for making notes on the large sheets of paper about the subthemes, themes, needs and coping strategies. This was enabled by using the audio recorder, as the facilitator/researcher didn't have to keep notes on the discussion.

One of the co-researchers volunteered to go first and showed the image/caption to the group, said the number on the image/caption and talked about the meaning of the image. The conversation mainly stayed between the co-researchers, with the facilitator asking questions to clarify the subthemes. As the conversation went on, subthemes grew into themes, which in turn were linked to subthemes. Examples of this are shown in the results in section 4.4. As patterns were identified, the themes were clarified and moved into the ‘needs’, ‘unmet needs’ or ‘coping strategies category. Occasionally, as a theme developed, it would be moved from one category into another. Sometimes a co-researcher would discuss an experience not linked to an image/caption in the study but often in response to an image. The facilitator would ask if any images/captions captured the experience or something similar. These experiences were recorded in the audio and are in the transcript but were not identified as a subtheme or theme. The facilitator would guide the discussion back to the analysis of the data in the room. The facilitator would often ask questions to help to clarify the subtheme or theme. Usually, when the group discussed the meaning of the subtheme, it would lead them to identify images that also showed the same theme or pattern.

The secondary analysis conducted by the facilitator of the discussion transcript in the second workshop, with images and captions embedded, was done using polytextual thematic analysis (Gleeson, 2011). Embedding the photographs into the transcript was recommended in published literature (Papaloukas et al., 2017) and allowed the transcript to be analysed along with the context of the discussion. There are 7 phases of polytextual thematic analysis: familiarisation, coding the data, searching for themes, thematic map, reviewing themes, defining and naming themes and producing the report (Gleeson, 2011). Polytextual thematic analysis was used to double-check the primary analysis and provide context to the research findings and ensure that the co-researchers were the primary drivers of the analysis. As a researcher, I played a background role facilitator. I asked open-ended questions to clarify points and kept the group discussion pace focused on the data. Originally the plan was to exclude any missed data during the discussion. However, the co-researchers asked if I would contact them if any of their images were missed. Once the audio was transcribed, a list of the numbers of the photographs showed that there were a couple of images missed by three of the co-researchers. They emailed back where the images fit within the themes identified.

A thematic map was produced as part of the analysis procedure. The themes developed during the primary analysis were recorded on the map in coloured ink, with the category they related to. After the secondary analysis, the links between the themes, context and further development of themes were recorded in black ink. This was added to make sense of the data and themes. Figure 5.10 is a photograph of the thematic map.

Figure 4.10 Thematic map after primary and secondary analyses



4.4.12 Techniques to Enhance Trustworthiness

After the secondary analysis was completed, the list of themes and subthemes within the categories of ‘needs’, ‘coping strategies’ and ‘unmet needs’ were sent to co-researchers. A copy of all the photographs and captions had been given to all co-researchers to verify the themes within the categories with the images. This ensured that all the images and captions were analysed and demonstrated that the themes were not altered. The data, analysis process, thematic map and co-researcher comments were discussed during regular supervision meetings. Reflexivity was also crucial in this research, and a reflective research logbook was used. Each Sunday, when images and captions were submitted, reflective writing followed. Professor Andy Turner had access to all the data, audio recording and transcription to ensure quality was maintained during the research process.

4.5 Results/Findings

This section will present a synthesis and interpretation of the findings and include examples of data that demonstrate how the synthesis and interpretation were established through data analysis. Table 4.1 lists all of the subthemes and themes that fall under the categories of 'needs', 'unmet needs' and 'coping strategies' that were identified during the data analysis process.

As part of the intervention development process, each need, unmet need and coping strategy was translated into an evidence statement that would, in turn, be included in the Theory of Change procedure. A copy of all the evidence statements produced from this study is included in the appendices (Appendix VIII).

Each of the psychological needs, unmet needs and coping strategies are discussed in this section, including photographs with captions and excerpts from the transcript.

4.5.1 What are the psychological needs of people living with endometriosis and/or adenomyosis?

The definition of the term 'need' was discussed in both workshops before analysis. The co-researchers understood a psychological need that anyone could have, e.g., love, connection with others, support in the workplace or professional, respectful, empathetic healthcare. However, during the discussion, it became clear that symptoms of endometriosis and adenomyosis can be a barrier or interfere with having those needs met. This was often linked to the invisibility of the conditions or the lack of knowledge about the health conditions from others. This leads to more specific needs related to the condition, such as the need for validation, continuity of care, and work/life/illness balance. From the start of data analysis, as themes developed and grew and were discussed concerning identifying needs, it became clear that there is minimal separation between physical and psychological or mental health. Each of the seven needs that were identified during data analysis are described.

Table 4.1. The needs, unmet needs and coping strategies identified using polytextual thematic analysis (Gleeson, 2011)

Needs	Unmet Needs	Coping Strategies
For Love & Connection **To Provide Evidence** • Apps • Medical Notes • Letters • Phone calls • Record Keeping • Proof **For Work Support** • Compromise • Understanding • Adjustments • Empathy • Equal Opportunity **For Professional, Respectful, Empathetic, Educated Care** **For Validation** **Need for Continuity of Care** **For Work/Life/Illness Balance** • PIP Judgement • Policies, e.g., Glassdoor • Endo Friendly Companies • Motivation	**Lack of Care** • Validation • Dismissal • Self-Diagnosis • Hysteria • Taboo • Unprofessional • Money **Pain Belief** • Psychological and emotional help/support/symptoms • Diagnosis **Sleep** **Lack of Trust in Healthcare Professional** • Need more collaboration and input **Unrelenting/Relentless/Hard** • ‘Deweeding’ the garden **Time’s Against Us** • Fertility • Being left behind **Mental Health** • Loneliness • Embarrassment	**Self-Management (diet, exercise, painkillers)** • Self-advocating • Another Job • Medication • ‘Magic’ pill • Supplements • Hope • Painkillers • Sleep aids • Diet • Exercise • Heat/hot water • Take a break • Support Group • Venting/moaning • Research/books • Finding inspiration • Mental health **Comfort** • Support (pets, partners) • Nature • Food **Humour** • Distraction **Learning to Appreciate your Body** • Acceptance and forgiveness

	• Resentful • Sensitive • Fragile • Body Image **Lack of Control** • Fertility • Body • Toilet/Hygiene • Power Imbalance **Femininity, Sexuality and Motherhood** **Sex (lack of)** • Relationship Impact • Guilt/Blame/Burden **Endo Belly** • Visible • Unpredictable • Ironic • Ashamed/Humiliated **Financial** • Poverty Trap **Fear of the Future** • Uncertainty • Infertility • Peer Pressure • Being Scared • Who will look after me? How will I look after others?	**Work Performance** • Putting on a mask • Overcompensating • Financial **Comparison (negative)** **Fuel/Caffeine** **Acceptance** • Different Type of Life • Community • New limitations **Compassion** **Nesting** • Taking the Mask Off and Slippers on **Responsibility** **Spirituality** **Creative Outlets as Therapy** • Art • Music **Recognising Good Days** **Understanding the Condition and Seeing it** • Evidence

4.5.1.1 Psychological Need – The need for love and connection

One of the most significant themes identified from the data is the need for love and connection with others. There are two perspectives of this psychological need: the need for loving relationships that everyone has and the effects of endometriosis and adenomyosis on relationships. The images and captions within this theme include discussing romantic relationships, future relationships, pets and reaching out for support from others with the same condition, which was also recognised as a coping strategy. Within the captions of the data in this theme are expressions of gratitude for the pets and people in their lives, the sense of being a burden and feelings of guilt about pressure their condition can have on romantic relationships. Below is an image and caption that belongs to the theme 'need for love and connection'.

Figure 4.11 Partnership

Partnership
My boyfriend has been there throughout my entire endometriosis journey. Through the initial symptoms, continuous GP appointments and countless tests. By my side in all of the hospital waiting rooms, the consultations and beside my hospital bed after surgery. Watching me helplessly as I'm curled up in pain knowing nothing, he can do to stop it. He has seen it all. Despite his continuous support and strength, he has given me – there is a strain between us that endometriosis has caused. It has impacted negatively on us to the point it nearly destroyed our relationship. For he has also suffered with me throughout this journey.

4.5.1.2 Psychological Need – The need to provide evidence

The need to provide evidence was identified from images and captions that captured filing medical letters, documenting symptom patterns, and proving to others that they were unwell. This referred to trying to get a diagnosis and, afterwards, getting treatment for their ongoing symptoms. This need was also linked to the invisibility of both endometriosis and adenomyosis but also pain in general. One image showed a co-researcher squeezing her boyfriend's hand to show how much pain she was experiencing. The co-researchers discussed their frustrations at having to prove they were in pain, that what they were experiencing wasn't just 'painful periods'. Below is an excerpt from the transcript from the second workshop, where I try to understand if the co-researchers are describing a coping strategy or a need.

> Me: "So, do you think that communication is a coping strategy because we have all the letters and you're communicating your pain and your circumstance. And you're self-advocating but it's not just about self-advocating because it's about communicating to get action. So, you, so like, it that- "
>
> Ria: *"I guess it's record keeping, isn't it? Because you're – Well I haven't done that as much but actually I think, by the sounds of it you guys, you're having to do that because they're not really doing it? And actually, I have that problem as well that I was saying earlier. They don't seem to pass on things."*
>
> Clare: *"You do keep a record on your app though. So, you do keep some form of recording,"*
>
> Ria: *"Yeah, I guess I just haven't looked into it very much."*
>
> Me: "So I've put down app. And then medical notes."
>
> Lara: *"I've never used the apps, is there any sort of way to record pain on the apps as well?"*
>
> Clare: *"Yeah, some of them have that."*
>
> Lisa: *"Yeah, there is. Alongside record making there's sort of about evidencing. Evidence. . . And just the word evidence immediately suggests a lack of belief doesn't it?"*
>
> Clare: *"They keep telling you to see different people. It's like we've got to keep the evidence to fight and prove that well this didn't happen. And I always have someone with me to prove what happens and what was said. "*

4.5.1.3 Psychological Need – The need for work support

The need for work support refers to needing extra help in the workplace due to their condition. This refers to being unable to take regular toilet breaks, feeling judged for taking more toilet breaks than others, feeling confident enough to ask for a chair, and using annual leave for sick leave to avoid triggering a disciplinary. There was a discussion around whether the co-researchers shared their diagnosis with their employer to get reasonable adjustments. The images and captions that led to the identification of this need were of items that were physically uncomfortable and contributed to the pain, such as work chairs, stairs, walking to work, navigating public transport and an image taken by a co-researcher of working on her laptop in her bed during an excruciating day. Another co-researcher discussed limiting how much water she drank during the workday as she could not go to the bathroom as often as she needed. Below is a photograph of Ria at work.

Figure 4.12 Fingers Crossed

Fingers Crossed
What do you do when you are in agony but you have a presentation to give?
You grit your teeth and cross your fingers – so many times when I'm at work I'm hiding how awful I feel.

4.5.1.4 Psychological Need – The need for professional, respectful, empathetic, educated care

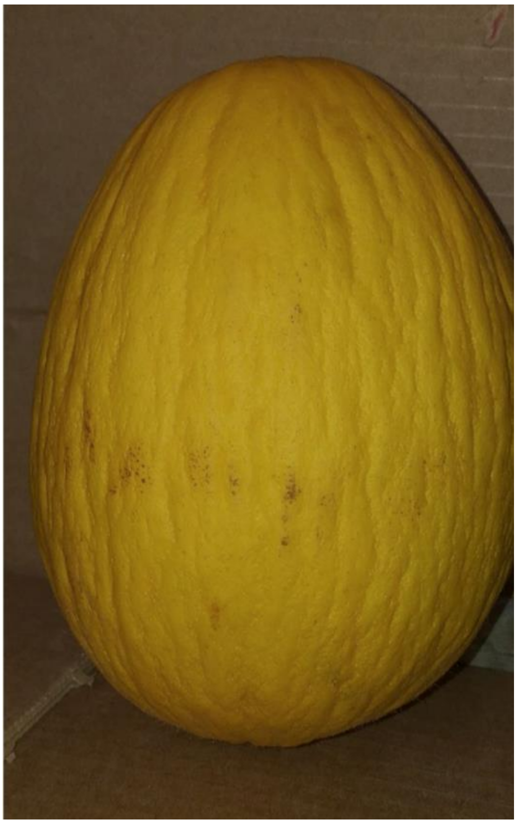
The need for professional, respectful, empathetic, educated care was identified very slowly and developed from many negative subthemes that are discussed in the unmet needs identified. The negative experiences discussed by the co-researchers contributed to identifying this theme but so did the positive experiences. Two co-researchers shared positive experiences with healthcare professionals, one during an ultrasound and one about two paramedics. They discussed how relieved they felt when they received professional, respectful, empathetic, educated care. The co-researchers acknowledged that this is the type of care that everyone should receive, but it was a type of care that they didn't experience often; they had more negative experiences than positive. The images and captions that led to the identification of this need were of medication, NHS information. They documented the process of trying to get out of hours advice on medication due to escalating pain. Below is an excerpt of the transcript, where the co-researchers gave examples of bad experiences of healthcare; I asked them what the opposite would look like if their needs were met, Shannon shared an example.

> Shannon: *"I have a picture, I don't if it's – it's 419 – it's a picture of how NHS 111 works. Em and I have em. I wrote: I wish it was as easy as they make it sound. Well, that Sunday morning I needed to get advice on dosage for meds for making sure my pain doesn't escalate and I ended up needing an ambulance. The first call I made I was given the advice to call my doctors on Monday morning. That's too late then. The second call I made, asking for the same information I got sent an ambulance. The ambulance guys were fantastic, I couldn't have asked for better care from them but if I could've spoken to a human that understood what I was saying then maybe I wouldn't have needed that service, the ambulance. . . The ambulance guys were amazing. The first time I've ever come across two guys that understood what I was going through. . . They were totally understanding. They were just so good. . . And I've never experienced two guys actually acknowledged my pain and made me feel, he said we have so many women not calling with and going to A & E because of endo and It's something I'm learning a lot about."*

4.5.1.5 Psychological Need – The need for validation

The need for validation is closely linked to the need for professional, respectful, empathetic, educated care. They discussed how it felt to have their experiences of having their pain or other symptoms acknowledged and understood. The co-researchers discussed the difference this made. One co-researcher took a photograph of a melon. The caption described her experiences of having a hysterectomy for adenomyosis privately after struggling to be heard in the NHS. She shared how she had lost so much blood due to adenomyosis that she wasn’t physically well enough initially for surgery, and her surgeon had to increase her red blood count before surgery. She discussed her relief but also her frustration at her symptoms being missed by her NHS doctor. The need was also linked to getting validation from loved ones and others with the same health conditions by attending a support group. One co-researcher hadn’t talked to someone else with the same health condition and wasn’t aware of support groups. Below is one of the images that led to the development of this need.

Figure 4.13 Melon Womb!



Melon womb!
I finally came to the have the hysterectomy. The beacon of support and understanding that was my new consultant took me and my partner through it all step by step. As he came to see me after surgery had finished we talked about how it had all gone. He continued to explain that whereas the womb should usually be the size of a large peach, mine had been stretched to the size of a yellow melon. This surface area, and that of the additional fibroids had created a huge surface are leading to the bleeding. It was then that I was told I had adenomyosis as well as endometriosis. Just having that information – an explanation – made such a difference. That, and the fact that someone had finally listened and helped me to get better.

4.5.1.6 Psychological Need – The need for continuity of care

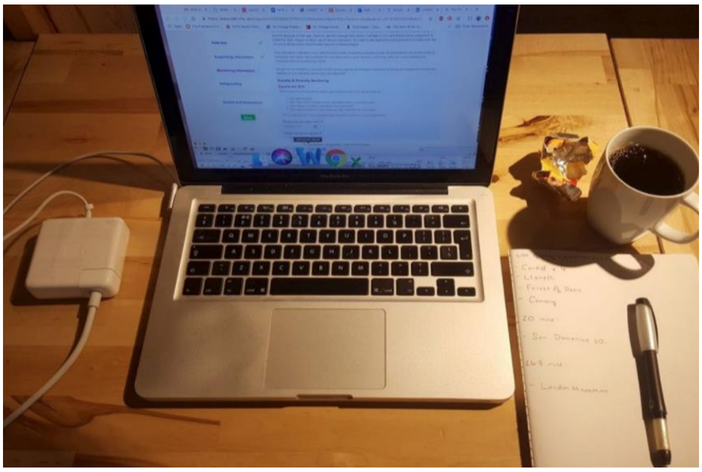
The need for continuity of care was linked to the need to provide evidence. The co-researchers talked about their frustration with waiting lists, always having to restart the process of seeing their GP to be referred to secondary care whenever their symptoms changed or worsened. They described feeling guilty for placing this burden on the NHS and discussed their time waiting for appointments, results, and surgery. One co-researcher waiting for nine months for ultrasound results. Another co-researcher discussed seeing a gynaecologist for a post-op follow up and seeing a doctor she had never met before and who gave her the wrong information. This need is also linked to the lack of trust of healthcare professionals.

> Clare: *After what they've said, I had to go and highlight it. Because em, that last letter, the surgeon said. She wasn't there. It was after my surgery in December, the post op. And she said em, oh I showed you a picture from the surgery and that picture was from a separate surgery. From years before. And I was like, that didn't happen. Like, why are you claiming that you showed me? And saying that you've done something? So, you look like you've achieved something. When they just read off a piece of paper. And you know, I could just read that myself. And she was like, ok, I'll go and ask another doctor, who was there. And I thought, why is he not here?"*
>
> Ria: *"You never see the same person, so you? I always find that really frustrating."*

4.5.1.7 Psychological Need – The need for work/life/illness balance

The need for work, life, illness balance was identified in images and captions that showed resting after or before work. They discussed prioritising work over health and prioritising employment and health over other aspects of life such as socialising, travelling, housework, cooking, shopping. While their symptoms often interfered with work, there were examples of work interfering with health. Other images included what happened when the co-researchers ignored their symptoms or sacrificed their health to attend music events.

Figure 4.14 Laptop in Ikea



Filling out a job application from in an Ikea. I like writing from Ikea occasionally because there are always seats, there's a place to plug in my laptop, and bathrooms are nearby. I'm in a lot of pain today and have a lot of bowel symptoms. My period is obviously on the way. I feel like coffee doesn't help my symptoms, but I'm relying on this and chocolate to give me 'energy'. I feel nervous about applying for jobs.

I've been working on a freelance basis for four years, which is flexible when I'm ill, but also means my income can be disrupted when I'm not well enough to work or look for work. Will having a salaried job be better? I'm not sure.

I don't know whether ticking the 'disabled' box in t the monitoring section will hinder me. I know in theory it should not, but I believe I've experienced discrimination at recruitment stage for this in the past.

4.5.2 What are the unmet psychological needs of people living with endometriosis and/or adenomyosis?

The unmet needs category was added to the study during the data analysis stage of the study. The co-researchers unmet needs were explained as needs specific to their symptoms or conditions that were not being met. Unmet needs are also what happens when their physical health needs not being met harm their psychological or mental health. There were 13 unmet needs identified; they are described in more detail below.

4.5.2.1 Unmet Psychological Need – The lack of care

Lack of care was identified gradually and developed from smaller sub-themes such as validation, dismiss, self-diagnosis, taboo, unprofessional and money. This unmet need links to the need for validation and the need for professional, respectful, empathetic, educated care. It differs from both of these needs, and it describes the impact that the lack of this type of care has. The discussion that led to the identification of this unmet need included one co-researcher discussing how a lot of the taboo around endometriosis and adenomyosis comes from others and not from those with the conditions. She described making an appointment with her male GP to discuss painful sex and ask for a referral for pelvic floor physiotherapy. Her GP stopped their conversation because it was inappropriate and should only be discussed with a female doctor. She described her GP as being embarrassed and that she found him to be unprofessional. Another co-researcher had taken a photograph of information about hormonal contraception, and the caption explained how she had been given conflicting advice about whether she should be taking two types of hormonal contraception to manage her symptoms. She had been left to educate herself to make the decision, but she didn't know what the side effects of taking both would be. This unmet need is also linked to the need to provide evidence. The co-researchers discussed how they worried if they didn't prepare for appointments properly, with evidence, that they would be labelled hysterical or be dismissed for complaining about period pains. One of the co-researchers explained the difference between private care and NHS care for endometriosis and adenomyosis. She talked about the lack of specialist treatment, lack of choice and long waits while often not seeing the same doctor twice. While this need is similar to those mentioned in the above paragraph, it was considered a different need. This need is specifically about the lack of care available and how this impacts their quality of life. This theme is about asking for treatment that they should receive, but it is withheld.

One co-researcher discussed not being referred to a menopause clinic because her GP considered her too young, even though she'd had a hysterectomy and was prescribed HRT. One of the photographs that caused the most reaction in the group was one of a jacket potato on a plate. This was served as an evening meal to a co-researcher admitted to the hospital after an escalation of pain after a hysterectomy. The other co-researchers responded compassionately, and the co-researcher agreed this was an example of needs not being met physically that also had an emotional impact. The co-researcher discussed how ashamed and guilty she felt for taking up a hospital bed that someone else could have used.

Figure 4.15 Healthy

Healthy
Really a hospital meal. Main choice meal was a jacket potato. I literally got one jacket potato and some butter.

No salad or vegetables.
My needs are not being met here.

Ended up in hospital due to pain. I hadn't eaten all day due to my pain, no breakfast and no lunch. Full of gas/air, morphine, paracetamol and gabapentin, timings of being brought into hospital.

I was hungry in the evening.

4.5.2.2 Unmet Psychological Need – Pain belief

This unmet need refers to needing to have pain believed and the difficulties when pain is ignored or dismissed. The co-researchers did not discuss their need for their pain to be reduced nor removed but believed. One co-researcher discussed seeing a gynaecologist after being on a long waiting list and being told that her pain could result from her father dying when she was a child and that psychological treatment might help. The other co-researchers expressed frustration and annoyance on her behalf. This led to another co-researcher sharing an image about needing psychological support or treatment but how the counsellor she saw didn't understand her diagnoses of Crohn's disease and endometriosis. The co-researchers discussed how symptoms of pain were often linked to psychological causes when the opposite was true. This unmet need was also linked to providing evidence as pain is invisible and difficult to explain to others. The co-researchers discussed how they tried different strategies in preparation for appointments to be believed and not dismissed. One of the images that led to identifying this unmet need was a pincushion full of needles and pins. The co-researchers often used metaphor and symbolism in their photographs, with the captions providing the meaning and context. One image was of a co-researcher squeezing her boyfriend's hand.

Figure 4.16 'Pain' Cushion

'Pain' Cushion
'Can you describe your pain?'
Every endometriosis sufferer has heard this question from GPs and Specialists, even from friends and family. Pain has become part of my everyday life.

Sharp, stabbing, piercing pain to a throbbing ache.

Reflecting more than just the stabbing in my uterus, this image also have a more personal reference as it's symbolic to my career within fashion.

4.5.2.3 Unmet Psychological Need – Sleep

Sleep was often an unmet need experienced by the co-researchers. They discussed how pain could interrupt their sleep, how they experienced fatigue even after sleeping, how depression had led to them spending more time in bed, and how the psychological and emotional impact of living with endometriosis and adenomyosis often led to insomnia. They worried about their fertility, how their conditions would impact their future and how they grieved or worried about not becoming mothers. One of the images that led to identifying this unmet need was a bedside table with sleep aids.

4.5.2.4 Unmet Psychological Need – Lack of Trust in Healthcare Professionals

All of the co-researchers in this study had negative experiences of the healthcare system not meeting their needs, feeling ignored or dismissed by GP's, and having their pain normalised or explained as psychological. The struggles they faced trying to get a diagnosis left them suspicious of advice or information was given by healthcare professionals they were unfamiliar with. They talked about keeping a record of their symptoms to provide evidence of their pain or medical condition. They also discussed how stressful doctor's appointments had become a source of anxiety and frustration.

> Shannon: *"Yeah and everything and getting my medical notes from the hospital and the doctor like, the reading and this week has been really quite raw to see everything. The timeline going back to 1990-whatever. Ans what they say, they conflict themselves. Like, I've been reading stuff and you just think. And they've got primary – I never realised how doctors record things and they've got like primary problem and secondary. And secondary was endometriosis going back and actually, looking back now that was my primary problem. You don't acknowledge what I'm saying and even things that they've typed out. I'm like, I didn't say that- "*
>
> Kate: *"Also, when doctors have ignored you for so long, when you know something is wrong, something invading your organs. You know it can cause severe organ dysfunction. And for 14 years you've been told there's nothing wrong, you're just weak. It's hard to have faith in being reassured that you are ok. I don't feel ok and I don't feel reassured because you told me that you years and I didn't believe you.*

4.5.2.5 Unmet Psychological Need – Unrelenting/relentless/hard

This theme was identified through several images and captions. The co-researchers lived experience of endometriosis and adenomyosis was that it was unrelenting, relentless and hard. The combination of symptoms, navigating the health system, pleading or being in conflict with healthcare professionals and trying to live what they considered to be a normal life seemed to overwhelm them. In particular, that endometriosis is a lifelong condition seemed a heavy burden, with no end in sight.

Figure 4.17 Relentless

Relentless
When describing my endometriosis and excision surgery to people I often compare it to weeds.

How weeds can spread throughout your garden. Its persistence and destructive nature stops flowers from growing. In order to remove the weeds, you need to get it root and stem. But there's no guarantee the weeds won't grow back.

> Clare: *"It's a picture of weeds. And it's when I was in hospital, just before my surgery and a lady asked me what I was having done. And I said they're basically just de-weeding the garden. And it's just how it comes, and it's stuck with me."*

4.5.2.6 Unmet Psychological Need – Time's against us

This unmet need was identified by discussing images and captions that included clocks, pregnancy tests and invitations. The co-researchers discussed time wasted spent waiting for a diagnosis, appointments and surgery. They also discussed watching friends get married and have children. They also discussed choosing between using hormonal contraception for pain relief and being in pain when trying to get pregnant. They were concerned that the time taken to get a diagnosis and treatment would put their fertility at risk. The co-researchers felt that time is against them because of the unmet need for a quick diagnosis and access to treatment for their condition. During the discussion around identifying this unmet need as it developed from a subtheme into a more prominent theme, one of the co-researchers, Kate, asked to add a photograph and image. Kate didn't provide context or hold up the image as she had at other times or explain where the photograph fit. In the secondary analysis, as the photographs and captions were inserted into the transcript, it became clear what Kate was trying to communicate.

Kate: *"I've got 309 for time is against us."*

Kate used the below image and caption (309) to communicate what fear of the future and time's against her meant for her. This image was also included in the unmet need of mental health.

Figure 4.18 A Silent Statistic

A Silent Statistic
A friend and endo sister took her life last week. She was 36 years old and desperately wanted her pain to end. With her suffering routinely dismissed by the health system for most of her life, and having only poor insufficient treatment available to her, this utterly tragic and preventable outcome came into being.

"Chronic pain has been shown to be associated with depression. This is not a surprising finding, as anyone who has lived with pain for any significant amount of time will know that the social isolation, inability to participate in normal activities of daily life, and sheer exhaustion, can lead to feelings of depression and hopelessness. Patients with chronic pain have a 2-5x increased risk for developing depression, and each condition affects the other: depression can worsen the perception of pain, and pain can worsen depression. Furthermore, studies have shown that when pain is moderate to severe, impairs daily functioning, and is difficult to treat, it is associated with worse depressive symptoms and outcomes.

We need to move towards recognition of endometriosis as the life-altering disease that it is. We need to continue to strive to make effective treatment accessible for all patients with endometriosis. We need to make all care providers understand the severity of the pain that endometriosis can cause, so that the pain itself can be treated appropriately. And we need to recognize the potential for depression and even suicide and bring these difficult discussions of the emotional consequences of living with endometriosis out into the open."

-Philippa Bridge-Cook, PhD, The Endometriosis Network of Canada.

One in four people with endometriosis have contemplated suicide.

4.5.2.7 Unmet Psychological Need – Mental Health

This unmet need was one of the first to be identified and one of the most prominent themes discussed. During the group discussion and data analysis, it became clear that mental health could not be separated from physical health. Images and captions that led to the identification of this unmet need included images of antidepressants, a rubbish tip, empty buildings and the use of symbolism. One image showed sunshine and greenery, and the caption provided context that the co-researcher had never felt less alive. The co-researchers discussed the loneliness and isolation they felt when they had to stay home and rest when they prioritised health over social relationships, of others, not understanding. They discussed feeling overwhelmed and resentful, and that some symptoms came with embarrassment, one image showed a bikini. The caption explained that the co-researchers felt self-conscious of her surgery scars. During the discussion, the co-researchers expressed frustration at how hard it was to access mental health services and that their physical health significantly impacted their mental health. One image featured funeral flowers, with the caption explaining how the co-researcher had lost a friend with endometriosis to suicide recently.

4.5.2.8 Unmet Psychological Need – Lack of control

The co-researchers images and captions used symbolism to show how their unmet needs made them feel like they had no control over their bodies, symptoms, fertility, and bodily functions such as bowel movements and urination. They discussed how they saw a power imbalance between themselves and healthcare professionals, which placed more control with the professionals. This theme is linked with the unmet need of mental health support.

4.5.2.9 Unmet Psychological Need – Femininity sexuality and motherhood

The co-researchers often discussed how they felt less than, not a real woman, disconnected from their sexuality and how motherhood felt out of their grasp. This is another theme that was identified through the recognition that the experience of living with endometriosis and the treatments available interfered with what the co-researchers considered a ‘normal’ life.

The images that led to the identification of this theme included images of condoms, of a body recovering from a hysterectomy and of plain, black underwear, worn instead of lingerie due to the symptoms of endometriosis.

Figure 4.19 Unused

Unused
Don't be fooled to think this is fully stocked due to an active sex life.

This drawer is full for the 'lack' of sex. The lack of intimacy that has crept its way into my life. Forcing walls and boundaries between my boyfriend and I that sometimes seem impossible to break down.

This symbolises a fear of inflicting pain, which shows endometriosis impacts not only the person it resides in but also the people who are closest to them.

4.5.2.10 Unmet Psychological Need – Sex (lack of)

This unmet need was linked to both femininity, sexuality and motherhood but also lack of control. The co-researchers discussed the unmet need of being in a sexual relationship or having sex while in a romantic relationship with equal parts frustration and humour. One of the co-researchers was single, but the others all discussed the impact of their symptoms on their intimate relationships. This unmet need was also linked back to the need for love and connection. One co-researcher addressed the effect of painful sex on her relationship; her partner felt fear and guilt over hurting her. Another co-researcher discussed not feeling young and sexy due to heavy bleeding, bowel symptoms and bloating. Another talked about feeling exhausted due to blood loss and her partner becoming her caring, putting bloody clothes and sheets in the washing machine. This unmet need was discussed without mention of fertility and pregnancy. Instead, it was considered in reference to Maslow's Hierarchy of needs, sex being a need of humans (Maslow, 1943, 1954).

> Ria: *"Like, I always, like I got the contraceptive implant at the moment, but it's ran out. Ans I've got to wait 7 weeks until I can get a new one. So, I've got, that's why I've got the box of pills and I've said I'm not going to take them, because I just had an awful experience on the pill. And I won't do it again. But they were just like. And I said, well I don't want to take the pill. And well they won't accept you if you're not taking at least two forms of contraception."*
>
> Kate: *"Who were saying this?"*
>
> Ria: "*And it's like-*
>
> Lisa: *"-I've never heard of that before!"*
>
> Ria: *"I know, and it's like. And I was like, ok, ok. I'm not going to take it now but maybe I'll take it before I'll have it. Well, I'd rather just stop having sex (Laughs). Than go back on the pill. I had a conversation with my boyfriend, and I was like, I can't, I'd rather. And he was like, he was really supportive. And really great. And I said, I don't want to take this because I know how this is going to make me feel. And it."*
>
> Kate: *"Yeah".*
>
> Ria: *'It's going to make me feel awful but that was 0 and then again, that was, you have to question everything that they say to you. And they're saying they won't insert this unless they know that you're not pregnant. So, you need to be on at least two forms of contraception. But well if I've been like celibate for, for four month, does that not count? (laughs)."*
>
> Clare: *"Also, what I've realised as well, is that my condition doesn't just affect me. It causes problems in my relationship. And I'm still with him, and we're still happy but em, he's got a fear of having sex with me. Of causing pain. And it wasn't until like, doing this that I've really understood. Although I get pain, I don't blame him, but he blames himself. So, I don't know where that can go."*

4.5.2.11 Unmet Psychological Need – Endo Belly

Endo belly is a symptom of endometriosis and adenomyosis that patients often discuss but is rarely mentioned by healthcare professionals or in the published scientific literature. Endobelly is the swelling of the abdomen that looks similar to pregnancy. Although with fatigue, it's often missing from the list of symptoms in patient information leaflets produced by charities and the NHS. This is a visible symptom of an invisible illness. This symptom often has a significant psychological impact as it can mimic pregnancy, including women who have had a hysterectomy or are infertile. The co-researchers used humour and sarcasm while discussing this topic, and it seemed to be one of the more emotionally painful subjects covered in the workshop. This need was moved into the unmet need category because it's a physical symptom that is also psychologically challenging to live with.

Figure 4.20 Swollen

Swollen
These pictures of me were taken 10 hours apart. The picture on the left was taken at 10.30pm. My stomach has dramatically swollen and my waist measured 32 inches. The picture on the right was taken at 8.30 am the following morning, I measured my waist again, which had shrunk to 28 inches.

Nothing out of the ordinary had caused this swelling. It is just a symptom that comes with endometriosis. The Endo Belly is not only uncomfortable but also embarrassing and humiliating. To balloon and swell where you look pregnant every night, the discomforting bloating hardly makes you feel desirable.

The irony is that one of the few visible symptoms of endometriosis makes you look like the one thing you can't become because of it.

Clare: *"Mmmm, body one, I've got, emmm, the swollen endobelly."*

Shannon: *"I once loved my endobelly, many years ago. I got on the train."*

Ria: *"Ha! I know what's coming."*

Shannon: (laughs) "Where's this going? Oh my god, I know where this is going. And it did. And like. I just made it up. He was like, when's your baby due? . . .And the next day I got back on and the guard was standing at the thin and looked at me and looked at my belly as if to say that's the girl from yesterday, but she doesn't look pregnant today."

Clare: *"I think it's ironic as well because it makes you look like the one thing you might not be."*

Kate: *"Exactly that."*

Clare: *"And humiliated."*

Shannon: *"Ashamed."*

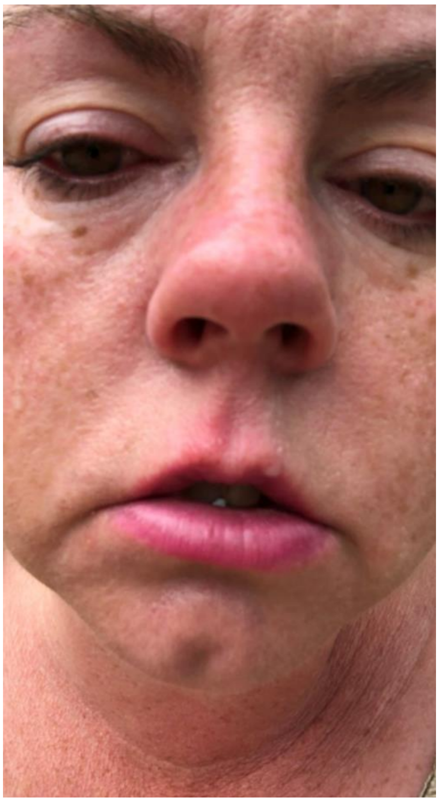
4.5.2.12 Unmet Psychological Need – Financial

The unmet needs of endometriosis and adenomyosis often have a financial burden on the co-researchers. Throughout the discussion, money and the cost of treatment came up. Co-researchers shared experiences of using annual leave instead of sick days after using up their sick day and not getting paid. Their self-management strategies often cost money, they have to pay for prescriptions, and they discussed the cost of private healthcare. Their health issues often impacted not only their working lives but also their long term career goals.

4.5.2.13 Unmet Psychological Need – Fear of the future

The number of needs not being met, the co-researchers experience of the progression of their conditions and how healthcare professionals have treated them has led to them having several fears for the future. This had resulted in increased feelings of anxiety, worrying about what the future may hold. For some co-researchers, it was uncertainty around fertility and getting married and having children; others were concerned about their quality of life further decreasing and how they'd cope with this. All of the co-researchers were fearful of spending the rest of their lives in pain.

Figure 4.21 Scared



Scared
Wednesday I couldn't take much more, spent the day in sobs of tears, terrified for my future. Due to pain I cannot work.

Scared of becoming stuck in the poverty trap.
Scared I'm going to lose my home.
Scared I'm going to have to give up my dog.
Scared I'm going to become old.
Scared I'm going to breakdown.
Scared I'm going to live my life in constant pain.
Scared I will never meet a man to share my dreams with.
Scared I will always sleep alone.
Scared I won't be able to walk.
Scared I'm never going to be able to live.

4.5.3 What are the psychological coping strategies of people living with endometriosis and/or adenomyosis?

Coping strategies were often discussed alongside the need or unmet that caused the need for a coping strategy. For example, the co-researchers addressed the need to provide evidence and recording keeping developed as a response and coping strategy due to this. Another example is the co-researchers experiencing fatigue and using caffeine to manage this. Below, the 14 psychological coping strategies identified during data analysis are explained, along with excerpts from the transcript and photovoice data.

4.5.3.1 Psychological Coping Strategy – Self-management (diet, exercise, painkillers)

This was the most prominent theme of all the themes in all three categories. It began as a comment, and then similar comments led to the development of the theme, along with a lot of subthemes placed underneath it. The three words after the coping strategy (diet, exercise, painkillers) were written down to remind co-researchers what self-management referred to, specific strategies they put into place, often to meet needs that weren't being met. A lot of the coping strategies were developed over time and involved trial and error.

The co-researchers discussed how sometimes they didn't know if the coping strategies made much of a difference in their symptoms, but they felt they had to do something; they could not be passive. They explained that having little control over their bodies and the impact of their symptoms, self-management strategies made them feel like they were actively managing their symptoms. Self-management coping strategies included: self-advocating, medication, painkillers, supplements, staying optimistic and having hope, sleep aids, diet, exercise, using heat or hot water, taking breaks, attending support groups, venting/moaning/complaining, researching their conditions, reading about their health conditions, finding inspiration and doing things to help their mental health. The images and captions discussed included images of being outside, in nature, metaphors for connection, medication, hot water bottles, flowers or plants, using music to improve mood and a self-management tool kit (dilators, heat pack, supplements, books). The discussion around these images and captions as this theme grew led to the co-researchers agreeing that self-management was almost like having another job. They talked about how they would try anything to try and reduce their pain and improve their quality of life. Having these coping strategies seemed to provide a sense of comfort and alleviated feelings of helplessness or powerlessness.

Figure 4.22 Good Ole Faithful

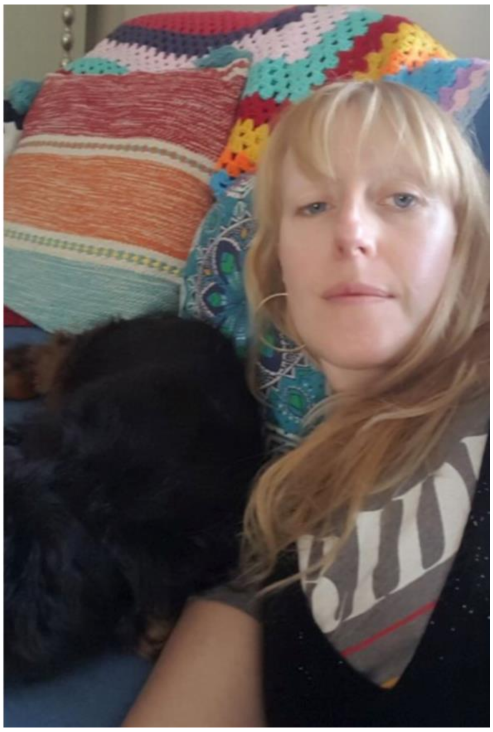
Good Ole Faithful

My water bottle has become a dear friend to me over the years.

A warming comfort in times of pain. I have a selection of hot water bottles and heat bags for every circumstance, depending on whether there is a kettle or microwave, either way I am prepared.

It has become a necessity to my everyday life. The simple item helps improve my quality of life with a chronic illness.

Figure 4.23 Lisa and her dog



Horizontal on the sofa with my dog. Saturday. I had a spontaneous celebration with some friends last night.

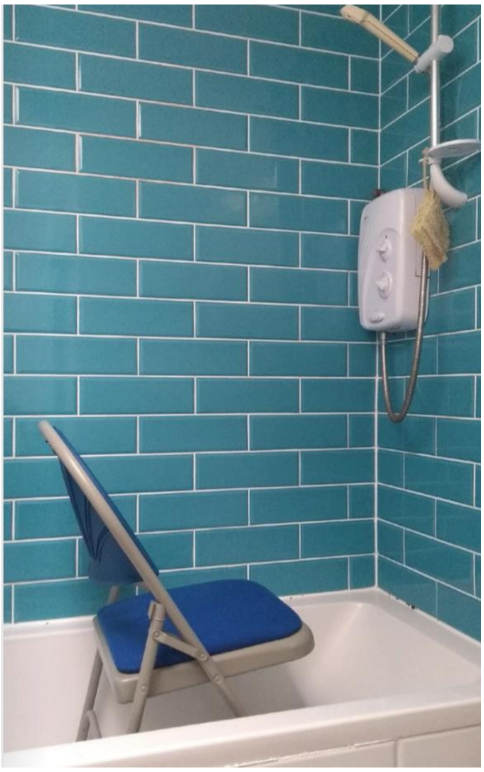
Today I'm suffering. I barely ever drink alcohol because my body feels fragile enough and cannot deal with the depletion. Today is a case study in this, plus my endometriosis period pain is in full swing.

I feel very annoyed at myself and guilty.

Having chronic illness makes me hyper aware of my lifestyle and very self-admonishing when my diet and lifestyle is anything less than pristine.

Logically, I feel I need to let off stream occasionally, but this does not stop the flood of emotion and guilt if I do. I wore a 'Pride' t-shirt and glittery jumpsuit in a bid to make me feel a bit better.

4.24 The Shower Challenge



The Shower Challenge
Sometimes this is what I feel like doing. Can't stand in the shower, take a chair. I haven't resorted to this because of the feeling of defeat, so self-care can often feel like the biggest triumph of the day.

4.5.3.2 Psychological Coping Strategy – Comfort

Like the self-management coping strategy, this coping strategy referred to both physical and psychological comfort. One image and caption that led to the identification of this theme was of chocolate, providing emotional comfort. Another was of a cat and titled 'comfort cat'. The discussion which led to the identification of this coping strategy involved the co-researchers sharing images of their pets, cats, dogs and a lizard. One image and caption showed a meal prepared by a co-researcher's partner, the caption said that she was grateful for the meal, but it wasn't part of an endo friendly diet.

4.5.3.3 Psychological Coping Strategy – Humour

Humour was present in some of the images and captions but also in the group discussion itself. The co-researchers discussed many emotional topics that negatively impacted their mental health, such as infertility, dissatisfaction with their bodies, hysterectomies, doctors not being able to treat their pain and at times, humour and sarcasm to lighten the mood. The wit and sarcasm were apparent over their reaction when sex was brought up by one of the co-researchers. They were all vocal about wanting more sex in their lives and laughed about it together. But afterwards, one co-researcher discussed how uncomfortable she felt with her body after a hysterectomy and wondered if she would always be single.

4.5.3.4 Psychological Coping Strategy – Learning to appreciate your body

The co-researchers had discussed the impact that surgery and their symptoms had on their bodies, and they often felt embarrassed or let down by their bodies. They discussed having to accept the changes in their bodies and forgive their bodies. Below is an excerpt from the transcript where Clare talks about not feeling confident in wearing a bikini because of her surgery scars. The image and caption that is being discussed are also included below.

> Clare: *"And it's like, learning to appreciate your body and your scars. I used to think they were negative but now I'm seeing them as positive."*
>
> Me: "Learning to appreciate your body. Is that part of like, fighting your illness?"
>
> Clare: *"Acceptance. It's acceptance. What did I say? Not to be so self-critical or self-baling. And to forgive yourself and not battle with yourself."*

Figure 4.25 Grow Through What You Go Through

Grow Through What You Go Through
I have accumulated several scars from the surgeries to tackle my endometriosis. My battle wounds. I originally felt uneasy about my scars, the constant little reminders of the pain I've been through. I also doubted my boyfriend would still find me attractive with them dotted around my torso.

One day I asked my boyfriend what he thought of my scars and if thought they were unattractive or repulsive. He told me that he loves me for who I am, that my scars are a part of me and they show the journey I've been on. It made me realise that I need to be kinder to myself.

To not be so self-critical, self-blaming and to appreciate my body more. Most importantly I need to forgive myself as I've often felt at battle with myself whilst fighting this condition.

4.5.3.5 Psychological Coping Strategy – Work performance

The impact of endometriosis on productivity at work, managing symptoms at work and trying to be comfortable while at work has been explained in the needs and unmet needs sections. The work performance coping strategy was identified when discussing the need to have a work/life/illness balance; the co-researchers discussed prioritising work over health to perform well at work and not feel like they were letting their employers or colleagues down. This part of the discussion was prompted by a photograph of Ria at work while in pain. The co-researchers shared similar experiences, such as using annual leave as sick pay and not getting paid sick pay. The co-researchers often worried they'd been seen as unreliable or that if they disclosed their medical conditions, it could prevent them from getting jobs or career progression.

4.5.3.6 Psychological Coping Strategy – Comparison (negative)

This negative coping strategy was discussed by co-researchers of comparing their selves with others. The co-researchers discussed how endometriosis and adenomyosis had interfered with the plans and goals they had aspired to. They described how their friends and families lives seemed to be on track. One image and caption were of a wedding and baby shower invites, and the co-researchers felt left behind by their peers. They also talked about how they were before their health conditions had progressed and how they regret some of the decisions they'd taken around their health and career. They talked about what their lives could have been like if they had been diagnosed sooner.

4.5.3.7 Psychological Coping Strategy – Fuel/Caffeine

There were a few images of coffee or tea with captions describing battling fatigue and the side effects of drinking coffee. Lisa can experience a flare-up of Crohn's disease symptoms while using caffeine to tackle her fatigue from her endometriosis. Clare also took a photo of her morning coffee, which she also uses to cope with fatigue.

Figure 4.26 Iced Coffee

Today. I'm working on Bristol this week, freelancing in a creative agency. I drive here from Cardiff, getting up at 5.30am and driving at 6.30 am for an hour or so, to miss the traffic.

I feel overly reliant on coffee recently, particularly since I've gone from not drinking it at all, to at least two cups each morning. Sometimes I feel shaky after drinking, and it sometimes triggers stomach pain, though without it I'm even more exhausted.

I'm not in a position to turn down these freelance opportunities, even if they leave me really tired. I cross my fingers each tie I go in, that I'll be well enough to get through the day and fulfil my workload.

4.5.3.8 Psychological Coping Strategy – Acceptance

This coping strategy was identified similarly as the comparison (negative) coping strategy. This coping strategy was also linked to the learning to appreciate your body coping strategy and the lack of control unmet need. It's also linked to the coping strategy of understanding the condition and seeing it. Below is an excerpt of the transcript discussing self-management coping strategies, which the co-researchers describe as developing through accepting their health condition and its symptoms, including pain. Once they have accepted that their health condition is lifelong, they try to find ways of coping with it, be themselves.

Me: “Do you think they go hand in hand? So, like, when you find you have a need because it’s not being met by any healthcare professionals or anywhere else, you then have to meet that need yourself?”

Lara: *“I don’t know if it’s ever that conscious, always.”*

Lisa: “*I think you find ways to cope, don’t you?”*

Lara: *“Yeah”*

Lisa: *“Yeah you find ways to cope uh, that you haven’t necessarily identified because of a particular need. Because day to day its sort of survival isn’t it?”*

Lara: *“Yeah. And I suppose, also because there’s so many different elements to how you feel it’s back to that kind of almost defining, which aspect of you that’s trying to fulfil. And again because of the need to self-diagnose. Things might have been because of pain and they might have been because of depression.*

Me: “Yeah, because it’s really weird everything you have been talking about. You haven’t ever said ‘I want my pain to go away’. It’s almost like you’ve accepted that you’re in pain and you just want somebody to believe you’re in pain.”

Clare: *“Um, I think for me, I had surgery in December and I’m still in pain. My pain subsided but I still have pain. So, I think I’ve come to terms that I’m going to have pain forever.”*

Me: “Yeah,”

Clare: *“You’re the same, aren’t you?* (To Shannon)*”*

Shannon: *“Yeah.”*

Lisa: *“And with acceptance of a different type of life I also mean that I can’t socialise like lots of my friends go out and many drink lots of alcohol. Stay up late. I feel like I’m always preparing for the next day or the next week. So, I’m kind of ok with that but I feel the need to distance myself from other people. . . You know and . . . yeah and the expectations is you know, I’m not in hospital now so I should be able to do everything but.”*

4.5.3.9 Psychological Coping Strategy – Compassion

This coping strategy was also discussed and identified similarly as the acceptance and comparison coping strategies. Shannon had shared her relief when the paramedics that took her to the hospital due to escalating pain acknowledged her pain and were compassionate. One of Clare’s images was of a bouquet of period products; her employer supplies them; Clare considers this an example of compassion

Figure 4.27 Bouquet

Bouquet
Menstruation is a normal part of being a woman, and we are told that pain is too.

My menstruation has always affected my life since it started when I was 12 years old, with insanely painful cramps, heavy bleeding, nausea and diarrhoea, combined with emotionally charged PMS mood swings.

Being told your period pain is 'normal' and every woman deals with it – why can't you? You start to doubt yourself.

Maybe I'm imagining that this pain is worse than I think it is? Maybe it is all in my head? Maybe I'm overacting.

> Clare: *"Yeah, yeah. And, like, I think that in one of my jobs now. My employer supplies tampons and sanitary towels. Where I've never seen that anywhere else. And I think that's really amazing. And it's only because she has problems herself that she does that."*
>
> Me: "So that's like compassion."
>
> Clare: *"Yeah but you won't get that anywhere else. I've not seen that anywhere else."*

Ria shared an experience of being at work; her pain was causing nausea. She could not go home due to having to give a presentation. Ria had said if someone else were feeling like she did, she would advise them to go home and rest. The group discussed how it was easier to say that to someone suffering rather than applying it to their situations. Ria also said that she judges herself by other people’s standards, meaning she finds it challenging to be compassionate towards herself because others aren’t compassionate to her.

> Ria: *“Because also, it’s supposed to be his responsibility to help with those things as well. But he was like, he was supposed to come. So, I was like, if I do throw up, I have to go back in and say, well I’ll have to run and leave and throw up. Or I have to say, like, I’m sorry but I cannot carry on. And I sort of thought, actually if I throw up, they’d probably understand it a bit more. But just the fact that I’m in pain.”*
>
> Shannon: *“Well it would be visible.”*
>
> Ria: *(laughs) “Yeah, no you’re right. If somebody asked me, I would tell them not to do it.”*
>
> Me: “And you feel, like, if other people aren’t being compassionate and having empathy towards you that you find it difficult to have compassion and empathy towards yourself as well?”
>
> Ria: *“Yeah, I think so because you sometimes sort of judge yourself by other people’s standards, don’t you? A little bit.”*

4.5.3.10 Psychological Coping Strategy – Nesting

The co-researchers all had images and captions that described resting on their couch or bed, often after work. One co-researchers discussed removing the mask she wears in public, pretending she is fine and healthy and getting home to put her slippers on and sit in her nest on her couch. She talked about spending a lot of time there in pain and while recovering from surgery. Having a comfortable place to rest is a crucial coping strategy both mentally and physically.

Figure 4.28 The Seat

The Seat
This is where you can find me, curled up with my hot water bottle and blanket. The days where I am in too much pain to move, the recovery time after my operation, and generally most evenings since my endometriosis took hold. I spend most of my time here.

This symbolises the paradox of comfort and pain. It also reflects the confinement endometriosis has brought to my life.

4.5.3.11 Psychological Coping Strategy – Responsibility

Taking responsibility for managing their symptoms and maintaining or improving quality of life was linked to self-management, unrelenting/relentless/hard and acceptance as a coping strategy. The co-researchers discussed having more of a responsibility than healthy people, of making responsible and healthy choices. Ria discussed always being responsible while out with friends because she didn't want to be hungover and in pain. Kate said she had had the same conversation with work friends. Clare discussed being vegan and eliminating many triggering foods from her diet. Shannon discussed eating healthily, not smoking or drinking but still having high blood pressure. They talked about feeling guilty if they did make an 'unhealthy' decision such as eating chocolate, drinking coffee or straying from their anti-inflammatory diet.

4.5.3.12 Psychological Coping Strategy – Spirituality

The co-researchers did not discuss religion, although one of the images was of a cathedral. They discussed spirituality as having a sense of peace and reassurance that everything would be ok. Shannon discussed thinking she had a guardian angel watching over her, making sure things would turn out ok.

4.5.3.13 Psychological Coping Strategy – Recognising good days

The co-researchers had images and captions that described being grateful for pain-free days or having days uninterrupted by symptoms. One image showed sunshine in the morning; another showed a gift of flowers from a friend. A few images showed co-researchers attending live music events, with them accepting it might worsen symptoms, but the experience of attending the event is worth the pain. Ria discussed her image of her wearing a red dress on a bike while on holiday. She's smiling and looks relaxed and healthy. Clare discussed how she could be pretty negative, and in taking part in the photovoice study, she saw that she did have good days. She talked about her 'wishful thinking' image of a dandelion, hoping for her dreams to come true.

Figure 4.29 Wishful Thinking

Wishful Thinking
Trying to stay positive and optimistic isn't my strongest attribute, although it is something I desperately need to be more of. Although my head is filled to the brim with fears and doubts, I do strive to be hopeful.

Hopeful for a happy future. Hopeful for a family. Hopeful that my pain doesn't return. After years of struggling and fighting to get better, having to sacrifice a normal life along the way: career, nights out, day trips, friends, holidays, family occasions etc.

There are a lot of things I'd like to achieve, dreams to try make reality and wishes that I hope will come true.

4.5.3.14 Psychological Coping Strategy – Understanding the condition and seeing it

This coping strategy was seen as necessary by all the co-researchers; all of the co-researchers had at times attempted to ignore their symptoms and the effect they had on their lives. This led them to not care for themselves or accept that their life was changing. This coping strategy was linked to the need to provide evidence and the coping strategies of responsibility and acceptance. One image showed a co-researcher, nude, in shadows, and the caption described the loneliness and isolation experienced by endometriosis. Another showed art images on a hospital wall and explained that having to accept their symptoms may impact how well they can carry out tasks at work. By understanding their condition, the co-researchers could problem solve and work out what treatments they needed, whether healthcare professionals were given the correct information and how they could take responsibility for managing their symptoms and health. Shannon discussed choosing to have a hysterectomy even though she didn't have children because her quality of life was so low, and she wanted to live a full life without pain. She is now seeking a second opinion because her pain has worsened. Shannon feels she knows more about the condition now and has taken steps to get support from a menopause clinic and asked for a referral to an endometriosis centre instead of her local hospital. She regrets not learning more sooner.

Figure 4.30 Right Side

This is my right side

This side feels great, as you can see I have a gap between my leg and stomach. This side is flat in comparison to my left side. Which should feel this way.
My operation was in March last year, my needs are not being met by:
1.Not having a post op check, them not listening to my 'squeezy pain' as I called it, right at the beginning after my surgery in my groin. Took me until October form March to see my surgeon. This is not acceptable.
2. I never had any counselling before or after my operation.
3. I wasn't told I was entitle to a menopause specialist because of my age.

Figure 4.31 Ashamed

Ashamed.
Another picture of my swollen belly because of my operation. I feel I wasn't given the right care from the start. My endometriosis was more complex. I should have had it done at a BSGE centre. Not a standard gynae. I wish I trusted myself and fought for better care within the NHS. But this care isn't standard and it should be, most girls have to go private.

This shouldn't be the case.

4.6 Integration into the intervention development process

Not all the needs identified in this study could be included in the psychological intervention. The same was true for the coping strategies; while most of them were helpful and had a positive impact on quality of life, some were negative. For example, caffeine to combat fatigue, which also came with side effects that included stomach pain and other bowel functions.

Before any decisions were made on what to include and exclude in the intervention, evidence statements were written (Appendix VIII), which clarified the needs to be addressed and the coping strategies that could be included. Figure 4.2 shows which needs and coping strategies were included in the intervention.

Chapter 5 provides more detail on the intervention development process after the needs assessment was complete. However, there were several needs that could not be addressed because the intervention could not provide helpful, ethical strategies to meet those needs. For example, it would be inappropriate for a psychological intervention to provide medical, legal, nutritional or financial advice (including information about legal guidelines in the workplace) for participants to name healthcare professionals or rate them in any way. It would also not be appropriate to provide relationship advice. However, links to other organisations such as the

NHS and Endometriosis UK were provided, including information on endometriosis and Covid-19.

Figure 4.2 Needs to be addressed by the psychological intervention and coping strategies included in the intervention.

4.7 Discussion

This study has shown that the psychological needs of people living with endometriosis are complex and challenging to separate from physical needs and symptoms. There were seven needs, thirteen unmet needs and fifteen coping strategies identified during the second workshop. The most prominent theme identified was the self-management coping strategy. There appears to be a strong relationship between physical health and mental health. The unmet needs of people living with endometriosis and adenomyosis seem to negatively impact their quality of life, as healthcare professionals cannot treat and altogether remove their pain and these painful symptoms affect their emotional and psychological health. This, in turn, leads to patients reporting being dismissed, feeling isolated, being scared of what the future holds and trying to balance self-managing their condition along with work and having a social life. The symptoms of endometriosis and adenomyosis can negatively impact every aspect of life, including employment, relationships, body image, life and career goals, work performance, sense of self and sexual partnerships. There is a need for more psychological support, in a formal way, designed specifically for the needs of this population.

People with endometriosis and adenomyosis construct psychological coping strategies in response to their unmet needs and accept that their health conditions have control over their symptoms and body. This study found that practical coping strategies often provide psychological or emotional comfort. Another finding was that people living with these conditions could develop negative psychological coping strategies, further reducing their quality of life by increasing painful symptoms or relying on negative thoughts or emotions such as guilt, shame or comparison with others. The coresearcher discussed how others treat them can affect how they feel towards themselves; for example, lack of validation can lead people with these conditions to self-blame or overcompensate by physical pushing themselves through pain instead of resting.

This study supports previous findings that ‘invisible illnesses’ are difficult for others to understand as symptoms may not be seen or objectively measured (Donaghue and Siegel, 1992). However, the most visible symptom of endometriosis and adenomyosis, ‘endo belly’, is rarely discussed outside of patients themselves and patient support groups. This symptom is the most physically visible but also one of the most psychological challenging, particularly for those unable to have the children they desired.

Grundström et al. (2016) found that healthcare professionals have found it challenging to diagnose and treat patients with endometriosis due to the difficulty of differentiating between normal and abnormal menstruation. This was also found in this study from the perspective of the patient. Another barrier to getting a quicker diagnosis may also be the lack of continuity of care, meaning patients do not regularly see the same healthcare professional. The co-researchers discussed their frustration with not following up with the same doctor and being sent to different specialities to search for answers to their symptoms. The co-researchers in this study also showed the difference between private healthcare and the NHS.

The findings of this study support the conclusions of Cosar et al. (2014), Cavaggioni et al. (2014 and Chen et al. (2016). The co-researchers reported poor sleep, fatigue and poor mental health at different points in their life before and after being diagnosed with endometriosis and/or adenomyosis. One co-researcher discussed her depression, and suicide was brought up by another co-researcher about fearing the future and feeling that time is against her. Yet, the co-researchers had not been offered to be referred to mental health treatment. Instead, they discussed how they felt they were considered to be hysterical and their pain was considered caused by psychological irregularities, not a physical illness.

This study also supports the findings of Culley et al.’s (2013) review and Aerts et al. (2018) study, people living with endometriosis do face the complex combination of living with pain, feeling ignored or not believed, having their daily activities interrupted by symptom, difficulties with sexual and intimate relationships, uncertainty about fertility and the future and disruption in education and the workplace. The findings also support Aerts et al.’s (2018) findings that psychological suffering may increase pain symptoms and worse treatment outcomes. The results of this study also add to the conclusions from Culley et al. (2013) and Aerts et al. (2018) by providing further insight into the psychological needs and coping strategies precisely. This study also shows how entangled physical and mental health are in those living with endometriosis and adenomyosis. This more detailed understanding led to the development of a psychological intervention designed to improve the quality of life in this population by meeting some of the psychological needs assessed in this study. This study also documents why self-management strategies develop and provides insight into psychological coping strategies, including negative ones, such as compassion, acceptance, comparison and responsibility.

The findings of this study also show that people living with endometriosis are solution-focused, with the implementation of many self-management strategies, some of which address physical symptoms such as pain or bowel irregularities, some which address the psychological impact of symptoms and some which address both, for example attending support groups and record keeping. The co-researchers in this study put a lot of effort and time into managing their health needs, advocating for themselves, educating themselves about their conditions and treatment options. Seear's (2009b) findings on the 'third shift', time spent by women to lessen the impact of their health condition was also echoed in this photovoice study, with co-researchers describing their coping strategies as 'another job'. One of the coping strategies identified by co-researchers, including being responsible, had been documented by Rimke (2000), who found that those who do not do everything they can for their health are considered 'irresponsible citizens'. This was further shown by the co-researchers seeking out private healthcare with the encouragement of their friends and family.

The complexities in the entanglement of the psychological needs and physical symptoms found in this study support the conclusions of Trappenburg et al. (2013) that not one size fits all when it comes to self-management interventions. This study has provided a comprehensive assessment of the psychological needs and coping strategies of those living with endometriosis. This assessment has been used to tailor a psychological intervention designed to improve the quality of life. However, not all of the needs identified during the assessment could be addressed by a psychological intervention and not all the coping strategies could be included. For example, there is a need for more support in the workplace, but a psychological intervention cannot offer this. However, the psychological suffering caused by lack of support can be acknowledged, and coping strategies can be provided.

4.7.1 Dissemination

Dissemination is built into this research method; the final presentation was a photography exhibition held on the 24th of October 2019. When the data for this study was being collected, the BBC had launched a survey on endometriosis, which had 13,500 responses. The main finding was the impact on mental health, with over 50% of respondents saying they had considered suicide (BBC News, 2019). The survey results were released in October 2019, which led to two inquiries, one in November 2019 about the impact of endometriosis in the workplace and another more extensive inquiry, led by Endometriosis UK and The All-Party Parliamentary Group for Endometriosis. The exhibition was held for one day only. There were many expressions of interest about the photographs and captions in the exhibition, which led to some of the photographs and captions being compiled into a book.

The graphic designer of the photo book, Kaye, also has endometriosis and was very sensitive in handling the data. Funding was secured from the Doctoral College, Coventry University and the physical copies of the books were printed. The books were sent to the APPG along with a briefing documenting the findings of the photovoice study. This was done in collaboration with the university's policy unit. They were also shared on social media, and many requests came in from the UK, Ireland, Europe, Canada and the USA. Requests came from patients, support groups, healthcare providers and researchers. Books were sent to The Center for Endometriosis Care (Georgia, USA), Endometriosis Association of Ireland, Cysters, University of Otago, New Zealand, Vagina Museum, Endometriosis UK, EXPPECT (Edinburgh University, Endometriosis and The Scottish Sun Newspaper. It has also been used as a teaching tool on the MSc Health Psychology courses at Coventry University and the University of the West of England, Bristol.

Due to the popularity of the physical copy and the costs associated with reprinting, a digital book was made available; this was done in collaboration with Hope for the Community. It was made available in January 2020 and has been read 17,295 times (11th November 2021). Two MP's reached out to discuss the photobook and the study's findings, Gill Furniss MP and Emma Hardy MP. A meeting in parliament was arranged in March 2020 but was cancelled when the COVID-19 pandemic lockdown began in the UK. The APPG inquiry paused due to the pandemic and restarted in autumn 2020, with the report being released in October 2020. The abstract for this study was also accepted at two conferences and one symposium; they have been postponed until 2021 due to the COVID-19 pandemic.

In 2021, the government published a call for evidence regarding women's healthcare experience; the results of the photovoice study and the book were submitted as evidence. It was argued that the 'Living with Endometriosis' book could be considered an intervention to help educate healthcare professionals about patients experiences of living with endometriosis. This could help improve the type of care that patients receive. The report on the women's healthcare strategy is due to be released in December 2021.

4.7.2 Limitations

There are a few limitations in this study. Although qualitative research is not meant to be generalisable, there is an aspect of lived experience that was captured in the images and captions, motherhood. All of the women in this study did not have children. However, some of them expressed concern over being able to get pregnant, grieving for children they cannot have or worrying over being able to care for a child, the needs and coping strategies of mothers with endometriosis and/or adenomyosis are not captured within the data of this study. This may be due to the commitment required from co-researchers in the study; the time burden on co-researchers was made clear in the recruitment strategy and participant information sheet. If potential co-researchers did have children, worked and had other commitments, as well as managing their conditions, they may not have had the time to commit to the study. The dates and times of the workshops were planned around the schedule of the co-researchers; perhaps an even more flexible approach is needed if mothers are to be recruited.

Another limitation also relates to the sample size, Wang and Burris (1997) recommend having 7-9 co-researchers in a group; there were six co-researchers in this study. Although a lot of rich data was collected, it's not clear if any other needs and coping strategies are missing in the data, just as motherhood is not represented.

Another limitation is connected with the participatory nature of this research. It could be argued that because the data is influenced by the research structure and aim of the study, that the participatory nature of the study has been diluted as the facilitator decided on the research question. The co-researchers advocated for the inclusion of ‘unmet needs’ during the data analysis. Still, if they had been completely involved in the research process from the beginning, perhaps the research question would have been different and more participatory. Also, the co-researchers were recruited via online methods and used their mobile phones to take the photographs; it could be argued that the recruitment strategy should have been more inclusive, including those who would not have seen the recruitment advert online. Again, this could be seen as diluting the participatory nature of the research, as there are issues with the representation of experiences of the conditions.

A practical limitation relating to funds may have also impacted recruitment, number of co-researchers and data collected. This study was part of a PhD; there were limited funds available. At the start of the study, there were no travel expenses available for co-researchers attending the workshops. This changed after data collection, and co-researchers were reimbursed for travel expenses for attending the two workshops and the exhibition. However, the lack of funding at the beginning may have deterred potential co-researchers from coming forward.

4.8 Conclusion

In conclusion, the psychological needs and coping strategies of people living with endometriosis are complex. Many of their needs exist due to the impact and interference their symptoms and health condition have on their lives, often resulting in low quality of life. The psychological coping strategies are developed in response to the number of unmet needs they have and the sense of responsibility they have over their health. Not all the coping strategies are helpful or positive; in fact, some strategies may worsen physical symptoms such as pain or bowel complaints. The negative coping strategies are used as the women were driven to meet other needs, such as financial security or to feel they belong with loved ones.

The most prominent theme identified within this study was the self-management coping strategy. Patients living with endometriosis self-manage their psychological and physical health to reduce the impact of physical symptoms and to meet their own unmet needs. The co-researchers said they’d tried many things, often unsure of how useful they were, e.g., supplements, yoga. This theme and others such as validation, compassion, acceptance, recognising good days, understanding the condition and seeing it, fear of the future, learning to appreciate your body and mental health were incorporated into the intervention.

A participatory approach led the co-researchers to feel a sense of duty and responsibility to the study. As a result, the data produced for this study is highly personal. However, some data showed that the co-researchers needs could not be addressed by a psychological intervention alone. The findings of this study may be helpful to healthcare professionals, stakeholders, policymakers, researchers and clinicians attempting to develop treatments and interventions to meet the needs of people living with endometriosis.

It is recommended that future research use participatory approaches to identify the needs of Black people, other minorities with endometriosis/adenomyosis, needs of trans and non-binary people and the needs and coping strategies of couples having trouble conceiving, painful sex and infertility.

Photovoice may be a helpful tool when researching other invisible aspects of life such as mental illness, drug and alcohol misuse, self-harm, infertility, recovery from trauma, as well as other medical conditions that are misunderstood due to their nature of being invisible. It could also be used for more reproductive health topics such as younger women's experience of menopause, the needs and coping strategies of nonbinary people or transmen living with endometriosis. The findings of these studies could also be used to develop an intervention tailored to their needs.

Photovoice also has the potential to be considered more than a participatory research method. Photovoice could be considered a type of intervention itself. For example, the findings could be disseminated as an educational tool for medical professionals or academics. It could also have the potential to be a psychological intervention, as the co-researchers in this study found it to be a therapeutic process that included validation, social support, compassion and understanding, in a supportive and safe environment. The co-researchers' photographs were at times very similar, and this provided them with emotional comfort.

Chapter 5 Intervention Development and Feasibility Randomised Controlled Trial

5.1 Overview

The literature review in Chapter 1 Introduction explained the impact of endometriosis and/or adenomyosis on quality of life. It also explored the gap in the treatment offered to people living with these conditions and the need for more psychological and self-management-based interventions. The systematic review showed a need for more high-quality studies investigating non-surgical, non-pharmacological intervention. The systematic review also highlights the lack of qualitative research into the patient experience of interventions. The systematic review findings showed that mind-body interventions have the most potential for improving the quality of life for people living with endometriosis and/or adenomyosis. The previous chapter (Chapter 4 Needs Assessment) discussed the needs assessment findings, providing data to tailor the intervention towards the psychological needs of people living with endometriosis and/or adenomyosis to improve their quality of life. This chapter details the last steps of intervention development, following the Medical Research Council's guidelines (Craig et al., 2019). This chapter (also discusses the findings of the feasibility randomised controlled trial. The Medical Research Council advises the use of the TIDieR checklist (Hoffman et al., 2014) and the CONSORT statement (Eldridge et al., 2016); these are included in this chapter (Craig et al. 2019).

5.2. Medical Research Council Guidance

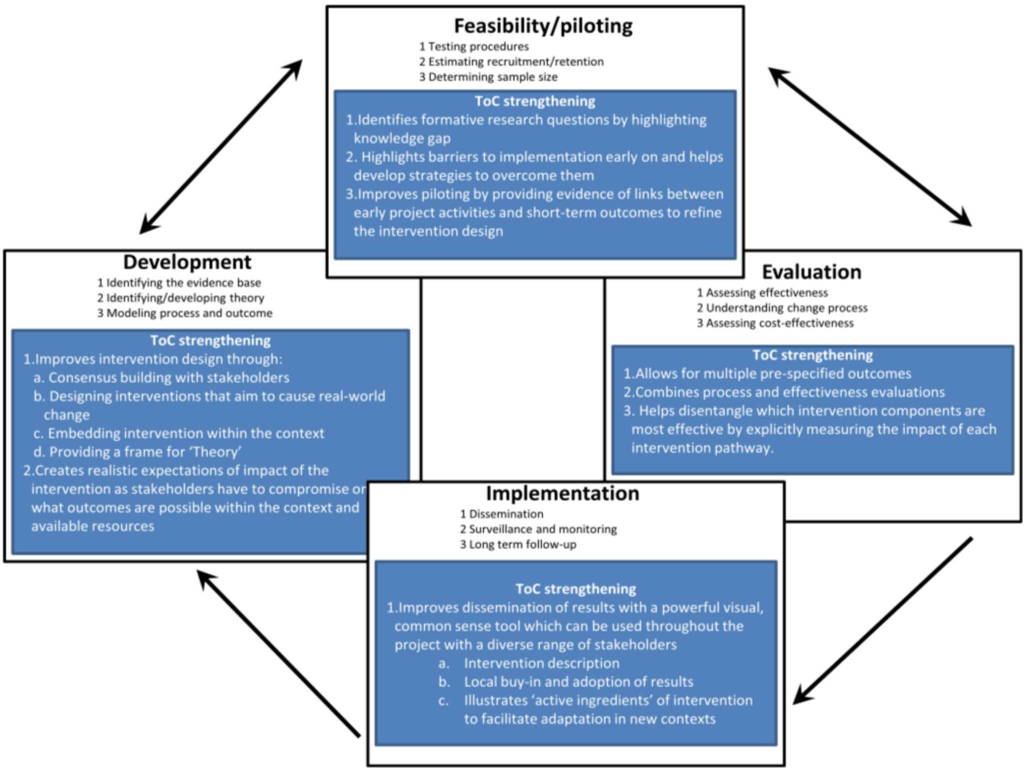
The Medical Research Council Centre for Reproductive health has compiled a list of the top ten priorities for endometriosis in the UK and Ireland. The list includes investigating the most effective way of managing the emotional and/or psychological, and/or fatigue impact of living with endometriosis (including medical, non-medical and self-management methods (Horne et al., 2018).

The Medical Research Council (MRC) Guidelines on developing and evaluating complex interventions advise that intervention development can be a lengthy process (Craig et al., 2019). The MRC state that all of the stages of intervention development are important; if the focus is too strong on one part of the process or not strong enough, then the result will be a weak intervention that is difficult to evaluate, less likely to be implemented and less likely to be worth implementing (Craig et al., 2019). The guidelines advise that the best practice in developing interventions systematically is by using the best available evidence and appropriate theory, then testing them using a carefully phased approach (Craig et al., 2019). Researchers should be informed about the relevant theories and rationales for their complex interventions to help ensure that their intervention is effective (Craig et al., 2019). Also, a sound theoretical understanding of the intervention, derived from careful development work, is key to choosing suitable outcome measures (Craig et al., 2019). The MRC guidelines also advise researchers to consider further questions, including: Can you describe the intervention fully? And Have you reported your evaluation appropriately? The guidelines direct researchers to use the Consolidation Standards of Reporting Trials (CONSORT) 2010 statement for the transparent reporting of clinical trials (Hoffmann et al., 2010). This chapter uses the Template for Intervention Description and Replication (TIDieR) checklist, which is an extension of the CONSORT 2010 statement as well as the CONSORT statement 2010: extension to randomised pilot and feasibility trials (Eldridge et al., 2016)

5.3 Theory of Change

Program theory was introduced in Chapter 2 Methodology; program theory is how an intervention contributes to a chain of intermediate results and finally to the intended or observed outcomes (Funnell and Rogers, 2011). Program theory has two components: a theory of change and a theory of action. Theory of Change allows for multiple pathways, levels, and feedback loops that reflect how complex interventions achieve their impact (De Silva et al., 2014). Theory of change incorporates an evidence base for each strand that feeds into the long-term outcome; this allows researchers to understand which components of the intervention have been successful or unsuccessful and how the components of the intervention have contributed to the change in outcomes (Funnell and Rogers, 2011). Whilst ToC is flexible; it also provides a theory-driven, evidence-based framework that leads to a complex intervention. Researchers can follow the steps and describe each stage of intervention development. This allows for tracking of the intervention components and processes but also allows for replication. Figure 6.1 shoed home the MRC Framework was strengthened by applying the Theory of Change to the intervention development process.

Figure 5.1 Shows the MRC Framework strengthened by applying Theory of Change (De Silva et al., 2014)



5.4 Development Process

There are many steps in the development process; the following steps were followed when using the Theory of Change approach to intervention development:

- **Situational Analysis** – identification/context of the problem, findings of the systematic review and evidence statements from the needs assessment.
- **Focusing and Scoping** – rationale for the focus of the intervention, feasible scope of the intervention
- **Assumptions**
- **Outcomes Chain**

5.4.1 Situational Analysis

The systematic review (Chapter 3 Systematic Review) was conducted to investigate the existing interventions and learn more about the evidence base around this area of research. Unfortunately, due to methodological issues such as missing data, conducting a meta-analysis was impossible. Instead, the results were synthesised in a critical narrative. There were two promising intervention types in terms of quality of methodology and effectiveness. Mindfulness interventions and acupuncture showed the potential to be the most effective. These two types of interventions contained links between the mind and body.

The systematic review has helped exclude non-pharmacological, non-pharmacological interventions or components from the intervention development process. For example, dietary and exercises interventions were searched for, and there were no results returned. (Appendix I – Systematic Review Search Strategy) is a copy of the Medline Search Strategy, which lists the terms used to search for studies.

Due to the lack of qualitative research included in the mixed-methods systematic review, a qualitative needs assessment approach was favoured when the next step of intervention was being planned. Photovoice was chosen as the method for the needs assessment as both endometriosis and adenomyosis are invisible illnesses. Participants have shared their experiences of living with endometriosis: pain restricting or preventing physical functioning, feelings of distress, sadness, self-consciousness and embarrassment about their symptoms, as well as depression and suicide ideation (Roomaney and Kagee, 2016). Participants reported using a combination of problem-focused and emotion-focused strategies to manage the impact of the disease and its symptoms on their HRQOL (Roomaney and Kagee, 2016). People living with endometriosis put significant effort into maintaining their health and minimising the impact of their symptoms by using self-management techniques. Women have taken steps to become 'expert patients', using the internet to educate and help themselves. This work has been described as a 'third shift' performed in addition to paid and unpaid work (Seear, 2009b). Becoming an expert patient with endometriosis can reduce and add to existing stress (Rimke, 2000).

Several needs, unmet needs and coping strategies were identified. To make sense of what the needs and coping strategies are, they were outlined in evidence statements. Evidence statements were created to summarise the rich and detailed data collected and analysed in the needs assessment. This is a helpful way of summarising key findings into a usable form of knowledge relevant to the design of the intervention (Rousseau et al., 2019). This stage has been referred to as 'translation', making sense of the qualitative academic findings and making sense of the information and ideas; this makes it easier to incorporate generated knowledge into the design of the intervention (Rousseau et al., 2019).

Here is an example of an evidence statement, the self-management evidence statement:

Self-Management (diet, exercise, painkillers)
This was the most prominent theme developed during the group discussion and in the secondary analysis. The size of this theme illustrates the effort and burden that the women in the photovoice shared in their data and the group discussion. Living with and managing endometriosis and/or adenomyosis does seem like a second job when all the aspects of this theme are observed. This theme included: self-advocating, 'another job', medication, 'magic' pill (contraceptive pill), supplements, having and maintaining hope, painkillers, sleep aids, diet, exercise, heat/hot water, taking a break, support group, venting/moaning, research and books, finding inspiration and managing poor mental health.

The evidence statements were created and considered if they fit into the scope of the intervention. As mentioned above, there was no evidence in the systematic review to suggest that dietary changes or specific exercises could improve quality of life, so they were omitted. For other needs or coping strategies, literature searches were conducted to investigate components further and build an evidence base.

From the start of the intervention development process, it was known that the intervention would be non-surgical, non-pharmacological and psychology based. Therefore, any component that was considered to be beyond the scope of the intervention was excluded; this was part of the tailoring process, along with the evidence statements. A copy of all the evidence statements is included in the appendices Appendix VIII Evidence Statements).

5.4.2 Focusing and Scoping

What is the rationale for the focus?

The needs assessment produced detail of the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis. It is impossible to include or address all of the unmet needs and coping strategies in one intervention. Focusing and scoping the intervention is about identifying and prioritising the needs of those within the reach and capacity of the intervention. It outlines which needs are within its scope and are beyond it (Funnell and Rogers, 2011).

What is the feasible scope of the intervention?

The intervention that is being developed:

- will be online and facilitator guided
- will be based in the field of health psychology
- will be mindfulness-based
- will address needs that are grounded in psychology or behavioural science.
- Will improve to improve quality of life

Below is a table of the needs and coping strategies that can be included and those that have to be excluded from the intervention because they are beyond the scope of the intervention. These needs are still important to people living with endometriosis and/or adenomyosis, but a psychological intervention cannot meet them. This is an integral part of intervention development, as it clarifies the boundaries for the intervention components.

Table 5.1. Needs and coping strategies included within the scope of the intervention, and those excluded for being beyond the scope of the intervention.

INCLUDE	EXCLUDE
Mindfulness – Introduction to evidence-based information, meditations, mindful inquiry, and mindful activities/action. Self-Compassion exercises, seeking out the pleasant/joy. Five facets of mindfulness – observing, describing, acting with awareness, non-judging of inner experience and non-reactivity to inner experience.	Financial or legal advice
Social Support – Being able to engage with others living with endometriosis and/or adenomyosis. This will help address feelings of isolation and loneliness.	Medical or Medication advice or recommendations
Pacing – emotional regulation systems, boom and bust cycle, behaviour change, evidence-based guidance. This will help address fatigue, feelings of burnout, negativity strategy of pressure to perform and feelings of guilt and responsibility.	Referral to medical professionals
Gratitude exercises – address the negativity bias.	Diagnosis of health conditions
Physiotherapy input.	Dietary advice
Coping strategies – pain management, establishing a meditation practice, combatting critical messages from healthcare professionals.	Relationship/couples counselling
Reflection, sharing and diary keeping	Raising awareness of the conditions or symptoms, including sharing of misinformation.
Goal Setting – behavioural change technique	Educating healthcare professionals or others of the conditions.

5.4.3 Assumptions

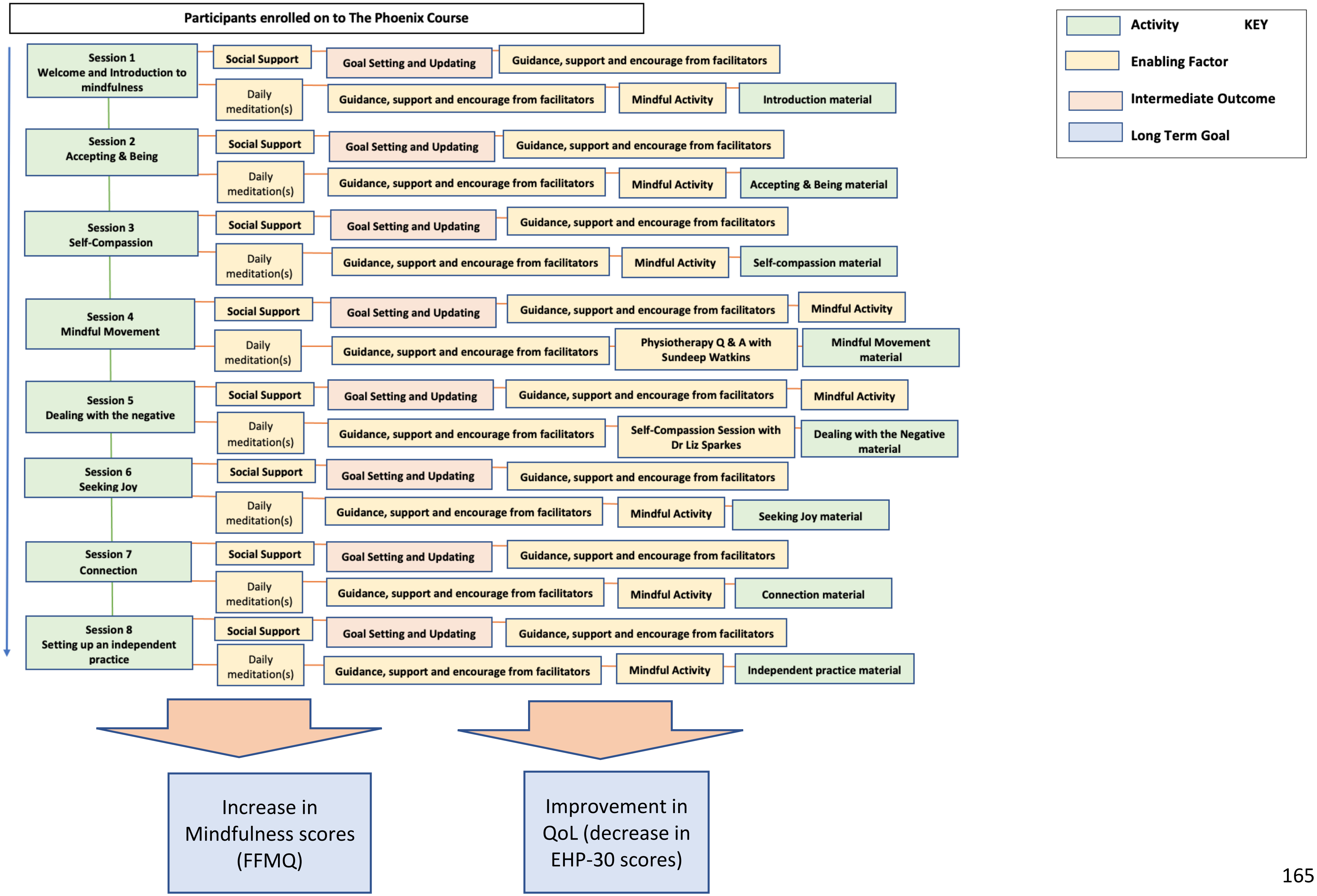
The theory of change of an intervention is designed to bring about changes in behaviour; the theory of action clarifies what the intervention will include in terms of outcomes and operations (Funnell and Rogers, 2011). The theory of action adds to the theory of change by clarifying the assumptions and information about the other factors that may affect the achievement of outcomes and should be considered during the intervention development stage (Funnell and Rogers, 2011). This section explains what the intervention will do to activate the theory of change. This involves providing a detailed statement about each of the outcomes in the outcomes chain.

Below is an outline of the components in the intervention and the evidence base for each component/outcome of the intervention, how this component will operate, any factors that can interfere with achieving the outcome and how these will be addressed within the intervention. Information will be given explaining the outcome chain.

5.4.4 Outcome Chain

An outcome chain is crucial as it is the primary device for thinking about how the program will function to achieve results and address the situation (Funnell and Rogers et al., 2011). The previous section explains why an online mindfulness-based self-management program has been developed, intending to improve the quality of life for people living with endometriosis and/or adenomyosis. This section will show the assumed cause-and-effect relationship between intermediate outcomes and the ultimate impact of the programme.

Figure 5.2 Outcomes Chain.



5.5. Intended Outcomes

The Outcome chain above shows how participants will progress through the online mindfulness-based course each week for eight weeks to achieve the intended outcomes of the intervention. The participants will benefit from the parallel processes such as social support and ease of accessibility of the course; these processes will strengthen and add to the course's main components and be beneficial. The facilitators and barriers will be discussed with participants as these will either help or hinder the participants' progression through the course. These are discussed whenever a participant hasn’t meditated, attempted the mindful activity or goal.

The online sessions will follow a traditional 8-week format, with some elements adapted to an online format and included specific examples of how and why mindfulness formal and informal practices can be used as self-management techniques for managing the impact of endometriosis and/or adenomyosis can have on the quality of life. However, there can be unintended outcomes or adverse events when using a mindfulness-based intervention like online support groups and social media. These are explored in more detail below.

5.6. Unintended Outcomes

When program planning and deciding on the intended outcomes and the theory behind the outcomes, it is vital to keep in mind that researchers have an ethical duty of care to their participants, including considering unintended outcomes and adverse events of an intervention. The unintended outcomes maybe be a reduction in pain symptoms but not an increase in quality of life scores or an increase in quality of life scores but no change in the mindfulness scores. Participants may report an increase or decrease in fatigue symptoms. Adverse events could include several things include an increase in psychological or physical symptoms. The below paragraphs outline research findings around adverse events associated with mindfulness-based interventions.

A systematic review on the safety of mindfulness-based interventions found participants reported excessive sleepiness, headache and dizziness and sleep disruption as minor and temporary unintended outcomes (Wong et al., 2018). This systematic review found 36 RCTs met their inclusion criteria, 25 were MBSR trials, and 11 were Mindfulness-Based Cognitive Therapy (MBCT) trials; there were 4031 participants, aged between 12.5 and 74.9 years, in the trials. There were 19 adverse events reported in the mindfulness intervention groups (1%) and 19 adverse events in the control group (0.9%). In the twenty-five MBSR studies, there were no serious adverse events reported; only three trials reported at least one intervention-related adverse event, including four cases of anger or anxiety in a pain trial, one case of soreness in an anxiety trial and one of a strained neck in a family caregiver trial (Wong et al., 2018). The soreness and strained neck appear to be related to the mindful movement component of the intervention, and this should be considered when teaching this component, particularly with participants who aren’t often active.

Two of the eleven MBCT trials reported serious adverse events unrelated to the intervention in the same review. One trial reported four cases of hospitalisations due to physical health problems and one hospitalisation due to overdose, and nine cases of hospitalisations in the control group. Another trial comparing the effectiveness of MBCT with maintenance antidepressant use for prevention of depression relapse reported ten serious adverse events. Still, the researchers stated that these events were not connected to the trial itself (Wong et al., 2018).

The review concluded that there were very few adverse events in the MBI trials, and even fewer were attributed to MBI’s. The authors of the review regarded MBSR and MBCT interventions to be relatively safe. Still, they urged researchers and practitioners to pay attention to temporary negative emotions and increased depression and anxiety, which could be reported when participants explore their inner experiences (Wong et al., 2018). This review has implications for research; researchers should consider reporting the potential adverse events and continue to take the necessary precautions, e.g., screening for vulnerable individuals, having a larger follow-up period, recognising the importance of control groups and following trial guidelines and reporting requirements.

Indeed, the MBCT implementation resource includes safety advice and caution over participants' health history in groups. The suggested exclusion criteria include active or recent physical addiction to alcohol or drugs, suicidality, psychosis, PRSD, acute depression, severe social anxiety and physical illness that prohibit attending a course (Kuyken et al., 2012). The National Center for Complementary and Integrative Health (NCCIH) states that meditation could cause or worsen some psychiatric issues and urges those with these problems to consider trying meditation to contact their doctor. On the same page, they say that some research suggests that meditation may physically change the brain and potentially help improve many health problems and promote healthy behaviours (NCCIH, 2020).

A critique of mindfulness research has expressed concerns that 'misinformation and poor methodology associated with past mindfulness studies may lead public consumers to be harmed, misled and disappointed' (Van Dam et al., 2018). The authors also expressed concern about potential adverse effects from practising mindfulness, not just taking part in intervention studies. They found more than twenty case studies and observational studies that reported meditation-related experiences that were serious enough to need additional treatment or medical treatment. These studies included reports of meditation-related psychosis, mania, depersonalisation, anxiety, pain, traumatic memory and other forms of 'clinical deterioration' (Van Dam, 2018). The authors also found that whilst 100% of pharmacology trials met the CONSORT requirements, including actively assessing adverse events, only 26% of meditation trials actively assessed adverse events instead of using spontaneous reporting.

5.7 Impact of Covid-19

In March 2020, the UK began the first lockdown due to the Covid-19 pandemic. Coventry University buildings closed for three months, with work becoming carried out remotely, at home. Several changes were made, including shortening the recruitment period from one month to ten days, not conducting semi-structured interviews, incorporating open-ended feedback within the course and using screen sharing to build the intervention and make changes. These changes led to amendments being made to the ethics submission. Once these amendments were accepted, recruitment for the trial began. The trial started in July, after lockdown had ended, meaning the control group ran during the second lockdown. As the trial was conducted during the pandemic, the implications are discussed further in the Discussion chapter (Chapter 6 Discusiion and Recommendations).

5.8 The Phoenix Course

The Phoenix Course is an 8-week online mindfulness-based self-management course designed to meet the psychological needs and improve the quality of life for people living with endometriosis and/or adenomyosis. It was developed following the MRC guidelines on the development and evaluation of complex interventions (Craig et al., 2019). A document containing the outline of the 8-week course is available in the appendices of this thesis (Appendix IX The Phoenix Course Outline). The intervention was tailored using the psychological needs and coping strategies identified by the needs assessment discussed in Chapter 4 Needs Assessment. A copy of the TIDieR checklist is included in the appendices of this thesis (Appendix X TIDieR Checklist).

The Phoenix Course was constructed in Microsoft Word documents before the content was uploaded to the Hope Platform. The content included photographs from the photovoice study and stock images, YouTube videos and text outlining the session's theme and aims. Each component that addressed the evidence statements was constructed based on literature searches. For example, self-management was one of the most prominent coping strategies identified; literature searches were conducted in databases to discover what self-management strategies contained. A development guide (Intervention Development and Evidence Base) was built alongside the content of each session. This document were sent to the supervision team to allow for critical feedback and discussion before the content was uploaded on the Hope Platform, where possible existing platform components were utilised.

The Phoenix Course was built and run on the Hope online platform. Below are some screenshots of the course.

Initially, videos were to be recorded for The Phoenix Course. However, time constraints meant only three videos were recorded. The rest of the video content was videos from The Hope Programme or found on YouTube. For example, a being and doing video was already used in The Hope Course; this was reused. Ted Talks and Mindfulness videos addressing compassion and chronic pain were also searched for. The titles of these videos are included in the course outline (Appendix IX The Phoenix Course Outline).

5.8.1 The Phoenix Course Component Evidence-Base

This section summaries The Phoenix Course evidence base. When developing or using an intervention, specific factors should be considered to lead to positive or negative psychological outcomes: demographic variables, endo-related variables and individual differences (self-esteem, body esteem and emotional self-efficacy) (Facchin et al., 2017). Women newly diagnosed with endometriosis have an increase in anxiety compared with those who have time to understand their diagnosis, and those with more severe pelvic pain are more likely to experience poor mental health (Facchin et al., 2017). Teaching and supporting patients ways of managing their physical symptoms and the psychological impact is a fundamental part of multidisciplinary treatment and can help minimise the devastating impact that endometriosis can have on the sense of self (Facchin et al., 2017).

A qualitative study explored what people with chronic illness describe as their strengths related to their health and wellbeing (Krisjansdottir et al., 2018); the findings of this study are similar to those of the photovoice needs assessment conducted as part of the development of this intervention. The study found that personal strengths could be categorised into three domains: internal strengths (being persistent, having a positive outlook, being kind and caring, experiencing positive emotions, being kind towards oneself, reconciling oneself with the situation, having courage and having knowledge and insight), external strengths (support from family and friends) and self-management strategies (being active, planning and prioritising, reducing stress, goal setting and seeking knowledge and help. The authors found that people with conditions who practice self-compassion reported lower stress levels. It's important that participants strengths be identified and incorporated into any psychological intervention. The support of friends and family can be helpful when attempting something new. Maintaining a positive outlook and taking a self-compassionate approach instead of a self-critical approach may also be beneficial when living and self-managing symptoms of a chronic illness.

Research into self-management interventions used by people diagnosed with endometriosis has shown that psychological interventions primarily focus on symptoms, especially the primary symptom of chronic pelvic pain (Buggio et al., 2017). An alternative has been suggested: interventions with distressed endometriosis patients should not exclusively focus on pain but instead facilitate the expression of thoughts and feelings about endometriosis and work to 'empower the female identity' (Buggio et al., 2017). The authors suggest the use of psychotherapy interventions, either group or individual. They argue there is a need for adequately designed trials to investigate the extent of the benefit of psychotherapeutic interventions such as CBT or psychodynamic therapy.

One of the first systematic reviews that evaluated the effectiveness of psychological therapies for treating chronic pelvic pain, not endometriosis specifically, demonstrated the scant nature of evidence on the use of psychological therapies and emphasised the need for more robust studies (Champaneria et al., 2012). Since then, more studies have been published, the results of a systematic review examining the evidence for psychological and mind-body interventions to improve endometriosis symptoms and the emotional impact (Evans et al., 2019) support Champaneria et al.'s (2012) and Buggio et al.'s (2017) findings that there is a lack of studies that have used the gold standard methodology, meaning definitive conclusions cannot be offered. The authors suggest that there is likely to be a transactional relationship between distress, pain and inflammation in endometriosis patients. The review examined interventions such as hypnosis, psychotherapy, mindfulness and relaxation. The authors found that almost all of 12 studies (89%) reported improved pain, all the studies that looked at anxiety and/or depression reported a reduction in symptoms, and one qualitative also looked at sleep and found that the women reported improvement in sleep (Evans et al., 2019). The authors of this study state that yoga can help endometriosis patients to develop greater self-knowledge, autonomy and self-care, causing them to reduce medication (Goncalves et al., 2016). The group environment also provided psychosocial support, women being around others with similar symptoms (Goncalves et al., 2016). The review concluded that there is an issue with low methodological quality but that there are positive findings that suggest psychological and mind-body interventions have the potential to reduce pain and other symptoms. The authors call for better designed RCTs, as it is likely that endometriosis patients will benefit from an MDT setting that includes psychological health and wellbeing (Evans et al., 2019). Another review aimed to determine the effectiveness of psychological interventions resolving psychological and pain related loss of function associated with endometriosis and to identify gaps in the literature (Van Niekeik et al. l, 2019). This review supports the findings of Evans et al. (2019): combined mindfulness, psychoeducation, and CBT showed significant improvements in pain coping and quality of life. However, there is a substantial need for evidence-based psychological interventions and high-quality studies that improve to reduce pain and improve the quality of life for those living with endometriosis (Van Niekeik et al., 2019). The results of these reviews are similar to the systematic review conducted to develop this intervention. However, that review looked at pain reduction, and the review for the intervention looked at the quality of life. Some of the same studies were included in both reviews.

A qualitative study of six focus groups evaluated the precepts of women with endometriosis and chronic pelvic pain regarding their social ties (Mellado et al., 2016). The study found social isolation was the central identified theme and was associated with a lack of understanding about endometriosis symptoms and resignation in the face of recurrent pain. The women in the focus groups reported avoiding partner intimacy and isolation from friends and family as components of social isolation. The authors recommend including rebuilding social ties in the objectives of multidisciplinary management of endometriosis and chronic pelvic pain (Mellado et al., 2016). Group interventions may be more effective for women with endometriosis as women can benefit from the therapeutic element and social support from others in the group. A quantitative study reporting the development and feasibility of a group-based yoga program for women with chronic pelvic pain (not endometriosis specifically) found that it was feasible to teach women with chronic pelvic pain to practice yoga to self-manage pain, improve Quality of Life and sexual function (Huang et al., 2017). The findings of the Goncalves et al. (2016a) and the Huang et al. (2017) studies suggest that group-based interventions are helpful because they provide social/peer support and the therapeutic element of yoga. In a quantitative study investigating the use of Hatha yoga as a treatment for endometriosis-associated pain, the women in the yoga group showed a significant reduction in pain, lower stress levels and greater relaxation than the control group (Goncalves et al., 2016b). The authors suggest that relaxation used in yoga practice can counteract the adverse effects of stress by restoring balance to the autonomic nervous system and the hypothalamic-pituitary-adrenal axis. The authors also found that improving one domain of quality of life may affect improvement in other domains of the EHP-30 (Jones et al., 2001). For example, having control and feeling less powerless might have improved self-image and emotional wellbeing (Goncalves et al., 2016b).

Yoga classes often include elements of mindfulness and meditation practice. It is helpful to consider the evidence behind yoga and mindfulness separately and note that there is an overlap between the two. Yoga is used as a form of exercise, mindful movement but is also used to allow meditators to practice prolonged mediation sessions. Mindfulness has been used and researched as an adjunct treatment for chronic health conditions since the 1970s (Kabat-Zinn, 1979). More recently, mindfulness has gained popularity clinically and commercially. A systematic review and meta-analysis of whether mindfulness can improve outcomes in patients with chronic pain (Bawa et al., 2015).

The review results found 11 studies; conditions included were fibromyalgia, rheumatoid arthritis, chronic MSK pain and failed back surgery syndrome (endometriosis was not included). The review found limited evidence for the effectiveness of mindfulness-based Interventions in chronic pain. Studies were generally small, and results were not always statistically significant. The meta-analysis revealed that mindfulness-based interventions might impact perceived pain control, with a moderate effect size.

In the last decade, several studies have been published that report the results of using mindfulness-based interventions to improve or reduce symptoms of endometriosis and chronic pain. Although systematic reviews have shown studies are often of lower methodological quality and often provide limited evidence, it can be helpful to look at the individual studies recommendations. Frequently these studies lack a control group as clinicians run the interventions for treating patients in the hopes of improving their quality of life. Endometriosis and adenomyosis symptoms may be lifelong conditions, and symptoms can reoccur after surgical and hormonal interventions. Most mindfulness-based intervention studies report the complexity of managing or treating symptoms and often call for further, more methodological sound studies. The studies are usually preliminary, pilot or feasibility studies. Chronic pelvic pain studies have been included in this section. It takes an average of 7.5 years to be diagnosed with endometriosis; undiagnosed endometriosis may be the cause of this pain.

A pilot study tested the feasibility of teaching mindfulness meditation to women living with chronic pelvic pain and found it can improve quality of life (Fox et al., 2011). The results of another pilot study with a 6-year follow-up show statistically significant and lasting effects on participants' pain level, well-being, and ability to function in daily life (Kold et al., 2012, Hansen et al., 2017). Most interventions for chronic health conditions use a form of MBSR, developed by Jon Kabat Zinn (1979, 1982) for this very purpose. This study used MBSR and contains three types of interaction: mindfulness training (body scan, sensory training, breathing techniques, music and bi-feedback support), psycho-education and group dialogue and one to one sessions that were adapted for the individual's personal goals and challenges. This intervention trained participants to notice their breathing and voluntarily change it from patterns associated with tension toward relaxation. The psych-education element included: grief process and emotions related to adopting healthy habits, social support and mind-body interactions (Kold et al., 2012). The results initially showed a complex pattern; the authors later issued a Corrigendum (2016) stating an error during data analysis. The results showed statistically significant improvements in all eight SF-36 subscales. They also used the endometriosis specific scale, the EHP-30 (Jones et al.,2001). All five standard scales showed improvements, and four of them still showed improvements at the one year follow up: pain, control and powerlessness, emotional wellbeing and social support. The sexual function scale failed to show improvement. The intervention successfully improved the physical, psychological and social aspects of the participants' problems. The authors concluded that using a mindfulness-based intervention with endometriosis patients experiencing pelvic pain is feasible and may produce positive effects on quality of life (Kold et al., 2012). The six-year follow up showed lasting improvements on almost all scales of the EHP-30 and SF-36 (Hansen et al., 2017).

Women serving in the military face unique challenges in treating and managing their chronic pelvic pain. A feasibility study investigated implementing an MBSR program for women serving in the military and experiencing chronic pelvic pain. (Crisp et al., 2016). The authors experienced difficulties regarding the availability of classroom space due to a permanent change of station for the researchers. They did find that the women in the study found that lifestyle challenges made sustained engagement difficult. Results showed that participation in an MBSR program could reduce pain and promote modulation of select pro-inflammatory cytokines. The authors recommend considering the structure and mode of program delivery of MBSR programs (Crisp et al., 2016). These findings are significant as it raises an issue that doesn’t just affect women in the military. Mindfulness interventions traditionally take place in the evening or weekend and require a 2-2.5 hour commitment to attend sessions face-to-face for eight weeks. Participants also have to commit to practising meditation at home six out of seven days a week. This can lead to the exclusion of single parents, people who don't work nine to five jobs, people who live in rural areas, those with transport issues, carers, those who travel for work or have other intermittent commitments, but mostly it excludes or makes attendance difficult for those the programs were designed for: disabled people. People who live with chronic pain often have many other priorities in their life and may have to prioritise rest over leaving the house in the evening.

An article written about what to do when chronic pelvic pain cannot be resolved or treated by surgery reviewed nonpharmacological therapies (Till et al., 2017). The authors recommend that effective treatment requires a multifaceted approach; they found evidence for the use of physical therapy and trigger point injections, neuromodulation techniques and TENS, behavioural strategies such as exercise, CBT and mindfulness. CBT and mindfulness were considered helpful for chronic pain patients as chronic pain is associated with prop coping skills and maladaptive avoidance behaviours. The authors stated the mindfulness had shown promise in fibromyalgia patients but that, unfortunately, CBT therapists that specialise in chronic pain can be challenging to find. Due to this, the authors recommended that web-based CBT and/or mindfulness interventions be used (Till et al., 2017).

Web-based interventions are an obvious solution to challenges with finding face to face therapy or interventions. A recent trial (Ball et al. 2020) used Headspace, a pre-existing meditation app for smartphones and a relaxation app (also designed by Headspace) as a control group for women in an outpatient clinical for chronic pelvic pain (not endometriosis specifically). The authors were disappointed by the low level of engagement, even though pre-study PPI focus groups showed that patients were enthusiastic about using an app. There were thirty-one participants in the intervention group, six used the app regardless of, and 4 used it when experiencing extreme pain. The authors found that barriers to use included: lack of familiarity and capabilities with technology, failure to establish a routine, busy life and lack of perceived benefit. Participant feedback included more guidance at the beginning of the study. The authors suggested that there needs to be an understanding of what motivates those with a clinical need to use an app for clinical reasons. Appropriate expectations need to be set from the beginning for participants, and that incentivisation (gamification) may improve motivation levels. The authors also suggested that future studies consider unexpected benefits, e.g., relieving stress rather than pain. This app was designed to be used individually; it lacked the psychosocial element that participants in face-to-face mindfulness and yoga groups had benefitted from. The authors advised that future studies include social support and a 'community practice'. This study used a pre-existing app, which did not include input from patients. It could be argued that the main finding from this study is that chronic pelvic pain has many causes and can be complex to treat; assumptions should be made about patient needs, including social support and psychoeducation. Understandably, chronic pain patients wouldn't respond to a meditation app that aims to reduce their pain rather than provide a tool to help them self-manage. One size does not fit all; a mediation app is designed to teach meditation and perhaps can't be considered a psychological intervention. Nevertheless, the findings of this study hold great value for researchers attempting to provide a self-management online course of many different modalities, e.g. mindfulness, ACT, CBT.

In summary, due to a lack of high-quality studies, there is limited evidence into the effectiveness of psychological and mind interventions in improving the quality of life for people living with endometriosis and or adenomyosis. Both CBT and mindfulness have shown they may have the potential for helping patients struggling with the impact of endometriosis on their mental health. The studies above highlight that self-compassion and the mind-body link are essential qualities to include in an intervention developed for people experiencing chronic pelvic pain. Mindful movement and relaxation exercises were be included. Several studies have shown that psychosocial support is just as crucial for women's quality of life as the therapeutic modality. Face to face group interventions can be challenging to access and attend. Therefore an online intervention should be provided as an acceptable solution to these issues. Any intervention developed needed to be designed with the needs of endometriosis patients in mind. Therefore, importance was placed on the data from the needs assessment. A control group was also used to determine if an online group mindfulness intervention was more beneficial than treatment as usual.

5.8.1.1. Online Resources and Tools

The literature search also included terms related to mHealth apps and online self-management courses for endometriosis, chronic pelvic pain and other chronic conditions. The internet can be a helpful resource for those newly diagnosed with endometriosis and/or adenomyosis. A systematic review investigated the accuracy of online information when the term endometriosis is Googled (Hirsch et al., 2017). The review found that the internet is '*<u>the</u> source of health information, as patients can access the information quickly, conveniently and privately*' (Hirsch et al., 2017). The authors evaluated websites for credibility, quality, readability and accuracy. They found that over a third of web pages did not attribute authorship, and almost half did not report sources. Over 750 pages were returned during searches, 54 were included in the review and only one page provided accurate, evidence-based information, clear communication in plain English. This study shows that the internet can be a helpful and easily accessed tool that women can use privately in the comfort of their own homes. However, there can be quality and accuracy issues with websites. The review did not include social media posts on Facebook, Instagram or Twitter, which women often use to connect with others experiencing similar symptoms, looking for information or social/emotional support.

Social media is another online resource that can be both helpful and come with inaccuracies and challenges. Social media can be beneficial for people living with chronic illness; it can provide a connection to others that they might not be in contact with otherwise. The therapeutic affordances of social media for people with chronic pain were investigated (Merolli et al., 2014). The authors argued that although research has suggested that social media is well suited to enhance the management of chronic health conditions, there is an absence of published studies examining the underlying therapeutic mechanisms of the use of social media. The authors suggested five therapeutic affordances: identity (used to present perceptions regarding disclosure of identity in online social environments), flexibility (the time-space freedom enabled by social media, such as the ability to interact at a time suiting the individual and where they choose), structure (the guidance and filtration present in information seeking that social media can provide), narration (encompassed social media's utility to provide a platform to share stories of illness) and adaption (referred to the capacity for one's self-management to evolve through social media to meet particular needs based on current symptoms). Social media can be helpful in several ways for those living with chronic pain and health conditions. However, it can be challenging to measure the clinical impact of social media on health outcomes (Merolli et al., 2014). Social media provides more than just a means of communication and contact with others; it allows users to research self-management strategies, construct an online identity, share stories of their experiences, and do this at a convenient time.

Women living with endometriosis can access social media to employ the therapeutic affordances explained above, but they can also access online support groups. These can take the form of closed Facebook groups or online forums. The therapeutic affordances of online support groups have been explained as connection (the ability to connect to support each other, exchange advice and try to overcome feelings of loneliness), exploration (the ability to look for information, learn and bolster their knowledge), narration (the power to share their experience as well as read about the experiences of others) and self-presentation (the ability to manage how they present themselves online (Shoebottom et al., 2016). The authors found that associated outcomes of using online support groups were primarily positive, getting reassurance and improved caring. The negative concerns included concerns about the accuracy of the information, arguments between members, overreliance on the groups, upsetting negative experiences or good news items and confidentiality. The accuracy of the information available about endometriosis online is a genuine concern, as Hirsch et al. (2017) have shown above. Online support groups can provide valuable support and combat the social isolation often reported by those living with endometriosis and chronic pelvic pain. However, users should use them with an awareness of the issues they may encounter.

Along with the internet, social media and online support groups, mHealth apps have increased in recent years. mHealth apps can take different forms. They may contain a self-management tool such as Headspace; they may encourage behaviour change such as smoking cessation or weight loss, or monitor symptoms or remind a user to take a medication. Incentivising or gamification is often used for health promotion to encourage users to engage with the app. A systematic review investigated health apps containing gaming elements and analysed the embedded behaviour change techniques (Edwards et al., 2016). The reviewers screened 168- medical, health and wellness or health and fitness apps, of which 64 met inclusion criteria. The apps included aimed to increase/improve exercise, improve fitness, smoking cessation, encourage oral hygiene, weight loss and blood glucose adherence. The median number of behaviour change techniques was 14. The most common behaviour change techniques were feedback and monitoring, behaviour comparison, and reward and threat. The most used individual techniques were: self-monitoring of behaviour, non-specific reward, non-specific incentive, social support unspecified and focus on past success. The authors found that smartphone games or apps can provide a potentially cost-effective platform for health promotion and could have a substantial public health impact. A study looked at the use and recommendation of mHealth apps by pharmacists, the public's perceptions of mHealth apps and awareness and use of these apps by people with diabetes in particular (Kayyali et al., 2017). Over half of the pharmacists (56%) that responded were aware of mHealth apps, 60% of which had recommended mHealth apps to patients. Over 76% of individuals in the general public own a smartphone, and the most used applications are health and lifestyle (24%), social app (19%), followed by news (18%). The authors concluded that despite the growing number of mHealth apps, patients and pharmacists' level of awareness and usability of these apps is low. However, the majority who use mHealth apps found them beneficial. (Kayyali et al., 2017). While the term gamification can have negative connotations associated with gambling, gamification can make an app more successful for both the developer and the user when viewed in terms of behaviour change techniques. Gamification in mHealth apps can lead to users developing healthier habits, self-monitoring and self-managing their symptoms and making lifestyle changes.

In summary, an online psychological or mindfulness intervention can be enhanced by importing elements of social media and support groups, enabling users to benefit from their social affordances and the therapeutic element of mindfulness. Online mindfulness courses or apps tend to be used by individuals and lack the psychosocial aspect of face to face mindfulness classes. Including an online forum allowed users to communicate and share similarly to social media or support groups could provide many therapeutic benefits, in addition to psychosocial support. However, ground rules were provided to minimise the risk for over-reliance, sharing inaccurate information, and disagreements between users and protect confidentiality. Combining the therapeutic affordances found in social media and support groups with gamification can lead to users encouraging each other to achieve goals or overcome challenges. As the users were new to an online mindfulness intervention, they could share their reflections on meditating and if they noticed any changes or improvements. To maximise accessibility and usability, the intervention had to function well on smartphones, tablets and laptops, and desktop computers. Mediations were available offline, and users could use the function of uploading and sharing photographs. Photography proved to be therapeutic for the co-researchers in the photovoice study and mimics the functionality of social media platforms such as Facebook, Twitter and Instagram.

5.8.1.2 Self-Management Strategies and Interventions

Self-management was the most prominent theme identified in the photovoice needs assessment study. The co-researchers shared the effort and sometimes burden of self-managing symptoms of endometriosis and adenomyosis. An online survey of Australians asked women with endometriosis about their self-management strategies (Armour et al., 2019). Self-management strategies used include heat (70%), rest (68%) and meditation or breathing exercises (47%). The women also reported using negative strategies with associated adverse events such as alcohol/hangover (52.8%), exercise/increased pain (34.2%), heat/burns (15.9%). The authors concluded that effective self-management strategies and lifestyle changes can play an important role in managing symptoms and may ‘empower’ women in taking more control over their health and providing an effective add on to their current treatment; they also stressed that women with endometriosis have unique needs and self-management practices need to be considered in light of the potential for flare-ups (Armour et al., 2019). As this study shows, it is crucial to evaluate adverse events of any intervention or self-management strategy, as even helpful strategies such as heat can also have adverse events/effects (burns). Both face-to-face and online, comprehensive self-management courses have shown benefits to people living with chronic health conditions, including chronic pain. Benefits have included reductions in pain, physical disability, pain self-efficacy, pain intensity, pain interference, pain catastrophising and depression and anxiety and alter patients feelings of empowerment and help prevent medication misuse (Mehlsen et al., 2015, Wilson et al., 2015, Riva et al., 2014, Nicholas et al., 2011). Web-based chronic pain management programs have advantages, including inexpensive to scale to provide services to more extensive and diverse populations, conveniently accessible about the clock and allowing a tailored experience to specific symptoms or needs (Nevedal et al., 2013).

An RCT tested the efficacy of an online chronic pain self-management program (Ruehlman et al., 2012). Participants were recruited online, not from a clinical setting. The program was an entirely self-directed and self-paced system that integrated social networking features and self-management tools into an interactive learning environment. The results showed significant decreases in pain severity, pain related interference and emotional burden, perceived disability, catastrophising and pain induced fear. The program included four categories: cognitive, behavioural, social and emotional regulation. The authors concluded that a self-paced, interactive pain management training program could achieve measurable effects on pain, mental health and learning outcomes (Ruehlman et al., 2012).

Another RCT investigated the outcomes of using internet self-management activities to reduce pain and improve quality of life (Rod et al., 2016). The results showed that internet-based self-management activities were helpful to those who could not access multidisciplinary pain management and found modest improvements in pain, anxiety, depression and quality of life (Rod et al., 2016). An online intervention was developed and evaluated for patients with bladder pain syndrome/interstitial cystitis (IC) (Lee et al., 2014). IC symptoms are often confused with endometriosis symptoms, although it is possible to have both conditions. The 8-week intervention included guided imagery/meditation, diet information and exercise advice. The intervention encouraged self-management strategies that were effective at improving quality of life and alleviating symptoms of IC (Lee et al., 2014).

An RCT examined the effect of an online self-management curriculum among breast cancer survivors (Smith et al., 2018). The curriculum consisted of web-based content and required activities, including attending one online introductory group meeting, viewing videos and completing cognitive reframing and mind-body exercises over an 18-week period. The results showed a significant difference in change between the intervention group depression scores and the treatment as usual control group scores. The authors reported a reduction in depression and fatigue but not pain severity and concluded that online programs could be a feasible and effective alternative to in-person support (Smith et al., 2018). A report of the results of three separate studies of web-based CBT and ACT interventions that included e-diaries and feedback through smartphones (Neset et al., 2013). The participants in the studies had either IBS, CWP or type 2 diabetes. Results showed that there are advantages to using the internet to deliver self-care and behaviour change interventions; interventions with strong theoretical foundations can achieve positive results in short and mid-term time frames.

A study collated the results of ten years of CBT pain self-management outpatient programmes for complex chronic conditions found that pain symptoms can be significantly reduced and depression and anxiety (Boschen et al., 2016). A systematic review investigated the effectiveness of a mHealth self-management intervention in improving sleep, psychological distress, fatigue and sleep in cancer survivors (Silva et al., 2009). The results showed that mHealth interventions that support self-management could improve pain and fatigue in cancer survivors, and some promise for psychological distress and sleep outcomes. The most promising outcomes are the improvements shown in fatigue outcomes. The improvements demonstrated for cancer survivors are promising for an endometriosis population as the level of quality of life for both populations is impacted in similar ways.

A literature review found a lack of theory-driven research and low use of behaviour change techniques in group-based self-management programmes (Keogh et al., 2015). Another review aimed to identify information needs and gaps in chronic pain management and technology features to inform the development of an internet-based self-management program (Gogovor et al., 2017). Thirty-nine articles related to twenty patient-orientated internet-based programs. Gaps included lack of knowledge, limited access to health care, suboptimal care and lack of self-management support. Patients considered essential features of an internet-based program as simple to use, user friendly with a little animation, bilingual, using language that patients can understand with clickable definitions when necessary and be accessible via mobile devices and also include non-medical activities of daily living (Gogovor et al., 2017).

There can be barriers and facilitators to chronic pain self-management (Bair et al., 2009). Barriers to pain self-management may include lack of support from friends and family, limited resources (e.g. transport, finances), depression, the ineffectiveness of pain relief strategies, time constraints, avoiding activity because of fear of pain exacerbation, lack of tailoring strategies to meet personal needs and not being able to maintain the use of strategies after study completion. Facilitators may include: encouragement from healthcare professionals, improving depression with treatment supportive friends and family and providing a menu of different self-management strategies to use (Bair et al., 2009).

Another facilitator may be encouraging participants to form habits related to self-management strategies. A study into the modelling of habit formation in the real world aimed to investigate the development of automaticity (Lally et al., 2010). Participants were asked to repeat behaviour of their choice, in response to a cue, in an everyday setting without an extrinsic reward. Results showed that for most participants, automaticity increased steadily over the days of the study, supporting the assumption that repeating a behaviour in a consistent setting increases automaticity (Lally et al., 2010).

Another potential facilitator of a self-management program for a chronic health condition is the concept of ‘social identification’ (Cameron et al., 2018). Social identification refers to the extent to which group membership shapes self-conception and contributes to self-evaluation and the emotional bond between the individual and group (Tajfel, 1978). Social identification can be a curative mechanism in group interventions, individuals experiencing a sense of belonging to a group. The potential benefit of belonging to a social group is that the members can facilitate goal attainment by lending each other a sense of efficacy in pursuing their aims. This study showed that social identification had a bolstering effect on participants confidence in managing various challenges of their chronic disease. Results suggest that social identification – the psychological link of the individual to a contextually meaningful group – can provide an avenue to several social processes and resources that promote health-related outcomes. These results confirm that group self-management programs can fulfil social needs and be enhanced by social identification (Cameron et al., 2018).

Evidence suggests that connectedness is also a protective factor against developing depression or of current depressive symptoms worsening (Cruwys et al., 2013). An RCT looked at how intersession coping skills practice mediates the relationship between readiness for self-management treatment and goal accomplishment in a CBT intervention (Heapy et al., 2005). The findings demonstrated that participants practice of pain coping skills and other actions designed to promote behavioural goal accomplishment account for a significant proportion of the variance is a measure of self-reported attainment of behavioural goals. The authors also found that participants beliefs about the relevance of learning and using behavioural and cognitive skills may be necessary for determining willingness to engage in a self-management programme (Heapy et al., 2005). The message taken from this study is that for participants to feel accomplished by the end of a self-management programme, they need to feel they have attained their goals. Self-management programmes can help participants achieve their goals by explaining the relevance of the skills they are learning and encouraging them to use the skills in between programme sessions.

This intervention for people living with endometriosis and/or adenomyosis will be delivered online using the iHOPE digital platform. This platform has produced positive face-to-face and digital results and peer-delivered self-management courses for cancer survivors (Turner et al., 2012, Martin et al., 2020). The face-to-face self-management support programme showed statistically significant improvement in general quality of life, cancer specific quality of life and goal planning (Turner et al., 2012). The 6-week digital, peer-delivered self-management programme included group curative factors of instilling hope, universality and altruism in the programme, and psychosocial factors mentioned above as beneficial for those living with endometriosis. The iHope, digital intervention results showed that 61% participated in all six sessions, the mean number of sessions undertaken was five, 45% completed at least three sessions, and the end outcome measures. Of the participants that completed the satisfaction questionnaire, over 90% found the programme easy to navigate, well-managed by the peer facilitators and the social networking tools valuable (Martin et al., 2020). This study found the feasibility evidence promising, showing that the peer-delivered digital iHOPE programme is acceptable and practical (Martin et al., 2020). The result of both of these studies shows that using the iHOPE platform for an online mindfulness-based intervention with a psychosocial element has the potential to be considered a feasible and acceptable self-management programme for people living with endometriosis and/or adenomyosis.

In summary, again, there are very few published research findings on the use of self-management programmes for people living with endometriosis and/or adenomyosis. However, there is some evidence when the net is widened to include chronic pain patients. Self-management programmes have the potential for reducing painful symptoms and improve mental health. They can provide users with coping skills and support them in goal attainment. Online self-management programmes can be helpful for those who find it challenging to engage with traditional face to face courses, and technology has been developed that now means these programmes can include e-diaries and social media like aspects. The increased use of smartphones now means that online self-management programmes are more portable and accessible than ever. There are several barriers and gaps that are discussed above; avoiding or addressing these can decrease the potential failure of the programme. There are also several facilitators to keep in mind and encourage participants to engage with a programme.

5.8.2 The Phoenix Course and The Hope Platform

The Phoenix Course is built upon the digital Hope platform. The platform has its own established and original 6-week self-management course, The Hope Programme. As the Hope Programme contains evidence-based self-management components, some of these components were included in the Phoenix Course. Hope components were included only when they aligned with the findings of the needs assessment. For example, gratitude was used as a positive coping strategy, which was already a component of The Hope Programme. Table 5.2 provides details on The Hope platform, The Hope Programme and The Phoenix Course and how they overlap

Figure 5.2 and 53. Screenshots from The Phoenix Course (editor view)

Welcome to the Phoenix Course

Hello, and welcome to the Phoenix Course, an 8-week Mindfulness-Based Course, specifically tailored to the needs of people living with endometriosis and adenomyosis. This course is based on scientific evidence and has been developed in consultation with a group of women living with different stages of both endometriosis and adenomyosis.

The Phoenix Course has been designed by researchers at Coventry University and uses the iHOPE platform, that was also developed at Coventr University. Our research has shown that living with endometriosis and adenomyosis often comes with a large burden that means a lot of time and energy goes into managing symptoms and trying to prevent flare ups. This course has been designed to ease this burden and provide you with help for self-managing your condition.

The aims of this course are:

- To teach you mindfulness skills
- To help you use these skills to manage your symptoms
- To connect you with others also living with endometriosis and adenomyosis

Clair and Hollie will be your course facilitators. They will support and guide you through your journey with us. You will find out more about them during the course.

We understand that COVID-19 is a source of concern for everyone right now, particularly for those with long term health conditions. Endometriosis UK has put together some helpful and reassuring information about endometriosis and COVID-19.

Session 2 - Acceptance and being

Welcome back to Session 2 of the Phoenix Course, we hope you enjoyed your first session of mindfulness.

In this session you will be adding to what you learned in session 1. Session two will be about accepting instead of avoiding experiences, even those of discomfort. This session will also discuss alternatives to fighting or battling against your body, your endo or your symptoms. We'll cover how to be kind to yourself, paying attention to all of you, not just the painful or uncomfortable parts or experiences.

There will be a new meditation to practice over the week, a new mindful activity and some familiar activities from the last session.

As always the facilitators will be providing support and encouragement and will be involved in discussions, feel free to message them if you have any questions or concerns.

We hope you enjoy this session and look forward to seeing your posts.

REVIEW OF SESSION 1

Before we move on to the Session 2 material, let's review what we've all been doing over the past week:

- We learned about what mindfulness is
- We learned about why mindfulness is helpful for managing endo/adeno symptoms
- We learned about the two arrows
- We introduced all the elements that make up the course.

Goal feedback

We would like you to **feedback** on how you got on with your goal by using the Feedback option, which can be found next to the confidence scores, its's the 3 horizontal dots ...

You can find your goal in **Journey**. You can comment on your goal e.g. how did it make you feel? And any challenges you may have faced. When you submit your feedback it will appear at the side of your goal.

It's OK if you haven't met your goal. Setbacks are a normal part of life and remember, you are learning a new skill. What would you say to someone here today who has not managed to complete their goal? We are sure you would give them words of comfort and encouragement for their next goal.

You might say 'that's ok, there were good reasons for not achieving your goal'. In other words, you would show them kindness and compassion.

If you did or didn't achieve your goal over the last week, it's important that you are kind to yourself.

Set a goal and post a gratitude

Our research has shown that the more activities you do the more benefit you get from the course. It would be great if you could set another g and share what you are grateful for. You can go straight to these activities from the top left navigation. On a desktop, this is always visible. On a mobile and tablet, just click the three horizontal lines to reveal the options.

Connect with other members

Table 5.2 Characteristics of the Hope platform, the Hope Programme and the Phoenix Course

Description	Established digital intervention platform. Including The Hope Programme – a 6-week self-management course. Includes multi-media content and evidence-based components.	8-week online mindfulness-based intervention built on the Hope platform. Includes elements designed for the Hope Programme. Includes findings from the photovoice needs assessment and literature searches.
How is The Hope Programme different from The Phoenix Course?	The Hope Programme – self-management-based course. Each component relates to supporting self-management for people living with different health conditions – MS, surviving cancer, PCOS.	Mindfulness-based course. Each component relates to building mindfulness skills, used as a self-management coping strategy. Created specifically for people living with endometriosis and adenomyosis.
Components	Includes multimedia components on goal setting, self-management strategies, gratitude, social support, Q & A forum, participant feedback. Includes live weekly sessions.	Includes multimedia components on goal setting (taken from Hope), social support (taken from Hope), mindful activities and mindful inquiry (building on Hope component that asks participants questions), physiotherapy, weekly MP3 mediations fitting with weekly themes, gratitude (identified in needs assessment but also existed in the Hope Programme) and supplementary material 'Living with Endometriosis photo book. Also included were weekly participant feedback (from Hope) and three videos recorded for The Phoenix Course: Introduction by myself, meditation by Dr Elizabeth Sparkes and Q & A video with specialist physiotherapist Sundeep Watkins. No live sessions.
Integrated Data Collection Methods	Microsoft Excel element built in the functionality of the Hope Platform. Registers interactions with participants, including weekly participant feedback, pages read in each component, course completion, comments and likes left on each component, completion rates, engagement rates.	Uses functionality of Hope platform: Microsoft Excel element built in the functionality of the Hope Platform. Registers interactions with participants, including weekly participant feedback, pages read in each component, course completion, comments and likes left on each component, completion rates, engagement rates.
Usability	Desktop computers, laptops, tablets and mobile phones. Windows, Mac, Android	Utilises the usability of the Hope platform. Desktop computers, laptops, tablets and mobile phones. Windows, Mac, Android

5.9 Feasibility Trial

The purpose of the TIDieR checklist is to provide researchers with a tool for reporting interventions (Hoffmann et al., 2014). Without a complete, published description of an intervention, other researchers cannot replicate or build on the findings of studies featuring interventions (Hoffmann et al., 2014). Both transparency and detailed reporting are essential when reporting and describing interventions. Using the TIDieR checklist is recommended by the MRC guidelines on the development and evaluation of complex interventions (Craig et al., 2019).

The MRC guidelines also emphasise having a feasibility/piloting stage that includes testing procedures for their acceptability, estimating the likely rates of recruitment and retention of subjects, and calculating appropriate sample sizes (Craig et al., 2019). This stage is often overlooked when conducting intervention research, leading to issues with acceptability, compliance, delivery of the intervention, recruitment and retention in extensive time consuming and expensive trials (Craig et al., 2019).

The MRC guidelines do not differentiate between pilot studies and feasibility studies. Still, they do recommend using the Consolidated Standards of Reporting Trials (CONSORT) states as a resource for transparent reporting of clinical trials (Craig et al., 2019). The CONSORT statement was first published in 1996, revised in 2010 and published in ten leading medical journals (Eldridge et al., 2016). In 2016, an extension to the statement was published for randomised pilot and feasibility trials (Eldridge et al., 2016). The extension was developed due to the growing number of studies described as feasibility or pilot studies and research that have identified weaknesses in reporting and conduct (Eldridge et al., 2016).

The National Institute of Health Research (NIHR) defines feasibility studies as ‘pieces of research done before a main study to answer the question: ‘Can this study be done?’ (NIHR, 2012). The NIHR also differentiates between a pilot study and a feasibility study. A feasibility study tries out pieces of an RCT; a pilot study tries out the operation of all the elements as they will be conducted in an RCT (NIHR, 2012). Feasibility studies are designed to build the foundation for a planned intervention study (Tickle-Degen, 2013). When feasibility studies are appropriately conducted, researchers determine the critical facts before research stakeholders commit to a significant investment in money and time for a larger trial (Tickle-Degen, 2013). The Phoenix Course was evaluated in a feasibility RCT and is reported with the CONSORT statement extension checklist (Eldridge, 2016). A copy of the CONSORT statement extension checklist for this feasibility study is included in the appendices of this thesis (Appendix XII Consort Statement).

5.10 Aim and Objectives

This study aimed to test the feasibility of an online mindfulness-based self-management intervention (The Phoenix Course) for people living with endometriosis and adenomyosis. This will inform the design of a definitive randomised controlled trial. Additionally, a preliminary assessment of the impact of the Phoenix Course via secondary outcomes will be used to assess signals of efficacy in a trial context.

The primary outcomes (trial feasibility objectives) of the study were to investigate:

- Recruitment rates for participation and randomisation
- Retention rates as the participants move through the trial
- Adherence rates to study procedures, intervention attendance and engagement
- Progression criteria for a definitive trial

The secondary outcomes are:

- Measures of quality of life and mindfulness skills

5.11 Methods

The following sections are written following the CONSORT statement extension for reporting pilot and feasibility trials (Eldridge et al., 2016).

5.11.1 Trial Design

This study employed a feasibility, randomised waitlist control group parallel design with a 1:1 allocation ratio. Participants were randomised to an intervention group (IG) or a waitlist control group (WLCG). The intervention group received access to the online 8-week Phoenix Course once the recruitment period ran from 27th June 2020 to 6th July 2020. The WLCG were placed on a waiting list for eight weeks. After that time, they received access to the same online 8-week Phoenix Course Key outcome measures were collected via online questionnaires at baseline (T0) for both groups and timeline 1, after week 8 of the intervention group (T1), once the WLCG completed the questionnaires they were sent a link to the online course.

5.11.2 Participants

Participants were recruited through two charities: Endometriosis UK and Verity PCOS; they were also recruited through the spread of a digital recruitment advert, which was shared through social media. The approach taken to recruitment was pragmatic. The impact of the pandemic had led to a shortened recruitment period and as the NHS was prioritising addressing the pandemic, using charities and social media appeared to be the most convenient way of recruiting participants. The recruitment period was ten days, and 98 participants were recruited. A copy of the participant information sheet (Appendix XIII RCT Participant Information Sheet) and the recruitment advert (Appendix XIV RCT Recruitment Advert) are included in the appendices.

Eligibility criteria for participants were as follows:

- A diagnosis of endometriosis and/or adenomyosis
- Adult (aged 18 years or older)
- Located in the UK
- Access to the internet and a device that allows them to engage with the intervention
- Fluent in English to be able to engage with all the material in the intervention.

The recruitment advert contained a link to a Qualtrics Survey, which contained the participant information sheet and the informed consent form. Once the consent form was completed, the participants were asked to complete a screening questionnaire (which asked questions about their diagnosis, current treatment and self-management strategies) and the outcome measures. All study data were collected online via questionnaires administered through

Qualtrics Survey Software (Qualtrics 2019, Provo, UT, USA, available from: http://www.qualtrics.com). The last page of the Qualtrics survey notified the participant of which group they had been assigned to; this was randomised using the Qualtrics software.

5.11.3 Intervention

The delivery of The Phoenix Course was supported by Hope for the Community (H4C) Community Interest Company, a research social enterprise spinout company from Coventry University (https://www.h4c.org.uk). H4C provides organisations with face to face and digital interventions to empower people to manage their health and wellbeing and flourish in their working and personal lives. The digital interventions are delivered on a digital innovation platform. The platform is hosted on Coventry University servers. Coventry University holds a Cyber Essentials certificate.

The H4C platform features include interactive activities (e.g., quizzes, self-monitoring tools, diaries) that participants can use to learn and consolidate course content and behaviour change strategies, peer support and social networking tools, e.g., forums, discussion topics and messaging. The platform is fully adaptable and scalable to a range of client and patient needs. The platform captures outcome and experience data; uses automated behavioural nudge features, reports, and analytics on user engagement.

Below is a table with the themes of each session of The Phoenix Course; more detail is provided in the course outline (Appendix 2). Each session encourages participants to engage in reflection (inquiry), set goals, share gratitudes, complete tasks and interact with other participants enrolled in the course. At the end of each session is a meditation and home practice to be practised during the week. Participants also have the opportunity to provide feedback to the course administrators and facilitators. The intervention group had two facilitators, Hollie Vercoe, an experienced online self-management facilitator and myself, an accredited mindfulness teacher. Also included in the course were modules taught by Sundeep Watkins, a pelvic health physiotherapist and Dr Elizabeth Sparkes, a health psychologist and mindfulness teacher. Each Monday for eight weeks, a new session was released to the participants in the intervention group, although they were reassured that they could work through the material at their own pace.

After eight weeks and completing the post-intervention measures, the control group were given access to the same course.

Table 5.5. Themes of each session of The Phoenix Course

Session No.	Theme
1	Welcome. The Mind-Body Connection
2	Accepting and Being
3	Self-Compassion
4	Mindful Movement
5	Dealing with the Negative
6	Seeking Joy
7	Connection
8	Next Steps – Setting up Independent Practice

5.11.4 Primary Outcomes

The primary outcome measures for this feasibility RCT were as follows:

5.11.4.1 Recruitment Rates

Recruitment rates for participation and randomisation were collected using Qualtrics Survey Software (Qualtrics 2019, Provo, UT, USA, available from: http://www.qualtrics.com) at the start of the trial. Online recruitment adverts were created and shared by Endometriosis UK (support groups, online Facebook groups) and PCOS Verity (followers online and in a blog post). The adverts were also shared virally on social media platforms such as Twitter, Instagram and Facebook. The link in the advert took potential participants to the participant information sheet, informed consent form, screening form and outcome measures. Recruitment rates were then calculated from those a) meeting inclusion criteria, b) providing consent, and c) completing baseline measures. Potential participants were given the option of enrolling in the course without having their data included in the survey.

5.11.4.2 Retention, Follow up and Completion Rates

Follow up was monitored via completion of online outcome measures. Participants who became lost to follow up were identified through Qualtrics as those not completing the post-intervention measures at the end of the intervention period. It is possible that participants could have attended some or all of the Phoenix Course sessions, despite not completing the measures. Therefore, participants retention rates were identified separately from the follow-up rate through engagement data, e.g., the number of course sessions attended.

5.11.4.3 Adherence Rates

The intervention platform (the Hope platform) collects user engagement data such as login frequency and duration, which assists the facilitators with participants engagement and experience. Participants also have the option of receiving system generated automatic nudge reminders sent to their email address, to remind them to access the course, to inform them if someone has liked or commented on one of their posts, to encourage them to continue and complete a session and to tell them of a session being release or of a new forum post. The user engagement data was analysed to generate usage patterns, activities completed, feedback left etc. This data provides an overview of participants engagement and adherence.

5.11.4.4 Sample Size and Effect Size Estimation

The standard deviations of key continuous secondary outcomes at baseline were calculated to inform sample size estimation for a future definitive trial. To estimate potential effect sizes for a primary outcome in a future definitive trial from pre to post-intervention, the difference between the mean pre and post-intervention was calculated for the intervention group and waitlist control group and divided by the pooled standard deviation at baseline (Cohen, 1988).

5.11.5 Secondary Outcomes

Sociodemographic and health data were collected at baseline only. Participants were asked to provide the following information via the screening form: when and how diagnosed with endometriosis and/or adenomyosis, medication, contact with healthcare professionals, details of surgery and symptoms, date of birth, free-response questions about self-management strategies already being used, employment status, time missed at school/work due to symptoms and if others have had to help out with housework, gardening or odd jobs due to symptoms.

Participants completed outcome measures at two-time points, baseline (T0) and after seven weeks (T1). Measures were emailed out during week seven of the course to the intervention group, with weekly reminders being sent out to encourage completion. The quality of life and mindfulness skills measures are detailed below. The control group were sent the measures seven weeks after baseline measures were completed.

The Endometriosis Health Profile 30 (EHP-30) questionnaire was developed to measure the health-related quality of life of people with endometriosis (Jones et al., 2001). The EHP-30 has two parts; the first part is a core questionnaire consisting of five scales that apply to everyone living with endometriosis (30 items). The second modular part contains six subscales that do not necessarily apply to all women with endometriosis (23 items). (Jones et al. 2001). Women with endometriosis were included in developing and evaluating the EHP-30 (Jones et al., 2006). This questionnaire was chosen as the systematic review showed the two leading quality of life measures used with participants living with endometriosis were the EHP-30 and the SF-36 (Ware et al., 1992). The EHP-30 was chosen over the SF-36 as the EHP-30 has explicitly been designed for measuring the quality of life in people living with endometriosis. It also developed with input from those living with the condition.

Only the core questionnaire of the EHP-30 was used in this feasibility trial. The core questionnaire covers domains including pain (found it difficult to walk because of the pain), control and powerlessness (felt symptoms ruling your life), social support (felt others do not understand what you are going through), emotional wellbeing (had mood swings) and self-image (felt your appearance has been affected). The questionnaire asks questions such as: ‘During the last 4 weeks, how often, because of your endometriosis have you . . . ‘, ‘Been unable to go to social events because of the pain?’ The responses are never (0), rarely (1), sometimes (3), often or always (4). Never is given a score of 0 and Always a score of 5. There are 11 questions in the pain domain, 6 in the control and powerlessness domain, 6 in the emotional wellbeing domain, 4 in the social support domain, and 3 in the self-image domain. The lower the score, the better the health-related quality of life of the respondent. A score is provided for each question and the domain overall. The formula for scoring each domain is the sum of scores for that domain, divided by the maximum score and multiplied by 100. A score of 0 is the best possible health status as measured by the questionnaire, and 100 is the worst possible health status. The total score overall (total of all domains) is calculated by dividing the sum of the five domains by five to create a score on a scale of 0-100.

The Five Facet Mindfulness Questionnaire (FFMQ) contains 39 items that aim to measure the five facets (observe, describe, non-judging of inner experience, acting with awareness and non-reactivity to inner experiences) that together form a single-order factor, mindfulness (Baer et al., 2006). An example question from this questionnaire is: ‘When I’m walking, I deliberately notice the sensations of my body moving’. Responses include 1-never or very rarely true, 2-rarely true, 3-sometimes true, 4-often true and 5-very often true or always true. There are eight questions in the observe facet (0 reversed), eight questions in the describe facet (3 reversed), eight questions in the acting with awareness facet (all reversed), eight questions in the non-judgement facet (all reversed) and seven questions in the non-react facet (0 reversed). The questions are not grouped by facet; the questions are mixed, with a scoring guide provided (Baer et al., 2006). The higher the score, the better when measuring the facets. The sum for each facet is the total of the scores of all the questions in that facet. The scores for each of the facets shows how often the respondent practices this facet of mindfulness. This questionnaire measures mindfulness as a multifaceted construct, meaning the higher the score of each facet, the more often a participant experiences that facet of mindfulness.

In line with CONSORT guidelines (Schulz et al., 2010), a per-protocol analysis was also performed on the secondary outcome data from intervention completers and is reported in the Ancillary Analyses section below. We used Wilcoxon Signed Ranks Test, and significance was set at $P \leq 0.05$)

5.11.6 Qualitative Component

The original research proposal included a qualitative component of semi-structured interviews with a small number of participants in the intervention. These participants would have given their consent to be contacted. Participants would have been asked about their experience of the course, both positive and negative. The participants would have been contacted whether or not they fully engaged in the course or dropped out. If participants withdrew from the trial, they would not have been contacted. Due to the impact of the Covid-19 pandemic, this component was removed entirely. The consent form was updated, and further ethics approval was sought. Instead, the participant feedback from the course collected by the H4C platform will be used to see what the participants liked, disliked, enjoyed, found useful or what they felt needed to improve or change.

5.11.7 Sample Size

All study participants were drawn from an opportunity sample (n=98) who met the inclusion criteria and were interested in enrolling on an 8-week online mindfulness-based self-management intervention. A formal power calculation is not a requirement for a feasibility study. However, a sample size of n=30 is considered an appropriately sized sample to infer a sample related to a population (Spiegel et al., 2001). All potential participants followed a link on the recruitment advert and were asked to read the participant information sheet and complete the informed consent form, screening form, and outcome measures before randomisation.

5.11.8 Randomisation – Sequence Generation and Allocation Concealment Mechanism

5.11.8.1 Sequence Generation

All participants who provided informed consent and completed the baseline measures were randomised into the intervention group or the waitlist control group using a 1:1 ratio via the randomisation function within the Qualtrics Survey Software.

5.11.8.2 Allocation Concealment Mechanism

Upon completion of the baseline measures, participants were informed via a notification in Qualtrics whether they had been randomised to the intervention group (starting July 2020) or the control group (October 2020).

5.11.9 Implementation

Participants were allocated to the intervention group or the waitlist control group via the randomisation in Qualtrics. This happened once the participant had completed the consent form, screening sheet and secondary measures. Participants were then emailed from the H4C online platform with a link to the Phoenix Course or a message to say they would be emailed a link to the course in eight weeks.

5.11.10 Blinding

Due to the nature of the study design, it was not possible to blind participants to their group allocation. They were informed once they had completed the baseline measures.

5.11.11 Statistical Analysis

Quantitative statistics were analysed descriptively using IBM SPSS Statistics 26 (IBM Corp, Released 2019. IBM SPPS Statistics for Mac, Version 26.0, Armonk, NY: IBM Corp). Initial analyses involved tabulated summaries of primary and secondary outcomes for each randomised group using means and standard deviations, and number and percentages for categorical variables to describe the full range of data at baseline and at timeline 1 (T1)

The study was not powered to perform inferential statistical analyses. To signal efficacy, pre and post-intervention mean differences and confidence intervals for scores on key secondary outcome measures are reported for the intervention group and the waitlist control group. The results section below also provides a table showing adherence and engagement rates. This was calculated from data collected by the platform as the participants posted gratitude entries, set goals, posted likes and comments.

5.12 Results

Sociodemographic and health information were collected at baseline for all the participants. The mean age of all the participants was 35.8 years. Participants were asked about previous surgeries and medication; 74 (75%) participants confirmed they had a surgical diagnosis of endometriosis, 4 (4%) participants had a surgical diagnosis of adenomyosis. All of the participants took pain relief to manage their symptoms. In the three months before the trial, 31 (31%) participants had seen a gynaecologist, 9 (9%) participants appointments had been cancelled due to Covid-19, with no new appointment arranged, and 58 (59%) participants had not seen a gynaecologist in the three months before the trial. Also, in the three months before the trial, 50 (51%) participants had missed work/university/college due to their symptoms. Table X. below presents the baseline characteristics of the participants in the trial, intervention group (n=45) and control group (n=53).

Before enrolment onto The Phoenix course, participants in this study were asked how they self-manage their conditions. The most common strategy used by participants in this study was heat; hot water bottles, heat pads and hot baths/showers. Heat was used by all of the participants in this study. The second was commonly used was exercise, including walking, running, yoga, swimming and Pilates. Some of the least common self-management strategies were physiotherapy, psychologically-based interventions and social support. The participants also used a variety of pain relief, hormonal medications and surgery. Most of the self-management strategies that were not pharmacological nor surgical were not evidence-based strategies such as dietary changes, supplements and homoeopathy. The strategies were similar to the ones recommended by the RCOG (RCOG, 2018).

Table 5.6. Participant Characteristics

Variable	**Intervention Group (n=45) mean**	**Control Group (n=53) Mean**
Age (years)	37.1) years	34.5 years
Diagnosis (surgical) Endometriosis	Endometriosis = 31 (68%) Adenomyosis = 3 (7%) Fibroids = 1 (2%) Awaiting surgery/results = 10 (22%)	Endometriosis = 43 (81%) Adenomyosis = 1 (2%) Awaiting surgery/results = 9 (16%)
Employment*	Full-time employment = 26 (57%) Part-time employment = 7 (15%) Student = 1 (2%) Homemaker = 3 (6%) Occasional/Casual Work = 2(4%) Unemployed = 6 (13%)	Full-time employment = 31 (58%) Part-time employment = 10 (18%) Student = 6 (11%) Homemaker = 5 (9%) Occasional/Casual Work = 2 (3%) Unemployed = 3 (5%)
Missed work in last 3 months due to symptoms	Yes = 27 (60%) No = 18 (40%)	Yes= 23 (43%) No= 30 (57%)
Use pain relief	Yes = 45 (100%) No = 0	Yes = 53 (100%) No = 0
Visited GP in last 3 months	Yes = 15 No = 30	Yes = 20 No = 33
Seen a gynaecologist in last 3 months	Yes = 17 (37%) No = 24 (53%) Cancelled due to Covid-19 = 4 (8%)	Yes = 14(26%) No = 34 (64%) Cancelled due to Covid-19 = 5(9%)
Changed diet to manage symptoms	Yes = 35(78%) No = 10 (22%)	Yes = 42 (79%) No = 11 (21%)
Tried/Use complementary/alternative therapies	Yes = 27(60%) No = 18(40%)	Yes = 29 (55%) No = 24 (45%)
Use Self-Management Techniques	Yes = 44 (98%) No = 1 (2%)	Yes = 52 (98%) No = 1(2%)

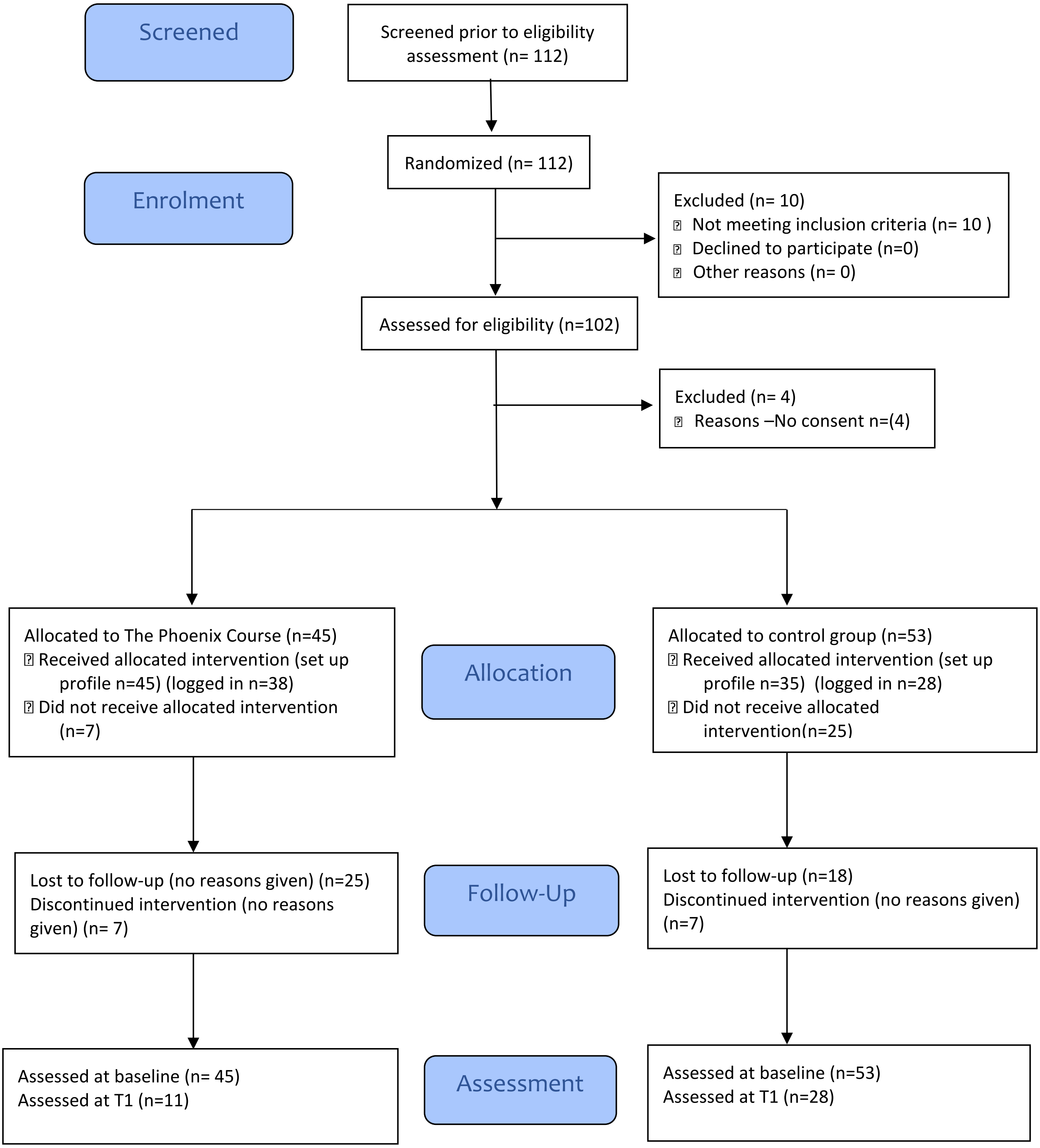
*Some participants fit in two categories e.g. student with a part-time job/occasional work.

5.13 Primary Outcomes

5.13.1 Recruitment Rates

The recruitment rate for this feasibility study was 67% (n=112). Recruitment adverts were shared by Endometriosis UK, Verity PCOS and shared online through social media. 167 people completed the screening sheet and partially completed the consent form but did not provide their details or complete the pre-intervention measures. Randomisation occurred at the end of the Qualtrics questionnaires. 112 participants completed the screening sheet, 4 participants did not provide consent. They were given access to the intervention but had their data excluded. There were 10 participants that did not meet the inclusion criteria; they were not from the UK, they were also given access to the course and had their data excluded from the analysis. This led to 98 participants (intervention group, n=45, control group, n=53) taking part in the trial, including those who missed the questionnaire's questions. An error was made in the randomisation stage, which meant that it could be randomised, even if the secondary outcome measures were not fully completed.

Figure 5.3. Participant Flow (CONSORT) (Eldridge et al., 2016).



5.13.2 Retention, follow up and completion rates

Retention rates were calculated by the number of participants from the intervention group that attended each Phoenix Course session (see Table 5.3.).

Follow up rate was calculated by completion of questionnaires at timeline 1 (T1). Across the whole group (n=98) 41 participants (41.8%) completed the timeline 1 questionnaires. In the intervention group, n=11 (28.8%) completed the timeline 1 (T1) questionnaires, and in the waitlist control group, n=28 (52.8%) completed the timeline 1 (T1) questionnaires.

The number of participants who completed all eight sessions were: all, n= 16 (16.3%), intervention group. Below is Table 5.7 that shows how many participants in the intervention group attended each session.

Table 5.7. Number of Phoenix Course sessions attended by the participants in the intervention group

Number of Sessions (s) attended	Intervention Group (n=45)
0	10
1	35
2	20
3	11
4	9
5	9
6	8
7	6
8	9

5.13.3 Adherence and Engagement Rates

Table 5.8 shows engagement data collected by the intervention platform. The percentage of pages viewed per session ranged from 92% to 17%. This table also shows the number of times participants engaged with the course by posting gratitudes (this function was available to use at any time and not linked to sessions), goals (which were encouraged at the end of every session), likes and comments (ways for participants to interact with the course content and each other).

5.13.4 Sample Size and Effect Size Estimation

Both sample size and effect size were calculated for a future definitive trial. The estimations were based on the EHP-30, the quality of life measure. The total (sum of domain scores) the mean for both the intervention group and the control group, 84 and 99, plus a combined SD of 49, which given a *prior* alpha of 0.05 would necessitate 45 participants per group to minimally detect effect sizes (Cohens' F) 0.6 (i.e., a moderate effect size), with a power of 0.80 (Cohen).

Table 5.8. Overview of engagement and adherence with The Phoenix Course for all the participants and by group.

Engagement Measure	**Intervention Group (n=45)**
	Mean (%)
Pages viewed in session 1 (range 0-12)	11(92%)
Pages viewed in session 2 (range 0-8)	4(57%)
Pages viewed in session 3 (range 0-9)	3(31%)
Pages viewed in session 4 (range 0-10)	2(26%)
Pages viewed in session 5 (range 0-10)	2(26%)
Pages viewed in session 6 (range 0-11)	2(23%)
Pages viewed in session 7 (range 0-10)	1(17%)
Pages viewed in session 8 (range 0-7)	1(26%)
Average pages viewed across all sessions (range 0-77)	28(37%)
	Mean (SD)
Gratitude entries (per session)	5(1.7)
Goals set (per session)	6.8(2.3)
Likes are given (per session)	35.7(17)
Comments posted (per session)	14(5)

5.14 Secondary Outcomes

Table 5.9. EHP-30 Subscale T0 and T1 scores for both the Intervention Group and the Control Group

EHP-30 Subscale (range 0-100) (↓ is better)	Baseline (T0) mean(SD)		T1 mean (SD)		Mean Difference (T0/T1)	
	IG (n=44)	CG (n=53)	IG (n=11)	CG (n=28)	IG	CG
Pain	55.56 (20.2)	52.49 (20)	44.21(22.5)	51.87(19.1)	-11.35	-0.62
Control & Powerlessness	69.54 (21.1)	68.79(25.2)	51.52(32)	65.33(21.4)	-18.02	-3.46
Social Support	63.89(19.2)	65.21(22.5)	43.18(31.3)	60(24)	-20.71	-5.21
Emotional Wellbeing	52.59 (19)	50.16(19.8)	37.88(24.2)	50.15(17.4)	-14.71	-0.01
Self-image	69.26(22.1)	61.48(29.7)	56.06(28.6)	65.77(23.4)	-13.20	+4.29
EHP-30 Total (0-100)	62.16(16.7)	59.62(20.1)	46.57(24.3)	58.63(16.7)	-15.59	-0.99

Table 5.10. FFMQ Subscale T0 and T1 means and SD for both the Intervention Group and the Control Group. An increase in scores for the intervention group shows an increase in mindfulness facets.

FFMQ Subscale (↑ is better)	Baseline (T0) means (SD) T)		T1 means (SD)		Mean Difference (T0/T1)	
	IG (n=44)	CG (n=53)	IG (n=11)	CG (n=28)	IG	CG
Observing	25.24(4.7)	25.79(5.4)	29.80(3.9)	24.88(5.2)	+4.56	-0.91
Describing	24.52(6.9)	25.62(6.7)	26.10(6.4)	26.22(5.7)	+1.58	+0.6
Acting with Awareness	21.86(6.1)	22(5)	26.90(4.7)	21.41 (4.8)	+5.04	-0.59
Non-Judging of Inner Experience	23.38(6.6)	23.35(6)	26.40(8.2)	23.8 1(6.9)	+3.02	-0.1
Non-reactivity to Inner Experience	18.45(4.3)	18.56(3.8)	21.30(5.1)	18.6 3(3.7)	+2.85	+0.1
FFMQ Multifaceted scores	113.4 (20.9)	115.3 (16.1)	130.5 (19.4)	114.9 (16.4)	+17.1	-0.4

5.15 Ancillary Analyses

Ancillary analyses were conducted as per protocol (PP) analysis, which included only those participants who completed all study questionnaires and attended at least four intervention sessions (n=11). Table 5.9 shows the data from the secondary outcome measures for these participants. Participants showed significant improvements from T0 to T1 across most subscales.

Table 5.11 Scores on secondary outcome measures for intervention completers

	IG (N =11)		P value*
	T0 (mean, SD)	T1 (mean, SD)	
EHP-30 Total (0-100) (↓ = better)	59.07 (23.3)	46.47 (24.3)	0.02
Pain	57.85 (22.5)	44.2 (22.5)	0.03
Control & Powerlessness	66.67 (28.3)	51.5 (32.0)	0.08
Social Support	61.36 (26.9)	43.18 (31.3)	0.03
Emotional Wellbeing	43.56 (19.8)	37.88 (24.2)	0.28
Self-image	65.91 (34.6)	56.06 (26.6)	0.21
FFMQ Total (↑ = better)	121.70 (17.6)	130.50 (19.4)	0.05
Observing	27.80 (2.8)	29.8 (3.9)	0.04
Describing	25.70 (6.7)	26.10 (6.4)	0.76
Acting with Awareness	24.30 (7.3)	26.90 (4.7)	0.05
Non-Judging of Inner Experience	23.70 (8.8)	26.4 (8.2)	0.03
Non-reactivity to Inner Experience	20.20 (3.3)	21.30 (5.1)	0.44

*Wilcoxon Signed Ranks Test

5.16 Participant Feedback

At the end of each of the eight sessions of The Phoenix Course, participants were invited to provide feedback. The collection of this data was built into the H4C digital platform. At the end of each session, participants could submit feedback. Most of the feedback received was positive. There were 52 comments (33 from participants in the intervention group and 19 from participants in the control group) submitted through the feedback function. The participants were aware that facilitators could read their feedback and the H4C privacy agreement explains how member content may be used to: 'Create reports and data for statistical, analytical and reporting purposes; research; and for evaluating and enhancing the website' (H4C Privacy Statement, accessed February 2021). The themes identified in the participant feedback were: content, technical issues, wellbeing, finding time, components and inclusivity. The most prominent themes were content and components.

An example of a comment about content:

"So much work has gone into this. I really enjoy the different videos that all have similar themes but change the way that it describes how so many of us feel day to day. I have enjoyed it". (Session 1, participant from intervention group).

An example of a comment about the components:

"Great content. Lots of things to focus on to help live a better quality of life despite the pain - pacing, compassion, gratitude, setting goals etc. I will definitely continue to use these ideas. The diaries, worksheets and further resources are also useful. Thank you!" (Session 8, participant from the intervention group.

Most of the participant feedback comments were positive. The negative or neutral comments provided areas that can be improved upon: technical issues and inclusivity. One participant had a problem with listening to meditations on their iPhone. This was a bug that the web developers resolved. Another participant's comment around inclusivity was, *"Please offer point of views but different cultural perspectives. Seeing representation from Black, Indigenous and People of Colour (BIPOC) helps!".* This should be kept in mind for any future course improvements.

5.17 Harms

Social and psychological interventions do have the potential to produce unintended effects, some that may be harmful. For example, The Phoenix course could have caused distress or led to the higher reported quality of life scores, which decreased the participants' quality of life. For this reason, facilitators needed to check into The Phoenix Course often, that participants could contact the facilitators privately and that they had access to additional resources such as the Endometriosis UK helpline. Participants could also provide feedback on the course. A set of community guidelines were also included at the start of the course to promote safe online communication within the course. Participants were also sent a debrief form at the end of the trial, with information on how to get more support via the NHS and how to join a local Endometriosis UK support group. No harms were observed or reported by participants or facilitators.

5.18 Discussion

5.18.1 Main Findings

This feasibility RCT of The Phoenix Course aimed to evaluate the primary outcomes measuring trial feasibility. It also aimed to evaluate the secondary outcomes of participant mindfulness facets and quality of life. Data were collected on the primary outcomes of recruitment, dropout, retention, adherence, engagement, follow-up, sample size, and effect size estimations.

5.18.2 Primary Outcomes

The recruitment rate was adequate 67% recruiting, randomising and assigning 98 participants to either the intervention group (n=45) or the control group (n=53). There were 176 that showed interest in the recruitment advert over a time frame of ten days. This indicates that it is feasible to recruit participants from patient charities/ support groups.

5.18.3 Dropout rate

The dropout rate is calculated by the number of participants that did not complete the trial. There was a high dropout rate, 58.2% of participants did not complete the T1 outcome measures.

5.18.4 Adherence and engagement rates

Adherence rates were calculated by looking at the number of pages viewed per session. Engagement rates were calculated by the number of times and how the participants engaged with the course, e.g., posted a gratitude entry, posted a goal, a comment or liked a post made by another participant or facilitator. There was a low adherence rate (38%). The engagement rate varied (92% to 17%).

5.18.5 Retention rate

Retention rates were calculated by the number of participants from the intervention group that attended each Phoenix Course session. There was a low retention rate (16%), 16 participants in the intervention group completed all eight course sessions.

5.18.6 Follow up rate

Follow up rate was calculated by completion of questionnaires at timeline 1 (T1). There was a low follow up rate (41.8%). Across the whole group (n=98) 41 participants (41.8%) completed the timeline 1 questionnaires.

5.18.7 Secondary Outcomes

The pandemic has been shown to impact wellbeing negatively; there were participants in the trial who had appointments cancelled or delayed due to the pandemic. Endometriosis UK also had to cancel face to face support groups. The participants faced a reduction in the support or treatment they can usually access. The Phoenix Course allowed people living with endometriosis and/or adenomyosis to connect with others with the same condition and provided an opportunity to learn new coping strategies in the form of mindfulness, practising gratitude, self-compassion and meditation. The participant feedback showed that the content of the course (videos, meditations, photographs) was enjoyable and sometimes useful for participants. The participants also enjoyed the components of the course (social support, mindfulness, self-compassion, goal setting, meditation).

Tables 5.9 and 5.10 present the scores of the secondary measures from T0 and T1 for both the intervention and control groups. The study was not powered for inferential statistics. The efficacy signal observed in the ancillary analyses (Table 5.6) showed significant improvements in the total score for the EHP-30 and the subscales for pain and social support. For the FFMQ, there were significant improvements for the total score and the subscales for observing, acting with awareness and non-judging of inner experience. These significant improvements should be considered with caution. However, they do signify that there is a possibility that

The Phoenix Course may improve quality of life by teaching people with endometriosis and/or adenomyosis by teaching them mindfulness skills and supporting them to self-manage.

The Phoenix Course aims to support participants in self-managing their symptoms' impact on their quality of life. The Phoenix Course is also a mindfulness-based intervention. The FFMQ measures mindfulness's five facets: describing, observing, acting with awareness, non-judgment of inner experience and non-reacting to inner experience. The participants in the intervention group showed improvement for all five facets when compared with the control group. Again, caution should be shown when considering the increase in these scores. However, it is promising, as the intervention intended on teaching participants mindfulness skills, and it appear that this component may have led to an increase in scores.

Two studies have also recently investigated the feasibility of using an online resource for patients living with chronic pelvic pain. Unlike the mindfulness studies identified in the systematic review (Chapter 3), these studies used control groups. The studies that tested the feasibility of using the meditation app Headspace for patients with chronic pelvic pain had similar findings (Forbes et al., 2020, Ball et al., 2020). The MEMPHIS feasibility trial reported a high recruitment rate (90 participants over 145 days) and adequate follow-up rates. However, they also had very low adherence rates, most participants did not complete any sessions on the app (Forbes et al., 2020). The authors suggest that their intervention may be improved by involving users in the design of the intervention. The needs assessment for the development of The Phoenix Course used a participatory research method; perhaps this can be utilised further in user testing. The authors also suggest that 60 days may be too long for a mindfulness meditation intervention (Forbes et al., 2020). In the qualitative study, the authors identified the following g themes: familiarity and capabilities with app technology, motivations to use the app, perceived benefits, relation to other therapies and opportunities to use the app (Ball et al., 2020). One solution presented in this paper is the use of an introduction or orientation video or tool to help familiarise participants with the intervention before the first session (Ball et al., 2020).

The MEMPHIS trial also did not include social support/interaction as a component of the intervention, which was discussed as a potential limitation by the authors. The Phoenix

Course did contain an element of social support/interaction. The EHP-30 showed an increase in social support scores for the intervention group. Social support is an essential element when considering a patients quality of life. Also, the participants that did engage did post comments, likes, goals and gratitudes. Further work should focus on why some participants did not engage with The Phoenix Course; perhaps an orientation video before recruitment could introduce the components and aims of the intervention and trial.

The literature shows that those living with endometriosis and adenomyosis have many self-management or self-care strategies to fill the gap that surgical or pharmacological interventions cannot fill (Brown and Fraquhar, 2014). When patients fail to find relief from symptoms or support from medical professionals, they turn towards alternative or complementary approaches (Laux-Beishlman et al., 2015). This is also shown in the many techniques that the participants in this study use to manage their physical symptoms and the psychological and emotional impact their conditions can have. Table 5.2 shows that most participants in this study engaged with self-management strategies and that all of the participants took a form of pain relief to manage their symptoms. The Phoenix Course aims to improve quality of life by supporting participants with self-managing their symptoms' impact on their lives.

Treatment as usual for endometriosis/adenomyosis patients involves waiting for secondary care NHS treatment whilst under the care of a GP and attempting to manage symptoms using the hormonal treatment and pain relief. Chapter 1 includes a diagram of the care pathway for those with endometriosis or suspected endometriosis. Charities such as Endometriosis UK provide information and support from a helpline and monthly support groups.

This study adds to the published literature on how mindfulness can be used by people living with physical health conditions, including endometriosis. Studies have shown that the primary outcomes that have shown improvement include: psychological distress, pain interference, negative affect, quality of life, ability to manage pain and physical health (Toivonen et al., 2017, Fox et al., 2008, Kold et al., 2012).

Also, when considering adherence and engagement rates, participants had to click to confirm they had read each page; it is possible to read a page of the course and not register that it has been read. Whilst reminders were sent, it is unclear if all participants confirmed they had read each page. There were fewer pages read/viewed in the middle of the course; this could suggest that the number of pages should be reduced, the number of sessions reduced, or improvements need to be made on the session with lower pages read/viewed. This indicates that further user testing could be helpful before a further trial.

Also related to constricted time frame was the reliance on existing YouTube material. This material was carefully chosen and often had a positive reaction from participants in the feedback submitted at the end of each session. However, it was not specifically tailored towards the participants as was intended. This was discussed in more detail in Chapter 4, the needs assessment chapter. However, the participant feedback comments often referred to both the course content and its components. This also indicates the need for further user testing to gain an insight into what content the users find useful or relevant and the content that doesn’t offer a positive contribution to the course.

There was also a large dropout rate in this feasibility RCT, which the semi-structured interviews would have hopefully addressed. However, it is unclear if this is due to the pandemic's end and furlough's ending for some, as the pandemic restrictions changed during the course timeframe. During the pandemic, there have been competing priorities: working from home, self-isolating, home schooling, and increased caring responsibilities. Without further data, conclusions cannot be made about how much the pandemic impacted the completion of secondary outcome measures.

Considering the positive participant feedback and the improvement in scores on the secondary outcome measures indicate that more work is required on trial design, increasing online participant engagement, adherence, retention and dropout rates.

5.19 Strengths

This is the first feasibility RCT to evaluate an 8-week online mindfulness self-management course tailored to the unmet needs of people living with endometriosis and/or adenomyosis.

Recruitment rates were high, and whilst the trial was not sufficiently powered. There was a good efficacy signal seen from the outcome measure. When the intervention group scores for the EHP-30 and the FFMQ were compared with the control group (n=53), improvements were in the expected direction. The secondary outcomes measure scores showed improvements for the intervention group.

5.20 Limitations

The main limitation of the trial was the low retention, adherence, engagement and follow up rates. These rates have been discussed in the previous section. These rates could be an indication that there needs to be further work on the content and length of the course. The authors of the MEMPHIS trial (Ball et al., 2020, Forbes et al., 2020) have suggested that 60 days (8 weeks) is too long for this type of intervention. Perhaps a shorter course or shorter modules should be considered, and it may be helpful to look into these options during user testing.

Another limitation was the incompletion of the T1 secondary outcomes measures from the intervention group. This could have substantially impacted the study results, as a higher response rate would have provided more confidence in the sample size calculation for a larger trial. As this study was run as part of PhD research, no support or funds were available to contact participants or offer incentives to complete the measures. This is an area that can be approved upon in a larger, funded trial.

Another potential limitation is the impact that the pandemic and related lockdowns had on participants adherence and engagement throughout the course. The online nature of the course had both benefits and challenges. An advantage was that The Phoenix Course provided an alternative option to face to face support groups, which were cancelled due to the pandemic. A challenge was the changing restrictions could have impacted the participants' intentions to commit to the course. Recruitment began during the first lockdown. However, restrictions started to lift once the course was running, meaning further changes to work and social life and caring responsibilities and home schooling. These changes could have impacted the level of participant engagement and adherence as priorities shifted.

5.21 Other Information – Registration, Protocol, Funding, Ethical Approval

Both the protocol and the feasibility trial have not been registered. This research was conducted as part of fully funded. PhD Studentship. Ethical approval was granted from the universities ethics committee (P97545).

5.22 Conclusion

This feasibility RCT supports The Phoenix Course as an adjunct resource, promoting mindfulness-based self-management alongside the surgical and pharmacological options currently offered to patients in the NHS. It provides flexibility, as participants can access the course online from the comfort of their own homes and can interact with others with the same conditions. Further user testing and a solution-focused approach to research design for a larger trial are recommended.

The next chapter discusses the findings of this study in more detail, including reflecting on the results of the previous two studies, making recommendations and discussing further implications of this feasibility study.

Chapter 6 Discussion and Recommendations

6.1 Overview

The previous three chapters each present a study that followed the guidance provided by the Medical Research Council on how to develop and evaluate a complex intervention (Craig et al., 2019). This final chapter will summarise the findings of the three studies of this PhD thesis and place the findings of these studies within the context of existing literature, examined in Chapter 1. This chapter will also outline and articulate the unique contribution and originality of the research presented in this thesis. Lastly, this chapter will discuss the impact of the research findings and outputs and make recommendations for future research, healthcare policy and clinical practice.

6.2 Key Research Findings

The objectives of the research discussed in this thesis were guided by the MRC Guidelines and were as follow:

1. To undertake a systematic review in order to identify and evaluate the effectiveness of existing non-surgical, non-pharmacological interventions designed to improve the quality of life for people living with endometriosis and/or adenomyosis.
2. Assessment of the psychological needs and coping strategies of people living with endometriosis and/or adenomyosis to tailor the intervention to the population's needs.
3. Development of an intervention based on the data from the systematic review needs assessment and informed by relevant theory, e.g. Theory of Change.
4. Evaluation of the feasibility of the intervention (The Phoenix Course) using a Randomised Controlled Trial.

Sections 6.2.1, 6.2.2, 6.2.3 and 6.2.4 below, exaine how these four objectives were achieved in the studies presented in this thesis and key findings of these studies.

6.2.1 Introduction – Literature Review

The symptoms of endometriosis and adenomyosis can cause a substantial reduction in quality of life. The average time for diagnosis is eight years; this contributes to the physical and psychological suffering of those living with these conditions. A significant gender bias in healthcare significantly impacts women who experience chronic pain and conditions such as endometriosis and adenomyosis. This bias affects the treatment received or not received by women with these conditions. This is a contributing factor in the delay in diagnosis of endometriosis and adenomyosis and the lack of treatments offered to people with these conditions. Treatment for both conditions is centred around surgical and pharmacological interventions. Endometriosis patients have reported their experience of healthcare professionals as double-edged, either constructive or destructive.

Meanwhile, healthcare professionals report the challenges they face in diagnosing and treating the condition. Gaps in the care pathway and limited treatments available leads patients to self-manging their symptoms. Unfortunately, even with using surgical and pharmacological interventions, the symptoms can reoccur or worsen. Conclusion: there is a need for long-term comprehensive care that supports patients to manage their symptoms beyond surgery and medication. The development of a psychological intervention to improve quality of life is warranted.

6.2.2 Systematic Review

There is a lack of high-quality studies evaluating the effectiveness of non-surgical, non-pharmacological interventions that aim to improve the quality of life for people living with endometriosis and/or adenomyosis. There is a lack of published studies on the patient experience of non-surgical, non-pharmacological interventions that aim to improve the quality of life of people living with endometriosis and/or adenomyosis. Most studies investigating the quality of life identified by the search strategy used either the SF-36 or the EHP-30 to evaluate the quality of life of people living with endometriosis and/or adenomyosis. Conclusion: Mind-body interventions (acupuncture, physiotherapy, mindfulness) have the most potential for improving the quality of life for people living with endometriosis and/or adenomyosis.

6.2.3 Needs Assessment

The psychological needs of people living with endometriosis and adenomyosis are varied and complex. It is challenging to separate psychological needs from physical needs; they are interconnected. The amount of unmet psychological needs that people living with these conditions experience has led to them developing several coping strategies. Self-management was by far the most prominent coping strategy. People living with these conditions spend a lot of time, effort and money on self-managing their painful symptoms, fatigue and the psychological impact of their symptoms. As endometriosis and adenomyosis are invisible illnesses, others find it challenging to understand their symptoms and the effect of these symptoms on physical wellbeing and psychological/emotional health. The most visible symptom of these conditions, 'endo belly', is also one of the most psychologically challenging. The needs assessment findings highlight the gap in the treatment available for endometriosis and/or adenomyosis. Conclusion: There is an urgent need for psychological support that can fit in with existing available treatment, which is focused on managing pain and infertility but not mental health.

6.2.4 Intervention Development and Feasibility Randomised Controlled Trial

The findings from the systematic review and the needs assessment were incorporated in the intervention design. Theory of change and theory of action were used to develop a complex intervention, following guidance provided by the Medical Research Council. A theory-driven, evidence-based complex intervention was developed. This intervention was psychological but incorporated mind-body elements such as physiotherapy, meditation, mindful movement and pacing. The Phoenix Course is an 8-week online mindfulness-based self-management course tailored to the psychological needs of people living with endometriosis and adenomyosis. The course aims to improve quality of life. A feasibility randomised controlled trial was conducted to evaluate The Phoenix Course. This was the first RCT of a self-management course designed specifically for people living with endometriosis and/or adenomyosis. The results of the feasibility RCT illustrate that it is feasible to recruit participants for the course. The primary outcome measures showed a need for improvements to be made before a more definitive trial is recruited, including digital user engagement, retention and follow up rates. The secondary outcome measures showed improved scores for the intervention group for both the quality of life measure (EHP-30) and the mindfulness measure (FFMQ). Participant feedback on the course was primarily positive from both the intervention group and the control group. Conclusion: This feasibility randomised controlled trial provided valuable insights for where improvements are needed, including incentives for completing measures and providing more information about the nature of the course and the digital platform. User testing should be conducted before a larger trial is designed.

6.3 Context of Research Findings

A thorough literature search was conducted and is presented and discussed in the Introduction chapter of this thesis. This section will discuss the context of the research findings in relation to some of the different themes presented in the Introduction chapter.

Melotti, Fanelli and Sorella (2019) reported that despite experiencing more pain and more severe, women are less likely to receive appropriate treatment and are at risk of undertreatment. The data from the needs assessment shows what this looks like in the everyday lives of women living with endometriosis and adenomyosis. Women experiencing chronic pain along with undertreatment leads to poor quality of life. Pain and lack of appropriate treatment harm every aspect of a person's life, including their mobility, how they progress in their careers, how they view themselves and the effort they have to make to self-manage their symptoms to fill the gap in healthcare treatment.

It has been reported that healthcare professionals may have gaps in their knowledge when it comes to treating women in pain; they may also not listen to female patients or believe their pain is real (Braksmajer et al., 2018, Driscoll et al., 2018, Grundstorm et al., 2017)). Some themes identified in the needs assessment data illustrate the impact these knowledge gaps have on patients and patient care. Some of the themes from the need assessment include lack of trust in healthcare professionals, lack of care and the need for professional, respectful, empathetic, educated care. The data showed that people living with endometriosis and/or adenomyosis work hard to educate themselves about their conditions and are frustrated when healthcare professionals are uneducated. Patients are fearful of being seen by healthcare professionals who are not well informed about the condition and the best forms of treatment. One of the co-researchers images showed that her pain had worsened after her hysterectomy; she suspects this is due to the surgeon not removing endometriosis tissue. She discussed how she blames herself for not knowing to ask to see a specialist.

Another theme identified in the needs assessment data is pain belief; the women in the study wanted healthcare professionals to start listening to them and believing them about their painful and debilitating symptoms. The women discussed how they spent years trying to figure out the cause of their pain; only once they were diagnosed, they often feel that doctors perceived them as hysterical. Medical encounters between female patients and healthcare professionals may become a tug of war, with patients feeling that healthcare professionals do not consider their health condition legitimate (Braksmajer et al., 2018). This can contribute to poor mental health in patients and lead them to be distrustful of healthcare professionals. They, in turn, seek validation from others with the same condition in the form of patient-led support groups and social media. This was shown in the needs assessment data; the co-researchers included images relating to social media, friends and family and support groups. The tug of war with healthcare professionals also leads patients to develop the coping strategy of keeping records of their interactions with the NHS and their symptoms. They use these records to provide evidence of the symptoms of their health condition.

It has been reported that women with endometriosis and/or adenomyosis feel upset, angry, depressed, uncertain, weak, powerless, helpless, defeated, disappointed, frustrated, exhausted, a burden, isolated and have suicidal ideation (Morardi et al., 2014, Culley et al., 2013). It is not surprising that women feel this way when living with a painful, debilitating lifelong health condition that healthcare professionals are not knowledgeable about. It takes approximately 7.5 years to be diagnosed with endometriosis due to the gaps in the knowledge of healthcare professionals. Even after diagnosis, women can be doubted by healthcare professionals about their painful symptoms. The combination of the condition with the lack of appropriate treatment within the NHS is responsible for the poor mental health and quality of life of people living with endometriosis and/or adenomyosis. The needs assessment data showed the isolation felt by the co-researchers, with one saying she felt unalive. Suicide was also discussed in the needs assessment concerning being fearful of the future and attending the funeral of a friend who died by suicide.

People with endometriosis and/or adenomyosis turn to self-advocacy as a coping strategy. Self-advocacy applies to fighting for diagnosis and appropriate treatment to reduce symptoms, maintain fertility and improve and maintain quality of life (Whelan, 2007). This was also found in the needs assessment; the co-researchers discussed how they educated themselves, kept records, and learned how to self-advocate.

To improve the quality of life for people living with endometriosis and/or adenomyosis, medical care should also address the conditions' emotional, sexual, and social impact (De Graff et al., 2013). The needs assessment findings support this, and the Phoenix Course is designed to address the psychological suffering of living with these health conditions. However, although there is space for discussion around painful sex, the Phoenix Course cannot meet the unmet needs associated with this. There is an element of physiotherapy in the course that does provide helpful advice on tension in the pelvic floor, which may contribute to painful sex.

People living with endometriosis and/or adenomyosis have unique needs, and self-management practices need to be considered in light of potential flare-ups (Armour et al., 2019). This was taken into account when considering the format of the Phoenix Course because it is an online intervention, it allows participants to use it in the use of their own home. It can be used on mobile phones or tablets; it was also carried around and accessed whenever a participant wants or needs to use it.

The needs assessment showed that while self-management can be a helpful coping strategy. However, it can also be a burden on time, energy levels, effort and finances. A self-management approach where patients and informed and supported by healthcare professionals can improve outcomes and reduce healthcare costs (Lorig and Holman, 2003, Bodenheimer et al., 2002). The needs assessment did not show that women are empowered by their self-management approaches to symptoms and flare-ups. They described self-management as something necessary due to the number of unmet needs they were living with. Self-management was incorporated in all aspects of their lives to reduce their suffering and improve their quality of life. Often self-management meant making a decision that could cause symptoms to flare, e.g., attending a live music event or making a decision that would lead to social isolation, e.g., staying home instead. A lot of problem-solving and planning went into each of the co-researchers' coping strategies. This has been called the 'third shift', the work carried out by women to lessen the impact of their condition, in addition to paid work and unpaid work (Seear, 2009b).

A review of online mindfulness-based interventions for physical health conditions found that they could improve primary outcomes such as pain acceptance, fatigue, stress coping efficacy and social engagement (Toivonen et al., 2017). The review also found that online mindfulness interventions may be particularly effective when tailored for specific conditions (Toivonen et al., 2017). The feasibility study adds to the findings of Kold et al. (2012) and Hansen et al. (2017) because the intervention was tailored for people with endometriosis and/or adenomyosis and used a control group. Although the feasibility trial was not adequately powered to conduct inferential statistical analysis, there were improvements in the primary outcomes. The EHP-30 domains included pain, control and powerlessness, emotional wellbeing, social support and self-image (Jones et al., 2006). The intervention group showed a reduction in scores (improvement) for all domains compared with the control group. This shows a positive signal efficacy that is encouraging. The combined score that illustrates the quality of life also showed a reduction for the intervention group compared with the control group. This indicates that there may be an improvement in quality of life if The Phoenix Course was evaluated in a more definitive and adequately powered trial.

Two studies were not identified by the systematic review search strategies because the trial targeted pain and pain acceptance rather than the quality of life. The authors also used chronic pelvic pain rather than specifying a medical condition, although people with endometriosis were included in the trial (Forbes et al., 2020, Ball et al., 2020). The MEMPHIS trial produced a quantitative and qualitative study investigating the use of Headspace with patients living with chronic pelvic pain. The authors investigated whether it was feasible to use the app to improve pain and pain acceptance (Forbes et al., 2020, Ball et al., 2020). The trial had a high recruitment rate, adequate follow-up, and low adherence rates (Forbes et al., 2020). The authors suggest that their intervention may be improved by involving users in the design of the intervention. The authors also suggest that 60 days may be too long for a mindfulness meditation intervention (Forbes et al., 2020). A solution presented in this paper is the use of an introduction or orientation video or tool to help familiarise participants with the intervention before the first session (Ball et al., 2020).

Although the MEMPHIS trial did include a module tailored towards patients with chronic pelvic pain, patients were not involved in the development of this module. The MEMPHIS trial also did not include social support/interaction as a component of the intervention. The feasibility trial (Chapter 5 Intervention Development and Feasibility Randomised Controlled Trial) also reported favourable recruitment rates but low adherence and engagement rates. The trial also had the function of allowing for social support as participants could communicate with each other and the facilitators. The MEMPHIS trial was also funded by the National Institute of Health Research (NIHR) and was conducted by a team of experienced healthcare professionals and researchers. With funding and a more extensive research team, it is hoped that a future trial of The Phoenix Course could determine if the course improves the quality of life for people living with endometriosis and/or adenomyosis.

Although the feasibility RCT of The Phoenix Course was not without limitations, the secondary outcomes indicate a positive efficacy signal, with the scores indicating improvements. Future research should further examine how the course performs as the pandemic comes to an end. The findings of the feasibility RCT indicate that it does have potential and warrants further investigation. Chapter 5 discusses the impact of the needs assessment study. The photo book has been well received by both healthcare professionals and patients with endometriosis and adenomyosis. It has become a useful resource for support groups. The promising results from the feasibility RCT has also meant that funding was secured, to further develop the course and included more tailored videos, a symptoms tracker and more user testing to make the course more user friendly. The feedback provided by the participants in the RCT will also be used to make improvements. The funding was awarded after an application was submitted to Coventry University's Launchpad competition, a competition for staff and students to apply with a product or business idea they would like funded. There are four awards of £5000, however, in 2021 the full award of £20000 was given to fund the improvements to the

Phoenix Course. This will also allow participants to pay and download the course as an app, that will self-fund the ongoing running and managing of the course. It is anticipated that the new and improved Phoenix Course will be relaunched in March 2022.

6.4 Impact of Research Findings and Outputs

There were two outputs produced from this research, the photo book 'Living with Endometriosis' and the Phoenix Course, an online mindfulness-based intervention.

6.5 Unique Contribution and Originality of Research

One of the objectives of a PhD is to make a unique contribution to research. This PhD has produced two resources for people living with endometriosis, an educational recourse, the 'Living with Endometriosis' photo book and online mindfulness-based intervention. These resources can be used together or separately by both patients of healthcare professionals. Both resources can also reduce the burden carried by patients by giving them a resource to share with healthcare professionals, family, friends and employers and supporting them to self-manage their symptoms and address the psychological suffering associated with endometriosis and adenomyosis. The photo book output from the needs assessment and the intervention fulfil the objective of making a unique contribution to research.

Another objective of a PhD is to produce original research. While the intervention was built on an existing online platform and included components from a current intervention, the Hope Programme, the Phoenix Course was designed to meet specific psychological needs of people living with endometriosis. Chapter 5 provides more detail on how the Phoenix Course differs from the Hope Programme and uses the functionality of the Hope platform. The needs assessment identified psychological needs to be addressed and which coping strategies to include in the intervention. The data from the needs assessment study were used to tailor a mindfulness-based intervention for people with endometriosis and adenomyosis. As both the Hope Programme and the Phoenix Course are evidence-based interventions for people with chronic health conditions, there is an overlap in some components such as social support and gratitude as the evidence base overlaps.

6.6 What do the findings add to existing healthcare policy?

NICE (2017) have stated in their guidelines that endometriosis can negatively impact all aspects of life; physical, sexual, psychological, and social. As a result, people living with endometriosis and/or adenomyosis may have complex needs, which NICE recommend are addressed by having access to a multidisciplinary team for treatment (NICE, 2017).

An online 8-week mindfulness-based self-management course, such as The Phoenix Course, can help fill the gap in the healthcare services that are currently not meeting the needs of people living with endometriosis and adenomyosis. The Phoenix course offers support in self-management and aims to teach participants evidence-based coping strategies, and provides a place where social support can be provided. As the participants live with the same condition and similar symptoms and experiences, participants may experience feeling validation from others (a needs identified in the needs assessment).

The Phoenix Course has the potential to improve the quality of life of people living with endometriosis and/or adenomyosis. There is also a proven gap in the current care pathway for an evidence-based, theory-driven self-management course.

6.7 What do the findings add to existing healthcare practice?

The literature shows that people living with endometriosis and/or adenomyosis are more likely to suffer from poor mental health and low quality of life than healthy controls. There is also a clear need for tailored psychological support.

The findings from the needs assessment can be used to inform GPs' and gynaecologists about the reality of the lived experience of people living with endometriosis and adenomyosis. This could be used as part of the APPG recommendations to help GPs' identify the signs and symptoms of potential endometriosis/adenomyosis and help them to refer patients to secondary care services sooner. The needs assessment also highlights that the patient journey does not end with diagnosis; patients are often dismissed after diagnosis and often find that symptoms will return or worsen. When patients with endometriosis notice symptoms returning or worsening after surgery or pharmacological treatment, they face going through the same process to see a gynaecologist. There is no process in place in primary care that allows for annual reviews of symptoms. Putting this in place could reduce the burden on the NHS by freeing up GP appointments and reducing the number of visits to A and E departments.

All of the participants in the feasibility RCT experienced painful symptoms and used a variety of pain relief, from over the counter medication to prescribed oramorph. The screening sheet for participants asked for details on diagnosis and treatment, including pain relief, 100% of participants in the RCT used pain relief. Some participants listed hormonal treatment as pain relief. Chronic pelvic pain is the primary symptom of endometriosis and adenomyosis, and it is also the main focus of pharmacological management of the conditions. The NICE guidelines empathise with the treatment of painful symptoms (NICE, 2017). The treatment or management of pain appears to focus on many research studies, including studies investigating non-pharmacological, non-surgical interventions. An alternative approach is to acknowledge that endometriosis-associated pain is challenging to manage, even with specialist treatment that includes excision surgery. An alternative approach is to collaboratively work with patients to improve their quality of life and manage painful symptoms.

The Phoenix Course is a tailored psychological intervention, which supports patients with endometriosis and/or adenomyosis to self-manage their conditions using an online platform to teach mindfulness skills. Suppose a further RCT determines that The Phoenix Course does improve the quality of life for people living with these conditions. In that case, it could be offered to patients alongside surgical and pharmacological options. As patients are already investing their time, effort and money into self-management, The Phoenix Course could reduce this burden. The Phoenix course could also be helpful to patients as the pandemic continues to impact the NHS by providing support to patients in their own homes. This has the potential to provide a tailored intervention whilst waiting for appointments or surgery.

The diagnosis and treatment of endometriosis and adenomyosis can be challenging for healthcare professionals (Grundstrom et al., 2017). However, improvements in how endometriosis/adenomyosis patients are treated in the healthcare system are needed to prevent further psychological suffering, as reported by the co-researchers in the needs assessment. The findings from the needs assessment show there is a need for more training on endometriosis and adenomyosis for healthcare professionals. Suppose GPs were more aware of the signs and symptoms of endometriosis and/or adenomyosis. In that case, they could help reduce the delay in diagnosis and prevent patients from attending A & E.

6.8 Future Research

The mixed-methods systematic review found a lack of high-quality studies, with gaps in the data presented. The review also did not return any qualitative studies in the 2017 searchers. This highlighted the need for more high-quality, robust quantitative research studies that investigated the effectiveness of non-surgical, non-pharmacological interventions at improving the quality of living for people living with endometriosis and/or adenomyosis. The review also highlighted the need for robust qualitative studies investigating the patient experience of these types of interventions. Another update in the systematic review in a few years would also be a good measure of the progress. More high quality, robust studies are being conducted and published that look at the effectiveness and patient experience of non-surgical, non-pharmacological interventions. Systematic reviews and meta-analyses are essential in all areas of research.

Photovoice has proven to be a helpful tool when used for a needs assessment in developing an intervention. The findings show that it is possible to use photovoice in intervention development but does not definitively show it’s more or less valuable than other qualitative research methods. However, it may be useful in developing interventions for invisible or ignored health conditions that others find difficult to understand. Future research could focus on more ‘invisible’ areas of the lived experience of endometriosis and/or adenomyosis. Women with these conditions may experience menopause earlier than women without these conditions. This can be due to surgery such as hysterectomy and hormonal treatments that induce chemical menopause, such as Orlissa. Photovoice could be used to collect data on this area of the lived experience of endometriosis/adenomyosis. Future research could also focus on minorities such as the LGTBQ+ and BAME communities to document their lived experience of these conditions and determine their specific needs to ensure an intervention can be tailored towards their needs.

The feasibility RCT of The Phoenix Course highlights areas for improvement that need to be made before a more definitive trial can be conducted. Funding would be required so that incentives could be applied to encourage participants to complete baseline measures and T1 measures to ensure an adequate sample size is reached and maintained. Funding could also be used for administrative support with contacting participants. Incentives for participants completing questionnaires is standard practice. Incentives can take the form of a gift voucher or entry into a prize draw. It has been found that a £5 gift voucher gave an absolute increase in the proportion of questionnaires returned about 7% and a relative increase of 10% (Gates et al., 2009). A third arm could be added, which would allow The Phoenix Course to be evaluated alongside another psychological intervention or an educational intervention such as a patient information leaflet or booklet. This will help determine if a tailored intervention is more effective at improving quality of life than one that's available to the general public or one that's also tailored towards the same population but educational rather than psychological.

6.9 Recommendations

Table 6.1 summarises the implications of the key research findings and recommendations based on these findings. The recommendations made focus on three main areas, policy, practice and research. The 'Living with Endometriosis' photo book output from the needs assessment study could be a valuable educational resource that healthcare professionals and patients could use. The photo book could also be used to train general practitioners, nurses, paramedics and other healthcare professionals. Employers could also educate them about endometriosis and adenomyosis to support their employees in the workplace.

Most of the recommendations focus on the Phoenix Course and its usefulness for improving and maintaining the quality of life for people living with endometriosis and/or adenomyosis.

Table 6.1 Implications and Recommendations

Implications and Recommendations			
		Implication	**Recommendation**
Policy			
	1	There is a need for the development of 'holistic services', integrating psychology, physiotherapy, fertility treatment and pain management within existing services	The NICE Care Pathway for endometriosis should be further developed to reflect the guidelines from 2017 and the update in 2019.
	2	There are gaps in the current care pathways for endometriosis and/or adenomyosis that need to be addressed.	True multidisciplinary teams should be implemented. There needs to be increased access to physiotherapy, psychology, pain management and fertility treatment.
Practice			
	1	Healthcare professionals find diagnosing and treating endometriosis and adenomyosis challenging. Healthcare professionals have reported that they don't have the skills to take a biopsychosocial approach to these conditions.	The Phoenix Course has the potential to be a valuable resource for healthcare professionals that recognise patients who require more support but feel unable to provide that support. The 'Living with Endometriosis' photo book could be a valuable educational tool for patients and healthcare professionals.
	2	People living with endometriosis and/or adenomyosis have complex psychological needs that are often entangled with their physical symptoms and experiences of navigating the healthcare system.	Further training is urgently needed for healthcare professionals, particularly GPs, to provide educated, professional, skilled and empathetic care to patients with these conditions.
	3	Patients with endometriosis and/or adenomyosis do not experience continuity of care. Once diagnosed that they do not receive regular appointments with specialists. If they require further surgery or treatment,	Suppose endometriosis nurses were located in GP surgeries. In that case, this could free up GP appointments, monitor symptoms and medication and avoid symptoms from escalating to the point that patients attend A & E.

		they have to repeat the process of referral and wait for an appointment.	
	4	There is not enough differentiating between endometriosis and adenomyosis. This can lead to patients having hysterectomies and remaining in debilitating pain.	Both patients and healthcare professionals need to be aware of the differences between the two conditions to move away from the myth that a hysterectomy will cure endometriosis.
	5	Changes to how healthcare professionals interact with patients can reduce the psychological suffering reported by patients.	Further training should be urgently provided; endometriosis is as common as asthma, and healthcare professionals need to be aware of this. Patients with these conditions should be given full treatment options, including side effects and referrals for physiotherapy, pain management and fertility treatment as needed. Patients need more options than choosing between fertility and pain.
Research			
	1	Photovoice can be used as a needs assessment tool to collect highly personal and intimate data.	Further use of this method for other invisible health conditions.
	2	Photovoice can be a validating process for co-researchers.	All the steps of the procedure must be followed; the final presentation is essential for dissemination but can also provide validation to others in the same community.
	3	There is a lack of high quality and robust research studies in the area of endometriosis and adenomyosis.	Further investment in this area of research is urgently required.
	4	The Phoenix Course may potentially improve the quality of life for people living with endometriosis and/or adenomyosis.	Further user testing, fully powered RCT to evaluate The Phoenix Course. Addressing limitations of the feasibility study in the future research design.

6.10 Strengths and Limitations of the research

A strength of this thesis is that a gap was identified in the evidence base and guidelines for a self-management course tailored towards the psychological needs of people living with endometriosis and/or adenomyosis. The course aimed to improve quality of life. People living with these conditions have already been using self-management techniques that were often not evidence-based nor recommended by NICE/ESHRE. The gap in the evidence base also highlighted the need for studies with a robust and robust research design, such as an RCT. A clear argument was made that there was a need within the patient group for a self-management course that could provide support and coping strategies.

Another strength of this thesis was using a participatory action research method to incorporate user involvement into the intervention design process. The photovoice study provided valuable insight into the unmet needs and coping strategies of those living with endometriosis and adenomyosis. The study's findings showed how complex this population's needs are and how entangled the physical symptoms of the conditions are with the emotional impact and burden.

Lastly, a major strength of this thesis is that it adds to the evidence base in this area of research by presenting the first feasibility RCT of a comprehensive self-management course, specifically tailored to improve the quality of life for people living with endometriosis and/or adenomyosis. The findings of this feasibility RCT indicate that a further, larger trial is warranted once more user testing has been conducted. The research design should include incentives for completing questionnaires at baseline and at timeline 1 (T1) to enable a large enough sample to perform statistical analysis to investigate the significance of any improvement in scores. The feasibility RCT of The Phoenix Course was conducted when access to medical treatment was far more reduced than helpful and when isolation increased. The digital nature of the course increases the accessibility of the course, allowing those with endometriosis and/or adenomyosis to connect with others with the condition whilst being supported in developing self-management strategies.

A limitation of this research could be the allegiance bias, the researcher's preference for a particular treatment (Munder et al. 2011). This was first discussed as a form of research bias in the methodology chapter. This type of researcher bias can impact outcome differences (Luborsky et al., 1975). As an accredited mindfulness teacher who was also the intervention developer, content creator and course facilitator, it may be that my involvement and preference for mindfulness over other types of psychological interventions influenced the behaviour of the participants and the positive feedback they provided. However, randomisation was used in the trial, there was a second facilitator, and I was supervised by experienced health and clinical psychologists. This is still a significant limitation to consider when designing any future trials.

6.11 Conclusion

This thesis presents the three stages taken to develop and evaluate a complex intervention, following the guidance provided by the Medical Research Council (Craig et al., 2019). The first stage was a mixed-methods systematic review, and the second stage was a participatory action needs assessment. The third stage involved applying the Theory of Change (Funnel and Rogers, 2011) to the MRC's guidelines to incorporate the first two stages into the intervention development process and then use a feasibility RCT to evaluate the intervention. By answering the research questions in each of the three stages, identified gaps have been addressed, leading to a novel intervention. Each stage of research within this thesis has produced findings that have implications and recommendations for healthcare policy, clinical practice and future research.

The research findings discussed within this thesis add valuable insights to the currently limited evidence based on non-surgical, non-pharmacological interventions designed to improve the quality of life for people living with endometriosis and/or adenomyosis. The COVID-19 pandemic has put the NHS under an enormous amount of strain, leading to cancelled appointments, postponed surgeries and long waiting times. The general population has faced increased stress and isolation, which people with endometriosis and adenomyosis were already dealing due to their conditions. An online mindfulness-based self-management course could provide psychological support at a time when the need is increased.

The findings from the photovoice study could also help inform further training for healthcare professionals on the lived experience of endometriosis and adenomyosis. It also demonstrated that photovoice could be used to collect highly intimate details from the lives of women. The co-researcher responded well to the method, and the data produced was highly emotive and meaningful. This method should be further explored for other areas of invisible illnesses, such as menopause and infertility. Since the co-researchers all identified as women, it isn’t clear if this method would work similarly for male co-researchers.

The findings discussed within this thesis make a unique contribution to limited research within the area of endometriosis and adenomyosis research. Further work needs to be done on disseminating the findings to contribute to healthcare policy, clinical practice and future research. The Phoenix Course is the first self-management course developed for people living with endometriosis and/adenomyosis. If a fully powered trial determines that it can improve quality of life, then the course should be made more widely available. The course can reduce the ‘third shift’ experienced by patients, provide a resource for healthcare professionals to refer patients to evidence-based patients and reduce the pressure on the NHS to offer more support.

References

Aerts, L., Graingier, L., Streuli, I., Dallenbach, P., Marci, R., Wenger, J.M. and Pluchino, N. (2018) ‘Psychosocial impact of endometriosis: From co-morbidity to intervention’. *Best Practice and Research Clinical Obstetrics and Gynaecology,* 50, 2-10

Ahn, A.C., Schnyer, R., Conroy, L., Lauffer, M.R. and Wayne, P.M. (2009) ‘Electrodermal measures of Jing-Well Points and their clinical relevance in endometriosis-related chronic pelvic pain’, *The Journal of Alternative and Complementary Medicine,* 15, 12, 1293-1305

Allaire, C., Willaims, C., Bodmer-Roy, S., Zhu, S., Arion, K., Ambacher, K., Wu, J., Yosef. A., Wong, F., Noga, H., Britnell, S., Yager, H., Bedaiwy, M.A., Albert, A.Y., Lisonkova, S. and Yong, P.J. (2017) Chronic pelvic pain in an interdisciplinary setting: 1-year prospective cohort, *American Journal of Obstetrics and Gynecology*

Armour, M., Lawson, K., Wood, A., Smith, C.A. and Abbott, J. (2019) The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australians. A national survey, *PLOS ONE*

Asthana, S., Moon, G., Gibson, A., Bailey, T., Hewson, P. and Dibben, C. (2020) Inequity in cardiovascular care in the English National Health Service (NHS): A scoping review of the literature. *Health and Social Care in the Community,* 26(3) 259-272

Baer, R.A., Smith, G.T., Hopkins, J., Krietemeyer, J. and Toney, L. (2006) Using self-report assessment methods to explore facets of mindfulness, *Assessment, 13, 27-45*

Bair, M.J., Matthias, M.S., Nyland, K.A., Huffman, M.A., Stobbs, D., L., Kroenke, K. and Damush, T.M. (2009) Barriers and facilitators to chronic pain self-management a qualitative study of primary care patients with comorbid MSK pain and depression, *Pain Medicine,* 10, 7

Ball, E., Newton, S., Rohricht, F., Steed, L., Birch, J., Dodds, J., Calvete, C.C., Taylor, S. and Rivas, C. (2020) mHealth: providing a mindfulness app for women with chronic pelvic pain in gynaecology outpatient clinics: qualitative data analysis of user experience and lessons learnt. *Obstetrics and Gynaecology,* 10(3)

Ballard K, Lowton K, Wright J. (2006) ‘What’s the delay? A qualitative study of women’s experiences of reaching a diagnosis of endometriosis. *Fertility and Sterility,* 2006; 5:1296 – 1301

Barlow, J., Wright, C., Sheasby, J., Turner, A., and Hainsworth, J. (20012) ‘Self-management approached for people with chronic conditions: A review’. *Patient Education and Counseling,* 48, 177-87

Bawa, F.L., Mercer, S.W., Altherton, R.J., Clague, F., Keen, A., Scott, N.W. and Bond, C.M. (2015) Does mindfulness improve outcomes in patients with chronic pain? Systematic Review and Mata-analysis, *British Journal of General Practice,* Bazot, M., Fiori, O., and Darai, E. (2006) Adenomyosis in endometriosis – prevalence and impact on fertility. Evidence from magnetic resonance imaging'. *Human Reproduction,* 20(8), 2309–2316

Beissner, F., Preibisch, C., Schweizer-Arau, A., Popovici, R.M. and Meissner, K. (2017) 'Psychotherapy with Somatosensory Stimulation for endometriosis-associated pain: The role of the anterior hippocampus, *Society of Biological Psychiatry*

Bertero, C, Alehagen, S. and Grundstrom, H. (2019) Striving for a biopsychosocial approach. A secondary analysis of mutual components during healthcare encounters between women with endometriosis and physicians, *Journal of Endometriosis and Pelvic Pain,*

Bragheto, A.M., Caserta, N., Bahamondes, L. and Petta, C.A. (2007) 'Effectiveness of the Levonorgestrel-releasing Intrauterine System in the Treatment of Adenomyosis Diagnosed and Monitored by Magnetic Resonance Imaging'. *Contraception,* 76(3), 195-199

Braksmajer, A. (2018) Struggles for medical legitimacy among women experiencing sexual pain: A qualitative study, *Women & Health,* 58:4, 419-433

Brown, J. and Fraquar, C. (2014) Endometriosis: an overview of Cochrane reviews, Cochrane Database of Systematic Reviews, 3

Brown, N. & Leigh, J. (2020) (Eds) '*Ableism in Academia – Theorising experiences of disabilities and chronic illnesses in higher education'*, London: UCL Press

Bodenheimer, T., Wagner, E.H. and Grumbach, K. (2002) Improving primary care for patients with chronic illness. *Journal of the American Medical Association,* 288,1775-1779

Boschen, K.A., Robinson, E., Campbell, K.A., Muir, S., Oey, E., Janes, K., Fashler, S.R. and Katz, J. (2016) Results from 10 years of a CBT pain management outpatients program for complex chronic conditions, *Pain Research and Management*

Buggio, L., Giussy, B., Facchin, F., Frattornolo, M.P. and Giorgio, A. (2017) Self-management and psychological-sexological interventions in patients with endometriosis: strategies, outcomes and integration into clinical care, *International Journal of Women's Health,* Vol 19, 281-293

Bukowski, K. and Buetow, S. (2011) Making the invisible visible: A photovoice exploration of homeless women's health and lives in central Auckland, *Social Science and Medicine,* 72, 739-746

Buhrman, M., Gordh, T. and Andersson, G. (2016) Internet interventions for chronic pain including headache: A systematic review, *Internet Interventions,* 4, 17-34

Burles, M. and Thomas, R. (2012) ‘But they’re happening to you at the wrong time’: Exploring young adult women’s reflections on serious. Illness through photovoice, *Qualitative Social Work,* 12(5), 671-688

Campbell, R. and Wasco, S.M. (2000) Feminist approaches to social science: Epistemological and methodological tenets. *American Journal of Community Psychology,* 28, 773-791

Cameron, J.E., Voth, J., Jaglal, S.B., Guilcher, S.J.T., Hawkes, G. and Salbach, N.M. (2018) “In this together”: Social identification predicts health outcomes (via self-efficacy) in a chronic disease self-management program, *Social Science and Medicine,* 28, 172-179

Catalani, C. and Minkler, M. (2010) Photovoice: a review of the literature in health and public health. *Health Education & Behaviour,* 37(3), 424-451

Cavaggioni, G., Lia, C., Resta, S., Antonielli, T., Panici, P.B., Megiorni, F. and Porpora, M.G. (2014) Are mood an anxiety disorders and alexithymia associated with endometriosis? A preliminary study. *Biomed Research International*

Champaneria, R., Daniels, J.P., Razza, A., Pattison, H. and Khan, K.S. (2012) ‘Psychological therapies for chronic pelvic pain: Systematic review of randomized controlled trials’, *Acta Obstetricia et Gynecologica,* 91 281-286

Charlton, J.I. (1998) Nothing about us without us: Disability oppression and empowerment. California: University of California Press

Chen, L.C., Hsu, J.W., Huang, K.L., Bai, Y.M., Su, T.P., Li, C.T., Yang, A.L., Chang, W.H., Chen, T.J., Tsai, S.J. and Chen, M.H. (2016) Risk of developing major depression and anxiety disorders among women with endometriosis: A longitudinal follow-up study. *Journal of Affective Disorders,* Vol. 190, 282-285

Chung, M.K., Chung, R.P., Gordon, D. and Jennings, C. (2002) ‘The evil twins of chronic pelvic pain syndrome: endometriosis and interstitial cystitis’. *Journal of the Society of Laparoendoscopic Surgeons,* 6(4), 311-314

Clareús, B. and Renström, E.A. (2019) Physicians’ gender bias in the diagnostic assessment of medically unexplained symptoms and its effect on patient-physician relations, *Scandinavian Journal of Psychology,* 60, 338-347

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I and Petticrew, M. (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance, *British Medical Journal,* 337

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. and Pettigrew, M. (2019) Developing and evaluating complex interventions: following considerable development in the field since 2006, MRC and NIHR have jointly commissioned an update of this guidance to be published in 2019, Medical Research Council, https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/

Creswell, J.W. and Creswell, J.D (2018) Research Design: Qualitative, quantitative and mixed methods approach (5th ed.) Thousand Oaks, CA: Sage

Crisp, C. D. (MAJ), Hastings-Tolsma, M. and Jonscher, K.R. (2016) Mindfulness-Based Stress Reduction for military women with chronic pelvic pain: A feasibility study, *Military Medicine,* 181, 9:982

Cruwys, T., Dingle, G.A., Haslam, C., Haslam, S.A., Jetten, J. and Morton, T.A. (2013) Social group memberships protect against future depression, alleviate depression symptoms and prevent depression relapse, *Social Science Medicine,* 98, 179-186

Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgaten, M. and Raine-Fenning, N. (2013) 'The social and psychological impact of endometriosis on women's lived: a critical narrative review'. *Human Reproduction Update,* Vol 19(4), 625-639

Cosar, E., Güngör, A.C., Gencer, M., Uysal, A., Hacivelioglu, S.O., Özkan, A. and Sen, H.M. (2014) Sleep disturbance among women with chronic pelvic pain, *International Journal of Gynecology & Obstetrics,* 126(3) 232-4

Cox H, Henderson L, Andersen N, Cagliarini G, Ski C. (2003b) 'Focus group study of endometriosis: struggle, loss and the medical merry-go-round'. *International Journal of Nursing Practice*, 1:2 – 9

Decker, M., Hemmerling, A. and Lankoande, R. (2010) Women front and center: The opportunities of involving women in participatory health research worldwide, *Journal of Women's Health, 19(11)*

De Graaff, A. A., D'Hooghe, T.M., Dunselman, G.A., Dirksen, C.D., Hummelshoj, L. WERF EndoCost Consortium and Simoens, S. (2013) The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Human Reproduction,* 28(10), 2677-85

Denny, E. (2004a) 'Women's experience of endometriosis'. *Journal of Advanced Nursing,* 46(6), 641-648

Denny E. and Mann, C.H. (2008) 'Endometriosis and the primary care consultation'. *European Journal of Obstetrics and Gynecology and Reproductive Biology,* Vol 139(1), 111–115

Denscombe, M. (2008) A research paradigm for the mixed methods approach, *Journal of Mixed Methods Research,* Vol 2, 3, 270-283

De Silva, M.J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C. and Patel, V. (2014) Theory of change: a theory-driven approach to enhance the medical research council's framework for complex interventions, *Trials,* 15:267

De Sousa, T.R., de Souza, B.C., Zomkowisk, K., da Rosa, P.C. and Sperandio, F.F. (2018) 'The effect of acupuncture on pain, dyspareunia and quality of life in Brazilian women with endometriosis: A randomised clinical trial', *Complementary Therapies in Clinical Practice,* 25, 114-121

Diabetes UK (accessed February 2019) https://www.diabetes.org.uk/resources-s3/2017-11/diabetes-key-stats-guidelines-april2014.pdf

DiDonato, N. and Seracchiolo, R. (2014) How to evaluate adenomyosis in patients affected by endometriosis? *Minimally Invasive Surgery*

Donoghue, P.J. and Siegel, M.E. (1992) 'Sick and tired of feeling sick and tired: living with invisible chronic illness', New York: W.W. Norton and Company

Dunselman, G.A.J., Vermeulen, N., Becker, C., Calhaz-Jorge, C., D'Hooghe, T., De Bie, B., Heikinheimo, O., Horne, A.W., Kiesel, L., Nap, A., Prentice, A., Sraidogan, E., Spriano, D. and Nelen, W., (2014) ESHRE guidelines: Management of women with endometriosis, *Human Reproduction,* 29, 3

Dures, E., Rumsey, N., Morris, M. and Gleeson, K. (2010) Mixed methods in health psychology – Theoretical and practical considerations of the third paradigm, *Journal of Health Psychology, Vol. 16(2), 332-341*

Driscoll, M.A., Knobf, M.T., Higgins, D.M., Heapy, A., Lee, A. and Haskell, S. (2018) Patients experiences navigating chronic pain management in an integrated health care system: A qualitative investigation of women and men, *Pain Medicine,* 19, S19-S29

Edwards, E.A., Lumsden, J., Rivas, C., Steed, L., Edwards, L.A., Thiyagora, A., Sophanpal, R., Caton, H., Griffiths, C.J., Munafo, M.R., Taylor S. and Walton, R.T. (2016) Gamification for health promotion: a systematic review of behaviour change techniques in smartphone apps, *BMJ Open,* 6

Eldridge, S.N., Chan, C.L., Campbell, M.J., Bond, C.M., Hopewell, S., Thabane and Lancaster, G.A. (2016) CONSORT 2010 statement: extension to randomised pilot and feasibility trials, *BMJ,*

Endometriosis UK (Accessed February 2019) https://www.endometriosis-uk.org/endometriosis-facts-and-figures

Endometriosis UK (Accessed July 2020) https://www.endometriosis-uk.org/coronavirus-covid-19-and-endometriosis

Engeler, D.S., Baranowski, A.P., Dinis-Oliveria, P., Elneil, S., Hughes, J., Messelink, E.J., van Ophoven, A., and Williams, A.C. (2013) 'The 2013 EAU guidelines on chronic pelvic pain: is management of chronic pelvic pain a habit, a philosophy or a science? 10 years of development'. *European Urology,* 64, 431-439

Evans, S., Fernandez, S., Olive, L., Payne, L.A. and Mikocka-Walus, A. (2019) ‘Psychological and mind-body interventions for endometriosis: A systematic review’, *Journal of Psychosomatic Research,* 124

Facchin, F., Barbara, G., Dridi, P., Alberico, D., Buggio, L., Somigliana, E., Saita, E and Vercellini, P. (2017) Mental health in women with endometriosis – searching for predictors of psychological distress, *Human Reproduction,* 32, No.9, 1855-1861

Farshi, N., Hasapour, S., Mirghafourvand, M., and Esmaelipour, K. (2020) ‘Effect of self-care counselling on depression and anxiety in women with endometriosis: A randomised controlled trial’. *BMC Psychiatry,* 20:391

Ferenczy, A. (1998) ‘Pathophysiology of Adenomyosis’. *Human Reproduction Update,* 4(4)
Flower, A., Lewith, G.T. and Little, P. (2011) ‘A feasibility study exploring the role of Chinese Herbal Medicine in the treatment of endometriosis’, *The Journal of Alternative and Complementary Medicine,* 17, 8, 691-699

Forbes, G., Newton, S., Calvete, C.C., Birch, J., Dodds, J., Steed, L., Rivas, C., Khan, K., Rohricht, F., Taylor, S., Kahan, B.C. and Ball, E. (2020) MEMPHIS: a smartphone app using psychological approaches for women with chronic pelvic pain presenting to gynaecology clinics: A randomised feasibility trial, *Obstetrics and Gynaecology,* 10(3)

Fox, S.D., Flynn, E and Allen, R.H.C. (2011) Mindfulness meditation for women with chronic pelvic pain: a pilot study, *Journal of Reproductive Medicine,* 56(3-4) 158

Frankl, O. (1925) ‘Adenomyosis uteri’, *American Journal of Obstetrics and Gynecology,* 10, 680-684

Funnell, S. C. and Rogers, P.J. (2011) Purposeful program theory – effective use of theories of change and logic models, San Francisco, CA: Jossey Bass

Gambadauro, P., Carli, V. and Hadiaczky, G. (2019) Depressive symptoms among women with endometriosis: a systematic review and meta-analysis, *American Journal of Obstetrics and Gynecology, Vol 220(3) 230-241*

Giamberardino, M.A. (2008) Women and visceral pain: Are the reproductive organs the main protagonists? Mini-review at the occasion of the “European Week Against Pain in Women 2007”, *European Journal of Pain,* 12, 257-260

Gillberg, C. (2020) ‘The significance of crashing past gatekeepers of knowledge: Towards full participation of disabled scholars in ableist academic structures’, in Brown, N. & Leigh, J. (2020) (Eds) ‘*Ableism in Academia – Theorising experiences of disabilities and chronic illnesses in higher education’*, London: UCL Press

Gleeson, K. (2011) ‘Polytextual thematic analysis for visual data – pinning down the analytic’, in Reavey, P. (ed.) *Visual Methods in Psychology – using and interpreting images in qualitative research.* Oxon: Psychology Press

Gogovor, A., Visca, R., Auger, C., Bouvrett-Leblan, L., Synmeonidis, I., Poissant, L., Ware, M.A., Shir, Y., Viens, N. and Ahmed, S.(2017) Informing the development of an internet-based chronic pain self-management program, *International Journal of Medical Informatics,* 97, 109-119

Goncalves, A.V., Makuch, M.Y., Setubal, M.S., Barras, N.F. and Bahamondes, L. (2016a) A qualitative study on the practice of yoga for women with pain-associated with endometriosis, *The Journal of Alternative and Complementary Medicine,* 00,0

Goncalves, A.V., Barras, N.F., Bahamondes, L. (2016b) The practice of hatha yoga for the treatment of pain associated with endometriosis, *The Journal of Alternative and Complementary Medicine,*

Gonçalves, A.C., Barros, N.F. and Bahamondes, L. (2017) ‘The practice of Hatha Yoga for the treatment of pain associated with endometriosis’, *The Journal of Alternative and Complementary Medicine,* 23, 45-52

Goldberg, S.B. and Tucker, R.P. (2020) Allegiance effects in mindfulness-based interventions for psychiatric disorders: A meta re-analysis. *Psychotherapy Research,* 30(6)

Grant, B.M. and Giddlings, L.S. (2002) Making sense of methodologies: A paradigm framework for the novice researcher, *Contemporary Nurse, 13:1, 10-28*

Grundstrom, A., Alehagen, S., Kjolhede, P. and Bertero, C. (2017) The double-edged experience of healthcare encounters among women with endometriosis: A qualitative study. *Journal of Clinical Nursing,* Vol 27(1-2)

Guidice, L.C. (2010) ‘Clinical Practice. Endometriosis’. *The New England Journal of Medicine,* 362:25

Guidice, L.C., Johannes, L.H. and Healy, D.L. (2012) ‘Endometriosis: Science and Practice’. Oxford: Wiley-Blackwell

Gustafson, D.L. and Brunger, F. (2014) Ethics, “vulnerability”, and feminist participatory action research with a disability community, *Qualitative Health Research,* 24(7), 997-1005

Hansen, K.E., Kesmodel, U.S., Kold, M. and 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,* 69:2, 100-109

Hansen, H. and Trank, C.Q. (2016) This is going to hurt: Compassionate research methods, *Organisational Research Methods,* 19(3), 352-375

Heapy, A., Otis, J., Stein Marcus, K., Frantsve, L.M., Janke, E.A., Shulman, M., Bellmore, W. and Kerns, R.D. (2005) Intersession coping skill practice mediates the relationship between readiness for self-management treatment and goal accomplishment, *PAIN,* 118, 360-368

Hernandez, R., Burrows, B., Wilund, K., Cohn, M., Xu, S. and Moskowitz, J.T. (2018) Feasibility of an internet-based positive psychological intervention for haemodialysis patients with symptoms of depression, *Trials,* 15, 267

Hirsch, M., Begum, M.R., Paniz, E., Barker, C., Davis, C.J., and Duffy, J.M.N. (2017) 'Diagnosis and management of endometriosis" a systematic review of international and national guidelines'. *British Journal of Obstetrics and Gynaecology,*

Hoffmann, T.C., Glasziou, P.P., Boutron, I., Milne, R., Perera, R., Altman, D.G., Barbour, V., Macdonald, H., Johnston, M., Lamb, S.E., Dixon-Woods, M., McCulloch, P., Wyatt, J.C., Chan, A and Michie, S. (2014) Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide, *BMJ,*

Horne, A.W., Saunders, P.T.K., Abokhrais, I. and Hogg, L. (2017) Top ten endometriosis research priorities in the UK and Ireland, *The Lancet,* 389(10085)

Horne, A. and Pearson, C. (2018) 'Endometriosis. The experts' guide to treat, manage and live well with your symptoms.' London: Vermilion

Huang, A. J., Rowen, T.S., Abercrombie, P., Subak, L. E., Schembri, M., Plaut, T. and Clao, M.T. (2017) Development and feasibility of a group-based therapeutic yoga program for women with chronic pelvic pain, *Pain Medicine,* 18, 1864-1874

Hulka, C.A., Hall, P.A., McCarthy, K., Simeone, J. (2002) Sonographic findings in patients with adenomyosis: Can sonography assist in predicting extent of disease? *American Journal of Roentgenology,* 179(2)

Huntington, A. and Gilmour, J.A. (2004) 'A life shaped by pain: Women and endometriosis'. *Journal of Clinical Nursing,* 14, 1124-1132

Ivankova, N. and Wingo, N. (2018) Applying mixed methods in action research: Methodological potentials and advantages, *American Behavioural Sciences,* Vol 62(7), 978-997

Johnson, R.B. and Onwuegbuzie, A.J. (2004) Mixed methods research: A research paradigm whose time has come, *Educational Researcher, Vol. 33, No. 7, p14-26*

Jones G, Kennedy S, Barnard A, Wong, J and Jenkinson, C. (2001) Development of an endometriosis quality-of-life instrument: The Endometriosis Health Profile-30. Obstetrics and Gynecology, 98, 258–64.

Kayyali, R., Peletidi, A., Ismail, M., Hashim, Z., Banderia, P. and Bonnah, J. (2017) Awareness and use of mhealth apps: a study from England, Pharmacy, Kelly, L., Burton, S. and Regan, L. (1994) Researching women's lives or studying women's oppression? Reflections on what constitutes feminist research in Maynar, M. and Puris, J.(eds) Researching women's lives from a feminist perspective (Gender and Society: Feminist perspectives on the past and present). Taylor and Francis

Kennedy, S., Bergqvist, A., Chapron, C., D'Hooghe, T., Dunselman, G., Greb, R., Hummelshoj, L., Prentice, A., Saridogan, E. (2005) 'ESHRE Guideline for the Diagnosis and Treatment of Endometriosis'. *Human Reproduction* 20 2698-2704

Kemmis, S. and McTaggart, R. (2005) Participatory action research: Communicative action and the public sphere. In Denzin, N.K. and Lincoln, Y.S. (eds), The Sage Handbook of Qualitative Research. Thousand Oaks, CA: Sage

Keogh, A., Tully, M.A., Matthews, J. and Hurley, D.A. (2015) A review of behaviour change theories and techniques used in group based self-management programmes for chronic low back pain and arthritic, *Manual Therapy, 20*

Kold, M., Hansen, T., Vedsted-Hansen, H. and Forman, A. (2012) 'Mindfulness-based psychological intervention for coping with pain in endometriosis', *Nordic Psychology,* 64:1, 2-16

Kuhn, T. (1962) The structure of scientific revolutions. Chicago: Chicago University Press.

Kunz, G., Beil, D., Huppert, P., Noe, M., Kissler, S. and Lyendecker, G. (2005) 'Adenomyosis in endometriosis – prevalence and impact on fertility. Evidence from magnetic resonance imaging'. *Human Reproduction,* 20(8), 2309-2316

Kuyken, W., Evans, A., Brejch, C., Holmes, L., Wilks, J., Crane, R., Mardula, J., Soulsby, J., Silverton, S., Butler, T, Williams, J., Dymund, M., Fennell, M., Johansson, M. and Suraway, C. (2012) MBCT implementation resources, Exeter University, Bangor University and Oxford University
https://www.bangor.ac.uk/mindfulness/documents/12MBCTImplementationResources.pdf

Kristjansdottir, O.B., Stenberg, U., Mirkovic, J., Krogseth, T., Ljosa, T.M., Stange, K.C. and Ruland, C.M. (2018) Personal strengths reported by people with chronic illness: a qualitative study, *Health Expectations,* 21, 787-795

Lally, P., Van Jaarsveld, C.H.H.M., Potts, H.W.W. and Wardle, J. (2010) How are habits formed: modelling habit formation in the real world, *European Journal of Social Psychology,* 40, 998-1009

Latz, A.O. (2017) Photovoice Research in Education and Beyond: A Practical Guide from Theory to Exhibition. New York: Abingdon

Laux-Biehlmann, A., d'Hooghe, T. and Zollner, T.M. (2015) 'Menstruation pulls the trigger for inflammation and pain in endometriosis'. Trends in Pharmacological Sciences, 36, 5.

Lee, M.H., Wu, H.C., Tan, T.H., Chan, P.C. and Chen, Y.R. (2014) Development and evaluation of an ehealth system to care for patients with bladder pain syndrome/Interstitial cystitis, *international Journal of Urology,* 21, 62-68

Leeners, B. (2012). 'Psychosomatic Aspects'. In L.C., Guidice, J.L.H, Evers and D.L. Healy, (Eds.), *Endometriosis: Science and Practice* (533-547). Chichester: Blackwell Publishing Ltd.

Leonardi, M., Horne, A.W., Armour, M., Missmer, S.A., Roman, H., Rombauts, L>, Hummerlshoj, L., Wattiez, A., Condous, G. and Johnson, N.P. (2020) Endometriosis and the Coronavirus (COVID-19) pandemic: Clinical advice and future considerations. Frontiers in Reproductive Health, Vol 2, Art. 5.

Liebenberg, L. (2018) Thinking critically about photovoice: Achieving empowerment and social change. *International Journal of Qualitative Methods,* 17,1-9

Lipskaya-Velikovsky, L. (2021) COVID-19 isolation in healthy population in Israel: challenge in daily life, mental life, resilience and quality of life. *International Journal of Environmental Research and Public Health,* 18(3) 999

Longhurst, R. (2011) Becoming smaller: Autobiographical spaces of weight loss, *Antipode,* 0(0)

Lorig, K.R. and Holman, H. (2003) Self-management education: history, definition, outcomes and mechanisms. *Annals, Behavioral Medicine,* 16, 1-7

Luborsky, L., Singer, B. and Luborsky, L. (1975) Comparative studies of psychotherapies: Is it true that "everyone has won and all must have prizes?", *Archives of General Psychiatry,* 32, 995-1008

Mackenzie, N. and Knipe, S. (2006) Research dilemmas: Paradigms, methods and methodology, *Issues in Educational Research, 16(2)*

Mackey, C. and Diercks, D.B. (2018) Gender bias in the management of patients still exists, *Academic Emergency Medicine,* 467-469

McFarlane, H. and Hansen, N.E. (2008), in Kindon, S., Pain, R. and Kesby, M. (eds.) (2008) Participatory Action Research Approaches and Methods: Connecting People, Participation and Place, Oxon: Routledge

Martin, F., Wright, H., Moody, L., Whiteman, B., McGillion, M., Clyne, W., Pearce, G. and Turner, A. (2020) Development and evaluation of a digital self-management programme: iHOPE for cancer survivors, *Journal of Medical Internet research,*

Maslow, A.H. (1943) A theory of human motivation. *Psychology Review,* 50(4), 370-396

Maslow, A.H. (1954) Motivation and Personality, 3rd ed. New York: Longman

Matsuzaki, S., Canis, M., Pouly, J.L., Robischony, B., Botchorishuil. R. and Mage, G. (2006) ‘Relationship between delay of surgical diagnosis and severity of disease in patients with symptomatic deep infiltrating endometriosis’. *Fertility and Sterility,* 86(5), 1314-1316

Mayo Clinic (Accessed February 2019) https://www.mayoclinic.org/diseases-conditions/adenomyosis/symptoms-causes/syc-20369138

Maxey, I. (1999) Beyond boundaries? Activism, academia, reflexivity and research. *Area, 31.3, 199-208*

Mehlsen, M., Heegaard, L. and Frostholm, L. (2015) A prospective evaluation of chronic pain self-management programmes in a Danish population of chronic pain patients. *Patient Education and Counseling,* 98(5) 677-680

Meissner, K. Schweizer-Arau, A., Limmer, A., Preibisch, C., Popovici, R.M., Lange, I, de Oriol, B and Beissner, F. (2016) ‘Psychotherapy with Somatosensory Stimulation for Endometriosis-Associated Pain’, *Obstetrics & Gynecology*, 128, 5

Mellado, B.H., Falcone, A.C.M., Pol-Neto, O.H., Rosaesilva, J.C., Nogueira, A.A., Candido-dos-Reis, F.J. (2016) Social isolation in women with endometriosis and chronic pelvic pain. *International Journal of Gynaecology and Obstetrics,* 133, 199-201

Melotti, R.M., Fanelli, A. and Sorella, M.C. (2019) Gender and Pain cited in Tarricone, A. and Riecher-Rössler, A. (eds), *Health and Gender,* Springer Nature: Switzerland

Meuleman C., Vandenabeele B., Fieuws S., Spiessens C., Timmerman D., and D’Hooghe T. (2009) ‘High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners’. *Fertility and Sterility,* 1:68 – 74

Merrolli, M., Gray, K. and Martin-Sanchez, F. (2014) Therapeutic affordances of social media: emergent themes from a global online survey of people with chronic pain, *Journal of Medical Internet Research,* Vol, 16 (12)

Mira, T.A.A., Giraldo, P.C., Yela, D.A. and Benetti-Pinto, C.L. (2015) ‘Effectiveness of complementary pain treatment for women with deep endometriosis through Transcutaneous Electrical Nerve Stimulation (TENS): Randomised controlled trial’, *European Journal of Obstetrics & Gynaecology and Reproductive Biology,* 194, 1-6

Moher, D., Liberati, A., Altman, D.G. (2009) Preferred reporting items for systematic reviews and meta- analyses: The PRISMA statement, *PLoS Med,* 6(7)

Moradi, M., Parker, M., Sneddon, A., Lopez, Z. and Ellwood, D. (2014) ‘Impact of Endometriosis on Women’s Lives: A Qualitative Study’. *Women’s Health,* 14:123

Morton, K., Dennison, L., May, C., Murray, E., Little, P., McManus, R.J. and Yardley, L. (2017) Using digital interventions for self-management of chronic physical health conditions: A meta-ethnography review of published studies, *Patient Education and Counseling,* 100, 616-635

Mosarel, M. and Sanders, K.D. (2010) Photovoice: a needs assessment of African American Cancer Survivors. *Journal of Psychosocial Oncology,* 28:6, 630-643

Munch Simonsen, S., Stromberg, C., Zoffman, V., Hartwell, D. and Linnet Olesen, M. (2019) 'About me as a person not only the disease – piloting Guided Self-Determination in an outpatient endometriosis setting'. *Scandinavian Journal of Caring Sciences,*

Munder, T., Gerger, H., Trelle, S. and Barth, J. (2011) Testing the allegiance bias hypothesis: A meta-analysis. *Psychotherapy Research,* 21(6)

Naftalin, J., Hoo, W., Pateman, K., Mavrelos, D., Holland, T. and Jurkovic, D. (2012) How common is adenomyosis? A prospective study of prevalence using transvaginal ultrasound in a gynaecology clinic. *Human Reproduction,* 27(12) 3432-3439

National Center for Complementary and Integrative Health (NCCIH) (2020) Meditation in Depth https://www.nccih.nih.gov/health/meditation-in-depth

National Institute of Care Excellence (NICE) (2020) NICE Pathway Endometriosis https://pathways.nice.org.uk/pathways/endometriosis#path=view%3A/pathways/endometriosis/managing-endometriosis.xml&content=view-index

Nes, A.A.G., van Dulmen, S., Wicksell, R., Fors, E.A. and Eide, H. (2016) Analysing change processes resulting from a smartphone maintenance intervention based on acceptance and commitment therapy for women with chronic widespread pain, *International Journal of Behavioural Medicine,*

Nevedal, D.C., Wang, C., Oberteiture, L., Schwartz, S. and Williams, A.M. (2013) Effects of an individually tailored web-based chronic pain management program on pain severity, psychological health and functioning, *Journal of Medical Internet Research,* 15(9)

NICE Guidelines. 'Endometriosis: diagnosis and management'. 6th September 2017, http://nice.org.uk/guidance/ng73

Nicholas, M.K., Asjhari, A., Corbett, M., Smeets, R.J.E.M., Wood, B.M., Overton, S., Perry, C. and Tonkin, L.E. (2012) Is adherence to pain self-management strategies associated with improved pain, depression and disability in those with disabling chronic pain, *European Journal of Pain,* 16(1) 93-104

Nnoaham, K.E., Hummelshoj, L., Webster, P., d'Hooghe, T., de Cicco Nardone, C., Jenkinson, C., Kennedy, S.H. and Zondervan, K.T. (2011) 'Impact of endometriosis on quality of life and work productivity: a multicentre study across ten countries'. *Fertility and Sterility,* Vol 96(2), 366-373

O'Brien, B.C., Harris, I.B., Beckman, T.J., Reed, D.A. and Cook, D.A. (2014) Standards for reporting qualitative research: a synthesis of recommendations, *Academic Medicine,* Vol 89, No.

O'Hara, R., Rowe, H and Fisher, J. (2019) Self-management in condition-specific health: A systematic review of the evidence among women diagnosed with endometriosis, *BMC Women's Health,* 19:80

Pearce, G., Thogersen-Ntoumani, C., Duda, J.L. and McKenna, J. (2014) 'Changing Bodies: Experiences of Women Who Have Undergone a Surgically Induced Menopause'. *Qualitative Health Research,* Vol 24(6) 738-748

Peplau, L.A. and Conrad, E. (1989) Beyond non-sexist research. The perils of feminist methods in psychology. *Psychology*, *of Women Quarterly,* 13, 379-400

Petrelluzzi, K.F.S., Garcia, M.C., Petta, C.A., Ribeiro, D.A., de Oliveira Monteiro, N.R., Céspedes, I., C. and Spadari, R.C. (2012) 'Physical therapy and psychological intervention normalise cortisol levels and improve vitality in women with endometriosis', *Journal of Psychosomatic Obstetrics & Gynecology,* 1-8

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P. and Rousseau, M.C. (2011) 'Proposal: A mixed methods appraisal tool for systematic mixed studies reviews'. *Retrieved on 19th April 2017 from* http://mixedmethodsappraisaltoolpublic.pbworks.com

Pryma, J. (2017) "Even my sister says I'm acting like a crazy woman to get a check": Race, gender and moral boundary – work in women's claims of disabling chronic pain. *Social Science and Medicine,* 181, 66-73

Reid, C. (2004) Advancing women's social justice agenda: A feminist action research framework, *International Journal of Qualitative Methods, 3(3)*

Rimke, H.M. (2000) 'Governing citizens through self-help literature'. *Cultural Studies,* 14(1) 61-78

Riva, S., Camerini, A.L., Allam, A. and Schulz, P.J. (2014) Interactive sections of an internet based intervention increase empowerment of chronic back pain patients: Randomised Controlled Trial, *Journal of Medical Internet Research,* 16(8)

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. and Herrera, D. (2014) 'Recurrence of endometriosis after hysterectomy'. *Facts, Views and Vision in ObGyn,* 6(4), 219-227

Robb, A and Mahmood, T. (2013) 'Medical and Surgical Management of Chronic Pelvic Pain'. *Obstetrics, Gynaecology and Reproductive Medicine,* 24:1

Robinson, M.E. and Wise, E.A. (2003) Gender bias in the observation of experimental pain, *Pain,* 104, 259-264

Rod, K. (2016) Finding ways to lift barriers to care for chronic pain patients: outcomes of using internet-based self-management activities to reduce pain and improve quality of life, *Pain Research and Management,* Vol 2016.

Rogers, P.A.W., D'Hooghe, T.M., Fazleabas, A., Corbett, C.E., Giudice, L.C., Montgomery, G.W., Rombauts, L., Salamonsen, L.A. and Zondervan, K.T. (2009) Priorities for endometriosis research: Recommendation from an international consensus workshops, *Reproductive Science,* 16(4), 335-46

Rogers, P.A.W. and Weston, G.C. (2012). 'Eye to the Future: Research, Diagnostics, and Therapeutics'. In L.C., Guidice, J.L.H, Evers and D.L. Healy, (Eds.), *Endometriosis: Science and Practice* (533-547). Chichester: Blackwell Publishing Ltd.

Roomaney, R. and Kagee, A. (2016) Salient aspects of quality of life among women diagnosed with endometriosis: A qualitative study, *Journal of Health Psychology, Vol 23(7) 905-016*

Rousseau, N., Turner, K.M., Duncan, E., O'Cathain, A., Croot, L., Yardley, L. and Hoddinott, P. (2019) Attending to design when developing complex health interventions: A qualitative interview study with intervention developers and associated stakeholders, *PLOS ONE,* 14(10)

Royal College of Obstetricians and Gynaecologists. The Initial Management of Chronic Pelvic Pain (Green-Top Guideline No. 41). London. Royal College of Obstetricians and Gynaecologists, 2012

Royal College of Obstetricians and Gynaecologists (2018) Patient Information: Endometriosis (Accessed March 2020). https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/gynaecology/pi-endometriosis.pdf

Samulowitz, A., Gremyr, I., Eriksson, E. and Hensing, G. (2018) "Brave Men" and "Emotional Women": A theory-guided literature review on. Gender bias in health care and gendered norms towards patients with chronic pain, *Pain Research and Management*

Sampson, H., Bloor, M. and Fincham, B. (2008) A price worth paying?: Considering the 'cost of reflective research methods and the influence of feminist ways of 'doing'. *Sociology,* Vol 42(5) 919-933

Scotland, J. (2012) Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretative and critical research paradigms, *English Language Teaching, Vol. 5, No. 9*

Schäfer, G., Prkachin, K.M., Kaseweter, K.A. and de C Williams, A.C. (2016), Health care providers' judgments in chronic pain : the influence of gender and trustworthiness, *Pain,* 157, 1618-1625

Schulz, K.F., Altman, D.G. and Moher, D. (2010) CONSORT Group, CONSORT 2010 statement: Updated guidelines for reporting parallel group randomised trials, *PLoS Med.*

Shaffer, R. (1983) Beyond the dispensary. Nairobi: The African Medical and Research Foundation

Sheldon, J. (2017) Problematising reflexivity, validity and disclosure: Research by people with disabilities about disability, *The Qualitative Report,* 22(4)

Shoebottom, A. and Coulson, N.S. (2016) Therapeutic affordances of online support group use in women with endometriosis, *Journal of Medical Internet Research,* Vol. 18(5)

Shuang-Zheng, J., Jin-Hua, L., Jing-Hau, S., Peng-Ran, S. and Jing-He, L. (2012) 'Health-Related Quality of Life in Women with endometriosis: A systematic review'. *Journal of Ovarian Research,* 5:29

Seear, K. (2009) 'The etiquette of endometriosis: stigmatisation, menstrual concealment and the diagnostic delay'. *Social Science and Medicine,* 69, 1220-1227

Seear K. (2009b) 'The third shift: health, work and expertise among women with endometriosis'. *Health Sociology Review*, 2, 194–206

Shrestha, A., Shrestha, R., Sedhai, L.B. and Pandit, U. (2012) 'Adenomyosis at Hysterectomy: Prevalence, Patient Characteristics, Clinical Profile and Histopathological Findings'. *Kathmandu University Medical Journal,* Vol 10 No. 1 53-56

Simoens, S., Dunselman, G., Dirksen, C., Hummelshoj, L., Bokor, A., Brandes, I., Brodszky, V., Canis, M., Colombo, G.C., DeLeire, T., Falcone, T., Graham, B., Halis, G., Horne, A., Kani, O., Kjer, J.J., Krietensen, J., Lebovic, D., Mueller, M., Vigano, P., Wullschleger, M., D'Hooghe, T. (2012) The burden of endometriosis: Costs and quality of life of women with endometriosis and treated in referral centres. *Human Reproduction,* 27(1), 1292-1299

Smith, S.K., MacDermott, K., Amarasekara, S., Pan, W., Mayer, D. and Hockenberry, M. (2018) Reimagine: a randomised controlled trial of an online symptoms self-management curriculum mong breast cancer survivors, *Supportive Care in Cancer*

Spiegel, M.R., Schiller, J.J., Srinivasan, R.A., Spiegel, M.R.S. and LeVan, M. Probability and statistics: based on Schaum's Outline of probability and statistics. New York, N.Y.; London: McGraw-Hill; 2001.

Teixeira, M.Z., Podgaec, S. and Baracat, E.C. (2017) 'Potentised estrogen in homeopathic treatment of endometriosis-associated pelvic pain: A 24-week, randomised, double-blind, placebo-controlled study', *European Journal of Obstetrics & Gynaecology and Reproductive Biology,* 211, 48-55

Thompson, J. and Blake, D. (2020) Women's experiences of medical miss-diagnosis: How does gender matter in healthcare settings. *Women's Studies Journal,* 34(1/2), 22-36

Tickle-Degnan, L. (2013) Nuts and bolts of conducting feasibility studies. *The American Journal of Occupational Therapy,* 67(2) 171-176

Till, S.R., Wahl, H.N. and As-Sanie, S. (2017) The role of non-pharmacological therapies in management of chronic pelvic pain: what to do when surgery fails, *Current Opinion Obstetric and Gynecology,* 29, 000-000

Toivonen, K., Zernicke, K. and Carlson, L.E. (2017) Web-based mindfulness interventions for people with physical health conditions: Systematic review, 19(8)

Trappenburg, J., Jaasma, T., van Os-Medendorp, H., Kort, H., de Wit, N. and Schuurmans, M. (2013) Self-management: One size does not fit all. *Patient Education and Counseling,* 92, 134-137

Tsui, K.M., Lee, W.L., Chen, C.Y., Sheu, B.C., Yen, M.S., Chang, T.C and Wang, P.H. (2014) 'Medical treatment for adenomyosis and or adenomyoma'. *Taiwanese Journal of Obstetrics and Gynecologists,* 53, 459-465

Turner, A., Bourne, C., Martin, F., Jessthan, J., McHattie, D., Surendranath, S. and Cooper, L. (2012) HOPE: A positive psychological group self-management support programme for cancer survivors, *Psycho-oncolcogy,* 21

Van Dam, N.T., Van Vugt, M.K., Vago, D.R., Schmalzl, L., Saron, C.D., Olendzki, A., Meissner, T., Lazar, S.W., Kerr, C.E., Gorchor, J., Fox, K.C.R., Field, B.A., Britton, W.B., Bretezynski-Lewis, J.A. and Meyer, D.E. (2018) Mind the hype: a critical evaluation and prescriptive agenda for research on mindfulness and meditation, *Perspectives on Psychological Science,* Vol 13(1) 36-41

Van Niekeik, L., Weaver-Pirie, B. and Matthewson, M. (2019) 'Psychological interventions for endometriosis-related symptoms: A systematic review with narrative data synthesis', *Archives of Women's Mental Health,* 22: 723-735

Vrekoussis, T., Siafaka, V., Tsitou, A., Tsonis, O., Navrozoglou, I, Makrigiannakis, A. and Paschopoulos, M. (2020) Endometriosis-related chronic pelvic pain: a mini review on pathophysiology and impact on mental health, *Journal of Endometriosis and Pelvic Pain Disorders,*

Wallace, D.A. and Dhingra, L.K. (2014) A systematic review of smartphone applications for chronic pain available for download in the United States, *Journal of Opioid Management*, 10 63-68

Wang, C. (1999) Photovoice: a participatory action research strategy applied to women's health. *Journal of Women's Health,* 8(2), 185-192

Wang, C. and Burris, M. (1997) Photovoice: concept, methodology and use for participatory needs assessment. *Health Education & Behaviour,* 24(3), 369-387

Ware, J.E., Snow, K.K., Kosinski, M., and Gandek, B. (1993) SF-36 Health survey and interpretation guide, Boston: MA, New England Medical Center, The Health Institute.

Wayne, P.M., Kerr, C.E., Schnyer, R.N., Legedza, A.T.R., Savetsky-German, J., Shields, M.H., Buring, J.E., Davis, R.B., Conboy, A., Highfield, E., Parton, B., Thomas, P. and Laufer, M.R. (2008) 'Japanese-style acupuncture for endometriosis-related pelvic pain in adolescents and young women: Results of a randomised sham-controlled trial, *Journal of Pediatric and Adolescent Gynecology,* 21, 247-257

Wheeler, K.J. and Early, J.O. (2018) Using photovoice to explore quality of life factors of adults with crouzon syndrome. *Qualitative Health Research,* 28(3), 357-370

Whelan, E. (1997) 'Staging and profiling: the constitution of the endometriotic subject in gynecological discourse'. *Alternate Routes*, 14, 45–68

Whelan, E. (2003) 'Putting pain to paper: endometriosis and the documentation of suffering'. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 7, 4, 463–82.

Whelan E. (2007) 'No one agrees except for those of us who have it': endometriosis patients as an epistemological community'. *Sociology of Health and Illness* 29(7), 957–982.
White, R.G. and Van Der Boor, C. (2020) Impact of the COVID-19 pandemic and initial period of adults on the mental health and wellbeing of adults in the UK *British Journal of Psychiatry open,* 6(5)

Wiersma, E.C. (2011) Using photovoice with people with early-stage Alzheimer's disease: A discussion of methodology. *Dementia,* 10(2), 203-216

Williams, S., Sheffield, D. and Knibb, R.C. (2016) A snapshot of the lives of women with polycystic ovary syndrome: A photovoice investigation. *Journal of Health Psychology,* 21(6), 1170-1182

Wilson, M., Roll, J.M., Corbett, C. and Barbosa-Leiker (2015) Empowering patients with persistent pain using a n internet based self-management program, *Pain management Nursing,* 16(4) 503-14

Wong, S.Y.S, Chan, J.Y.C., Zhang, D., Lee, E.K.P. and Tsoi, K.K.F (2018) The safety of mindfulness-based interventions: a systematic review of randomised controlled trials, *Mindfulness,* 9: 1344-1357

Young, K., Fisher, J., and Kirkman, M. (2018) "Do mad people get endo or does endo make you mad?": Clinicians discursive constructions of medicine and women with endometriosis, *Feminism and Psychology,* 29(3)

Young, K., Fisher, J. and Kirkman, M. (2020) Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis, *Feminism and Psychology,* Vol 30, Issue 1, 22-41

Appendices

Appendix I – Systematic Review Search Strategy

Medline Search Strategy 12th July 2017

CONDITION/SYMPTOMS

S1	AB (MM "Endometriosis") OR (MH infertility+") OR (MM "Adenomyosis")	73985
S2	AB (MH "Chronic Pain") OR (MH "Abdominal Pain+") OR (MM "Pelvic Pain+")	38975
S3	TX "persistent pelvic pain"	56
S4	TX "severe pain"	9701
S5	TX "debilitating pain"	300
S6	TX "non-cyclic pain"	32
S7	TX "painful intercourse"	110
S8	TX "pain during intercourse"	168
S9	TX dyspareunia	4028
S10	TX "heavy periods"	82
S11	TX "prolonged periods"	5708
S12	TX "irregular periods"	120
S13	TX menorrhagia	5406
S14	TX "painful urination"	57
S15	TX "pain when urinating"	5
S16	TX dysuria	3762
S17	TX "painful bowel movements"	24
S18	TX dyschezia	237
S19	TX "excessive bleeding"	1585
S20	TX menometrorrhagia	1
S21	TX fibroid*	5432
S22	TX cyst*	440834
S23	TX fatigue	86988
S24	TX depression and anxiety	76575
S25	TX anaemia	29648
S26	TX adhesion*	248234
S27	TX lesion*	239091
S28	TX "recurrent disease"	12014
S29	TX "difficulty conceiving"	49
S30	TX subfertility	2884
S31	TX sub-fertility	161
S32	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31	1693500

QUALITY OF LIFE

S33	AB "Quality of Life"	198330
S34	AB "Health-Related Quality of Life"	30109
S35	AB quality of life inventory	7375
S36	AB quality of life scale	31835
S37	AB quality of life questionnaire	40057
S38	AB wellbeing or well-being or well being or quality of life or wellness or health or positive affect or mental health	1478751

S39	AB emotional well-being or psychological well-being	17396
S40	AB physical well-being or wellbeing	21052
S41	AB material well-being or wellbeing	9468
S42	AB development and activity	199900
S43	AB activities of daily living	8
S44	TX “Short Form Health Survey”	4292
S45	TX EQ-5D	5503
S46	TX “interpersonal relationships”	3032
S47	(MM Resilience, Psychological	2049
S48	(MH “Catastrophization”) OR (MH “Attitude to Health”) or (MH “Attitude to Health”) or (MH “Attitude” or (MH “Behavior, Behavior Mechanisms”) or (MH “Anxiety”)	279578
S49	AB body image or self-esteem or self-image or body dissatisfaction	39955
S50	“sex life”	1104
S51	TX work attendance	1878
S52	TX “work commitment”	73
S53	(MH “sleep”) or (MH “sleep deprivation”) or (MH “sleep hygiene) or (MH “Stress, Psychological”)	150166
S54	TX “standard of living”	1238
S55	(MH “Health”) or (MH “Occupational Health”) or (MH Holistic Health”) or (MH “Mental Health”) or (MH “leisure activities”) or (MH “recreation”) or (MH “Women’s health”)	123295
S56	(MM “Quality of Life”)	67198
S57	S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56	2093621

	NON-SURGICAL NON-PHARMACOLOGICAL INTERVENTIONS	
S58	AB (MM “Pain Management”) or (MM “Pain Clinics”) or (MH “Disease Management”)	44698
S59	AB (MM “Mindfulness”) or “mindfulness” or (MM Psychophysiology+”)	406146
S60	AB (MM “Acceptance and Commitment Therapy”) or (“acceptance and commitment therapy”	507
S61	AB (MM “Cognitive Therapy+”) or (MM “Psychotherapy+”) or (MM “Behavior Therapy+”)	121375
S62	AB (MM “Counseling+”) or (MH “Distance counselling”)	18978
S63	AB “psychological therapy”	673
S64	(MM “Psychoanalytic Therapy”)	10615
S65	AB (MM “Physical Therapy Modaliteis+”) or (MM Physical Therapy Speciality”)	86414
S66	AB pelvic floor muscle training	696
S67	AB pelvic floor physical therapy	258
S68	AB (MM Self-Help Groups+”) or (MM “Social Support”)	26540
S69	AB “online intervention”	212
S70	AB “online support group”	85
S71	TX peer support groups”	188
S72	TX “infertility counselling” or TX infertility treatment	24209
S73	TX fertility treatment	28524
S74	(MM “Psychotherapy, Group+”)	16260

S75	TX yoga	4047
S76	(MM “Exercise Movement Techniques”) or “Pilates”	4874
S77	MM “Massage”	3339
S78	TX “psychological intervention for pain management”	3
S79	TX “peer counselling”	235
S80	“online support group”	97
S81	S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80	718648
S82	S32 AND S57 AND S81	

Appendix II Data Extraction

Table 3.4 Data Extracted from the Studies.

Study	Measures	Intervention Type
Ahn et al 2009	Endometriosis Health Profile -30 and Paediatric Quality of Life Inventory	Acupuncture

Results provided by authors

Participant characteristics at baseline

Baseline characteristics	Subjects (n=14)
EHP-30	36.7(18.6)
Pediatric QOL Inventory	67.0(12.8)

Univariable analyses: association between treatment/electrodermal measures and clinical outcome

Treatment and electrodermal measures	Endometriosis HRQOL-30	Pediatric QOL
Intervention Treatment Designation (sham as reference)	-19.64 (p<0.0001)	8.47 (p=0.013
Treatment * time	-3.52 (p<0.001)	1.87 (p=0.0003)

Multivariable analyses: adjusted associations between treatment/electrodermal measures and clinical outcome

Dependent variables	Endometriosis HRQOL-30	Pediatric QOL
Treatment designation (acup vs sham)	-19.8 P<0.0001	8.47 (p=0.013
Right-left asymmetry	2.1 P=0.0008	
		1.87 (p=0.0003)
	-3.52 (p<0.001)	

Yin-yang asymmetry		-1.36 P=0.0008

Study	Measures	Intervention Type
Allaire et al 2017	Endometriosis Health Profile – 30	Interdisciplinary Treatment

Secondary outcomes	**N**	**Baseline**	**Follow up**	**P-Value**
Quality of Life EHP-30 pain subscale (0-100%), mean (SD)	268	42% (26%)	29% (25%)	<0.0001
Quality of Life EHP-30 pain subscale >59 (75th centile), n (%)	268	90(34%)	41(15%)	<0.0001

Study	Measures	Intervention Type
Beissner et al 2017 Meissner et al, 2016	SF-12	Combination of psychotherapy and somatosensory stimulation

Outcome	**Intervention (1) Mean (SD) baseline**	**Intervention (2) Mean (SD) baseline**	***p*-value**
SF-12 Physical health	45.6(7.4)	42.5(7.4)	0.110
SF-12 Mental health	42.1(11.4)	40.8(11.2)	0.639

Study	Measures	Intervention Type
De Sousa et al, 2016	Endometriosis Health Profile-30	Acupuncture

Outcome	Intervention (1) Mean (SD) Baseline	Intervention (2) Mean (SD) Baseline	Total (Average)	Intervention (1) Mean (SD) After treatment	Intervention (2) Mean (SD) After treatment	Total (Average)	*p*-value
EHP	71.50(16.31)	66.36(14.65)	68.81(15.49)	31.00(10.21)	56.59(11.89)	44.40(16.97)	0.0008

Outcome	Intervention (1) Mean (SD) baseline	Intervention (2) Mean (SD) baseline	Total (Average)	Intervention (1) Mean (SD) After treatment	Intervention (2) Mean (SD) After treatment	Total (Average)	*p*-value
EHP Work	26.00(19.03)	42.5(7.4)	24.52(20.39)	8.00(8.34)	20.45(18.89)	14.52(15.96)	<0.0001
EHP Relationship with children	39.00(31.10)	18.64(24.36)	28.33(29.29)	8.50(14.61)	15.45(20.17)	12.14(17.88	0.6377
EHP Sexual relationship	66.00(18.75)	58.18(18.93)	61.90(19.03)	22.00(9.51)	50.91(15.09)	37.14(19.29)	<0.001
EHP Relationship with doctors	42.00(18.81)	44.09(16.52)	43.10(17.46)	12:00(15.08)	35.45(15.03	24.29(19.02)	0.0021
EHP Relationship with treatment	49.00(15.86)	45.91(11.82)	47.38(13.80)	4.50(7.59)	37.27(13.86)	21.67(19.99)	<0.001
EHP Infertility	35.00(45.48)	55.91(43.82)	45.95(45.32)	23.50(33.60)	52.73(41.42)	38.81(40.26)	0.5900

Study	Measures	Intervention Type
Flower et al, 2011	Endometriosis Health Profile-30	Chinese Herbal Medicine

Outcome	Intervention (active) Mean (SD) baseline	Intervention (placebo) Mean (SD) baseline	Intervention (active) Adjusted mean at week 16	Intervention (placebo) Adjusted mean at week16	Adjusted mean difference b/n baseline and week 16 (active)	Adjusted mean difference b/n baseline and week 16 (placebo)	Clinical important change >0.5pt change (active)	Clinical important change >0.5pt change (placebo)	Adjusted mean difference b/n groups (95% CI)

EHP-30 Pain			16.4	16.7	-6.43(10.1)	-6.11(10.3)	Y (0.64)	Y (0.59)	-0.32 to -10.3 (9.64)
EHP-30 Control and powerlessness			10.5	12.2	-7.49(5.83)	-5.76(5.99)	Y (1.28)	Y (0.96)	-1.73 to -8.36(4.67)
EHP-30 Emotional well-being			10.2	10.58	-4.49(4.16)	-4.12(4.28)	Y (1.08)	Y (0.96)	-0.37 to -5.15(4.10)
EHP-30 Social Support			6.53	9.84	-4.19(4.52)	-1.48(4.69)	Y (0.93)	N (0.32)	-2.71 to -7.67(2.25)
EHP-30 self-image			5.14	4.95	-2.57(2.79)	-3.03(2.86)	Y (0.92)	Y (1.06)	0.45 to -2.30(3.21)

Study	Measures	Intervention Type
Goncalves et al, 2011	Endometriosis Health Profile-30	Yoga

Outcome	Intervention (yoga) Mean (SD) baseline	Intervention (control) Mean (SD) baseline	Intervention (yoga) Mean (SD) Post	Intervention (control) Mean (SD) Post	Effect group p-value	Effect time p-value
EHP-30 Pain	60.80(15.59)	58.71(15.41)	32.39(21.95)	55.05(21.49)	0.0705	0.0046*
EHP-30 Control and powerlessness	68.90(18.13)	66.67(20.41)	34.44(15.71)	54.17(16.67)	0.1085	0.0006*
EHP-30 Emotional well-being	65.03(21.41)	69.44(24.51)	41.67(15.67)	48.15(29.47)	0.8098	0.0009*
EHP-30 Social Support	66.07(24.62)	59.38(23.16)	45.42(23.32)	56.94(26.78)	0.2036	0.1228
EHP-30 self-image	66.37(26.40)	52.08(32.59)	41.11(25.68)	43.52(33.28)	0.1801	0.0087*
EHP-30 Work	59.06(21.31)	43.75(26.55)	23.13(22.19)	40.00(27.39)	0.0268	0.0027*
EHP-30 Relationship with children	50.00(27.48)	56.25(17.68)	37.50(35.36)	43.75(27.10)	0.5893	0.1093
EHP-30 sexual intercourse	56.88(28.20)	65.56(25.55)	45.00(30.00)	57.14(29.84)	0.7978	0.1362
EHP-30 doctor relationship	25.23(26.43)	19.79(26.36)	26.95(24.76)	23.44(21.33)	0.9917	0.7464
EHP-30 treatment	48.61(19.45)	66.67(31.91)	35.26(28.90)	48.15(20.74)	0.4265	0.0245

EHP-30 infertility	48.03(33.47)	45.54(43.41)	31.25(34.66)	38.75(50.47)	0.2091	0.9891

Study	Measures	Intervention Type
Hansen et al, 2017	Endometriosis Health Profile-30 and Short Form-36	Mindfulness Based Intervention

Outcome	Intervention Mean (SD) baseline	Intervention Mean (SD)12 months follow up	Intervention Mean (SD) 6 years follow up	Difference between 12months and 6 years follow up 95% CI	Difference between 12months and 6 years follow up p-value
EHP-30 Pain	52.53(12.52)	28.18(15.9)	24.55(11.97)	-10.83-18.1	0.583
EHP-30 Control and powerlessness	65.28(18.98)	35.42(22.5)	31.67(14.46)	-12.24-19.74	0.609
EHP-30 Emotional well-being	52.08(16.23)	34.17(19.02)	29.17(16.2)	-8.09-18.09	0.41
EHP-30 Social Support	52.50(25.89)	31.88(20.72)	25.63(14.86)	-10.87-23.37	0.430
EHP-30 self-image	41.67(21.52)	30.00(22.64)	25.00(15.21)	-11.91-21.91	0.52
EHP-30 Work-life	47.86(29.94)	13.75(13.15)	3.75(4.79)	-15.15-35.16	0.29
EHP-30 Relationship with children	46.43(22.49)	12.50(10.09)	5.36(9.83)	-14.84-29.14	0.457
EHP-30 sexual intercourse	66.67(12.82)	59.79(29.12)	58.13(32.40)	-22.85-26.19	0.877

Outcome	Intervention Mean (SD) baseline	Intervention Mean (SD)12 months follow up	Intervention Mean (SD) 6 years follow up	Difference between 12months and 6 years follow up 95% CI	Difference between 12months and 6 years follow up p-value
SF-36 Physical functioning	69.50(14.80)	82.50(12.96)	78.50(16.68)	-12.07-20.01	0.587

SF-36 role-physical	15.00(21.08)	50.00(39.09)	60.00(35.75)	-45.97-25.97	0.545
SF-36 bodily pain	31.30(14.39)	57.80(12.52)	59.10(24.96)	-22.82-20.22	0.894
SF-36 general health	36.10(14.08)	55.40(22.25)	56.40(20.35)	-12.45-10.45	0.848
SF-36 vitality	27.50(17.83)	49.00(20.11)	55.50(24.55)	-23.28-10.28	0.404
SF-36 social functioning	47.50(24.86)	70.00(26.48)	83.75(18.68)	-26.00-1.50	0.0032
SF-36 role-emotional	23.33(35.31)	50.00(42.31)	76.67(35.31)	-65.28-11.95	0.153
SF-36 mental health	59.20(22.69)	69.60(9.13)	75.60(9.13)	-18.08-6.08	0.290

Study	Measures	Intervention Type
Kold et al, 2012	Endometriosis Health Profile-30 and Short Form-36	Mindfulness Based Intervention

Outcome	**Intervention Mean (SD) baseline**	**Intervention Mean (SD) post intervention**	**Difference between Pre – post p value**	**Intervention Mean (SD) 6 month follow up**	**Difference between pre and 6 months follow up**	**Intervention Mean (SD) 12 month follow up**	**Difference between pre and 12 month follow up**	**Repeated measures ANOVA**
EHP-30 Pain	52.53(12.52)	33.18(15.46)	0.005	31.59(12.88)	0.001	28.18(16.04)	0.003	3.24(df) 18.06(F) 0.000*p*
EHP-30 Control and powerlessness	65.28(18.98)	37.50(10.58)	0.005	38.33(11.42)	0.009	35.42(22.50	0.003	3.24(df) 18.06(F) 0.00 *p*
EHP-30 Emotional well-being	52.08(16.23)	34.17(15.06)	0.008	29.58(13.81)	0.003	34.17(19.02)	0.010	3.27(df) 16.22(F) 0.000 *p*
EHP-30 Social Support	52.50(25.89)	31.25(15.59)	ns	38.75(17.38)	ns	31.88(20.72)	ns	3.27(df) 4.89(F) 0.008 *p*
EHP-30 self-image	41.67(21.52)	25.83(17.76)	0.027	26.67(21.08)	ns	30.00(22.64)	ns	3.27(df) 2.59 (F) ns

EHP-30 Work-life	47.86(27.36	28.13(26.85)	ns	14.29(10.97)	ns	15.00(11.73)	0.011	3.12(df) 4.15(F) 0.031 *p*
EHP-30 Relationship with children	46.43(22.49)	25.00(19.09)	ns	12.50(14.94)	0.036	12.50(19.09)	ns	3.18(df) 4.15(F) 0.002 *p*
EHP-30 sexual intercourse	66.67(19.69)	56.00(22.58)	ns	56.25(32.49)	ns	62.59(30.62)	ns	3.18(df) 1.28(F) ns
EHP-30 medical professional	33.33(32.99)	28.57(32.25)	-	18.75(33.46)	-	26.79(31.19)	-	N=2 -
EHP-30 treatment	69.44(21.52)	26.67(19.00)	-	41.67(28.26)	-	47.92(24.88)	-	N = 3 -
EHP-30 infertility	21.88(30.94)	15.63(22.10)	-	47.92(46.91)	-	81.25(26.52)	-	N=1 -

Outcome	**Intervention Mean (SD) baseline**	**Intervention Mean (SD) post intervention**	**Difference between Pre – post p value**	**Intervention Mean (SD) 6 month follow up**	**Difference between pre and 6 months follow up P value**	**Intervention Mean (SD) 12 month follow up**	**Difference between pre and 12 month follow up P value**	**Repeated measures ANOVA**
SF-36 Physical functioning	69.34(14.62)	77.00(18.14)	ns	83.50(12.03)	0.082	82.50(12.96)	ns	3.27(df) 3.96(F) 0.018 *p*
SF-36 role-physical	15.00(21.08)	37.50(39.53)	ns	47.50(41.58)	ns	50.00(39.09)	0.040	3.27(df) 3.95(F) 0.019 *p*
SF-36 bodily pain	23.00(27.51)	61.00(8.76)	0.002	64.00(6.99)	0.004	59.00(7.38)	0.007	C1.43, 12.87 (df) 23.18 (F) 0.00 *p*
SF-36 general health	69.20(12.66)	63.40(13.81)	ns	66.33(13.86)	ns	59.40(9.81)	ns	3.24(df) 3.80(F) 0.023 *p*
SF-36 vitality	55.50(4.97)	53.00(7.15)	ns	49.84(9.83)	ns	52.00(10.06)	ns	3.27 (df) 1.37 (F) ns
SF-36 social functioning	60.00(9.86)	47.50(5.27)	0.090	46.25(8.44)	ns	50.00(10.21)	ns	C2.00, 18.04 (df) 5.48 (F) 0.014 *p*
SF-36 role-emotional	23.33(35.31)	76.67(35.31)	0.050	63.33(36.68)	ns	50.00(42.31)	ns	3.27(df) 5.48(F) 0.005 *p*

SF-36 mental health	65.80(8.56)	66.40(3.27)	ns	66.00(9.09)	ns	68.00(10.33)	ns	3.27(df) 0.15(F) ns
SF-36 1 item health transition	3.30(0.48)	2.40(1.07)	ns	1.90(1.07)	ns	1.90(0.74)	0.001	3.24(df) 9.50(F) 0.000 *p*
SF-36 Phys health composite	37.34(2.93)	42.34(4.34)	ns	46.51(6.02)	0.031	45.22(3.52)	0.001	3.24(df) 9.50(F) 0.000 *p*
SF-36 Mental health composite	42.62(4.82	44.89(4.34)	ns	41.68(5.09)	ns	41.11(5.52)	ns	3.24(df) 1.71(F) Ns

Study	Measures	Intervention Type
Mira et al, 2015	Endometriosis Health Profile- 30	TENS

Outcome	**Intervention 1 Mean (SD) baseline**	**Intervention 1 Mean (SD) post**	**p value**	**Intervention 2 Mean (SD) baseline**	**Intervention 2 Mean (SD) post**	**P value**	**G1 x G2 comparative analysis between improvement in score before and after treatment Mann-Whitney test**
EHP-30 Pain	11.60(3.23)	7.46(2.89)	0.01	15.33(4.51)	11.91(5.05)	0.05	0.40
EHP-30 Control and powerlessness	5.91(2.32)	3.35(1.50)	0.001	7.43(1.31)	4.97(2.47)	0.003	0.92
EHP-30 Emotional well-being	6.18(2.02)	4.32(1.62)	0.004	8.05(1.65)	5.67(2.07)	0.002	0.30
EHP-30 Social Support	4.53(1.52)	3.25(1.60)	0.002	4.77(1.28)	4.08(1.68)	0.28	0.84
EHP-30 self-image	2.42(1.56)	1.90(1.06)	0.17	3.42(1.21)	2.83(1.46)	0.5	0.36
EHP-30 core score	30.64(8.75)	20.28(6.38)	0.002	39.00(7.23)	29.47(10.49)	0.01	0.79

EHP-30 Work	2.90(1.50)	1.90(1.11)	0.07	3.35(3.66)	2.63(2.40)	0.43	0.81
EHP-30 intercourse	0.90(0.80)	0.86(0.87)	1.00	0.62(1.22)	0.41(0.92)	1.00	1.00
EHP-30 relationship with children	6.74(2.64)	4.08(2.17)	0.003	7.74(1.29)	5.56(2.87)	0.01	0.47
EHP-30 medical professional	3.01(1.41)	1.86(1.02)	0.01	2.80(1.46)	2.80(1.87)	0.86	0.06
EHP-30 treatment	2.87(1.17)	1.83(1.34)	0.02	2.90(1.04)	1.93(0.82)	0.003	0.55
EHP-30 infertility	0.93(1.73)	1.28(1.74)	0.75	4.77(2.29)	4.08(2.39)	0.153	0.16
EHP-30 modular score	17.34(4.16)	11.81(3.97)	0.002	22.18(4.53)	17.41(5.88)	0.04	0.56
Total Score	47.98(11.18)	32.09(8.65)	0.002	61.18(9.32)	46.88(13.91)	0.01	0.79

Study	Measures	Intervention Type
Petrelluzzi et al, 2012	Short Form-36	Physical therapy and psychological intervention

Outcome	**Intervention Mean (SD) baseline**	**Intervention Mean (SD) post intervention**	**Student's t-test p value**
SF-36 Physical functioning	26(6.5)	38(7.5)	P<0.05
SF-36 role-physical	61(3.7)	62(4.6)	Not sig
SF-36 bodily pain	33(3.9)	37(5.0)	Not sig
SF-36 general health	43(4.0)	47(4.7)	Not sig
SF-36 vitality	30(3.9)	39(4.6)	P<0.05
SF-36 social functioning	45(5.0)	48(5.0)	Not sig
SF-36 role-emotional	33(7.4)	38(8.0)	Not sig

SF-36 mental health	37(4.4)	39(4.3)	Not sig

Study	Measures	Intervention Type
Teixeira et al, 2017	Short Form-36	Homeopathy

Outcome	**Intervention Mean (SD) baseline**	**Intervention Mean (SD) post intervention**		**Placebo Mean (SD) baseline**	**Placebo Mean (SD) post intervention**	
SF-36 Physical functioning	46.3±23.6			54.6±21.9		
SF-36 role-physical	40.2±40.4			22.2±32.8		
SF-36 bodily pain	23.4±15.3	13.71	95% CI – 25.49 to -1.92 p=0.013	28.3±11.6		
SF-36 general health	34.5±14.5			35.9±14.6		
SF-36 vitality	26.5±17.1	13.82	95% CI – 26.38 to -1.27	25.6±12.0		
SF-36 social functioning	32.1±19.9			40.7±15.7		
SF-36 role-emotional	26.1±34.8			25.9±37.4		
SF-36 mental health	30.6±18.5	14.35	95% CI - 27.58 to -1.12 p=0.025	36.9±14.5		

‘Placebo group showed no significant improvement’.

Study	Measures	Intervention Type
Wayne et al, 2008	Endometriosis Health Profile-30 Paediatric Quality of Life Inventory	Japanese style acupuncture

Outcome	**Intervention (1) Mean (SD) Baseline**	**Intervention (2) Mean (SD) Baseline**	**Intervention (1) Mean (SD)**	**Intervention (2) Mean (SD)**	***p*-value**	**Intervention (1) Mean (SD)**	**Intervention (2) Mean (SD)**	***p*-value**

			Difference from baseline to week 4	Difference from baseline to week 4		Difference from baseline to week 8	Difference from baseline to week 8	
EHP	36.5 (20.2)	44.9(16.5)	-17.2(18.3)	4.3(15.0)	0.065	-16.6(24.8)	3.1(13.4)	0.137
P QoL I	65.1(14.4)	61.9(13.0)	6.6(16.0)	-3.5(9.5)	0.137	11.1(19.9)	-3.1(9.7)	0.107
Activity Scale	6.6(2.3)	6.3(2.5)	-3.4(2.5)	-0.5(1.5)	0.029	-2.6(3.2)	-0.8(2.1)	0.272
PSS	1.6(0.7)	1.8 (0.6)	-0.5(0.6)	0.1(0.6)	0.136	-0.4(0.7)	-0.1(0.6)	0.864

Outcome	**Intervention (1) Mean (SD) Difference from baseline to 6 months**	**Intervention (2) Mean (SD) Difference from baseline to 6 months**	***p*-value**
EHP	-17.9(21.9)	3.0(10.8)	0.282
P QoL I	15.1(18.2)	0.2(7.8)	0.147
Activity Scale	-3.6(2.6)	-1.9(3.5)	0.253
PSS	-0.3(0.6)	0.1(0.4)	0.254

Outcome	**Intervention (1) Mean (SD) Baseline**	**Intervention (2) Mean (SD) Baseline**	**Intervention (1) Mean (SD) Difference from baseline to week 4**	**Intervention (2) Mean (SD) Difference from baseline to week 4**	***p*-value**	**Intervention (1) Mean (SD) Difference from baseline to week 8**	**Intervention (2) Mean (SD) Difference from baseline to week 8**	***p*-value**
EHP Pain	36.7(20.3)	44.8(19.4)	-14.6(16.5	7.1(20.1)	0.083	-14.6(19.0)	5.9(19.8)	0.137
EHP Powerlessness/control	46.5(26.8)	55.8(23.4)	25.6(26.0)	2.0(27.1)	0.121	-25.0(35.5)	-3.3(23.2)	0.284
EHP Emotional well-being	25.8(20.7)	39.6(17.4)	-13.0(25.6)	3.3(6.8)	0.179	-12.5(28.0)	6.9(12.8)	0.118
Social Support	36.3(27.1)	50.8(21.2)	-16.7(22.1)	-1.3(12.0)	0.251	-13.2(28.7)	-7.3(10.8)	0.930
Self-image	40.8(34.6)	25.0(28.9)	-23.1(24.6)	6.7(22.4)	0.064	-23.1(43.3)	8.3(16.7)	0.120
P QoL I Physical	74.1(11.4)	74.6(16.7)	-0.7(9.7)	-17.5(8.4)	0.012	0.8(13.4)	-8.3(17.4)	0.137
P QoL I Emotional well-being	63.0(17.8)	60.6(14.7)	7.8(14.4)	-3.0(10.4)	0.220	13.9(23.8)	-8.3(19.9)	0.135
P QoL I Social Support	89.5(13.8)	89.4(12.9)	2.8(11.8)	-5.0(17.7)	0.820	3.3(16.4)	-6.7(15.7)	0.593
P QoL I School	58.3(26.2)	50.4(18.9)	10.0(27.4)	0.0(3.5)	1.000	14.7(37.9)	4.2(10.7)	0.752

Outcome	Intervention (1) Mean (SD) Difference from baseline to 6 months	Intervention (2) Mean (SD) Difference from baseline to 6 months	*p*-value
EHP Pain	15.7(18.3)	7.1(10.9)	0.438
EHP Powerlessness/control	27.2(33.1)	1.0(26.1)	0.226
EHP Emotional well-being	14.4(21.1)	1.7(16.0)	0.381
Social Support	18.1(24.1)	8.8(21.0)	0.417
Self-image	-17.6(41.8)	15.0(21.6)	0.173
P QoL I Physical	4.9(14.0)	-15.0(4.6)	0.013
P QoL I Emotional well-being	21.7(16.4)	6.0(15.6)	0.204
P QoL I Social Support	3.3(16.6)	-11.0(10.2)	0.094
P QoL I School	16.7(22.2)	10.0(10.0	0.725

Appendix III Table 3.5 Study Characteristics

Table 3.5. Characteristics of Papers

Authors, year of publication, country of analysis and participants (if different)	**Study aim/research question**	**Research design and methods**	**Sample**	**Intervention Summary**	**Outcome Measure Used**	**Results**	**Quality Score (MMAT)**	**Bias (Cochrane Collaboration Tool) (low, medium, high)**
Ahn et al. (2009) USA	To determine whether electrodermal measures at Jing-Well acupuncture points, "indicator" points located at the tips of fingers and toes are associated with clinical measures in adolescent women with chronic pelvic pain.	Quantitative Randomised sham-controlled trial.	14 young women with laparoscopically diagnosed endometriosis and chronic pelvic pain. Recruited through hospital/clinic.	Acupuncture	1-10 Pain Scale Endometriosis Health Profile-30 Paediatric Quality of Life Perceived Stress Scale Participant generated list of 3 activities made difficult due to pain Blood tests	Quality of Life was used as a secondary measure. Quality of life scores not fully reported. Based on the univariable analyses, pelvic pain is more commonly associated with electrodermal measures than the other clinical outcome measures. This may stem from components within the various QoL assessments that have indirect relevance to the physiological state of the body. For instance, the control/powerlessness, self-image and social support subscale with the EHP-30 or the social health and school participation subscale within the PQoL may be poorly linked with electrodermal measures and this contributes to fewer univariable associations. However, the fact that these QoL scores were significantly associated with general imbalance variables and not with specific meridian measures denotes the specifically of these imbalance variables to more global/qualitative assessment of health. Limitations – technical limitations of the device. Limited sample size and power.	75%	No clear description of randomisation procedure. No clear description of allocation procedure. No missing outcome data. Treatment protocol available, Small sample size. Other bias low risk in a separate publication. MEDIUM RISK
Allaire et al. (2017) Canada	To describe trends and factors associated with chronic pelvic pain severity over a 1-year prospective cohort at an	Quantitative Prospective 1-year cohort study.	296 women (57% response rate at 1 year, 296/525).304/525	Interdisciplinary treatment	Questionnaire using the Research Electronic Data Capture System Endometriosis Health Profile-30	Quality of life was s secondary outcome measure. Reduction in pain was the primary measure.	75%	No missing outcome data. Protocol not available but not all expected outcomes have been reported.

	interdisciplinary centre, with a focus on the role of comorbidities and controlling for baseline pain, demographic factors and treatment effects.		had endometriosis Recruited through hospital/clinic.		Patient Health Questionnaire-9 General Anxiety Disorder-7 Pain Catastrophising Scale	For the secondary outcomes, there was a significant reduction in the number of subjects with a physician or emergency visit in the last 3 months. Observed improvements in chronic pelvic pain severity, functional quality of life and health care utilisation. Psychological comorbidities also decreased at 1 year and fewer patients met diagnostic criteria for IBS ad painful bladder syndrome. Higher pain catastrophising was the factor at baseline that was associated with chronic pelvic c pain severity at 1 year follow up. Other diagnostic comorbidities were not associated, including endometriosis, depression, anxiety, IBS, PBS and abdominal wall or pelvic floor pain. Strengths include its prospective nature, and its sample size. Even if treatment improves chronic pelvic pain, catastrophising patients may still magnify pain symptoms, thereby resulting in less improvement in patient-reported chronic pelvic pain severity scores. Authors recommend that mental health assessment in women with chronic pelvic pain include catastrophising in addition to depression and anxiety. Patients with high catastrophising may be more likely to be treatment resistant even in an interdisciplinary setting. This study suggests that psychological treatment of catastrophising should be considered as part of the management of chronic pelvic pain, in addition to treatments that directly reduce pain (surgery, hormonal treatment). Such treatments could include cognitive behavioural therapy designed to address catastrophising, mindfulness-based stress reduction or strategies to improve sleep.		Appears to be free of other sources of bias. However, no control group. LOW RISK
Beissner et al. (2017) Meissner et al (2016) Germany	To investigate the central nervous system mechanisms of a novel combination of psychotherapy and somatosensory stimulation that exploits the interrelation of bodily sensations and	Quantitative Randomised controlled trial.	67 women with severe endometriosis associated pain with sufficient knowledge of German. Recruited through hospital/clinic.	Integrative psychotherapy combining elements from hypnotherapy, mindfulness-based psychotherapy, cognitive	Maximum pain and average pain assessed retrospectively over the last 4 weeks by means of a numeric scale Hospital Anxiety and Depression Scale State-Trait Anxiety Inventory	Primary outcome measures were focused on brain connectivity and MRI data. Not all post intervention data was available. The authors studied a combination of psychotherapy and somatic stimulation for endometriosis-associated pain using functional brain imaging. This novel approach produces remarkable reductions in pain, anxiety, and depressive symptoms up to complete	50%	No clear description of randomisation not allocation concealment. No missing data. Study protocol not available but all outcomes have been reported. Appears

	painful memories and has recently shown remarkable effects in reducing pain, anxiety and depressive symptoms in patients with endometriosis-associated pain.			behavioural therapy and problem-solving therapy. Also, traditional Chinese medicine.	Short-From Health Survey 12 item MRI Scanner	symptom relief in patients with endometriosis. The authors did not find direct evidence to explain the most striking therapeutic effect, of pain reduction. The identified a cortical network comprising the right anterolateral hippocampus – a region modulating the hypothalamic-pituitary-adrenal axis – and somatosensory, viscerosensory and interoceptive brain regions. Regression analysis showed that reduction in connectivity predicted therapy-induced improvement in patients anxiety.		to be free of other sources of bias MEDIUM RISK
De Sousa et al. (2016) Brazil	To observe the effects of an acupuncture protocol on chronic pelvic pain, dyspareunia and quality of life in women with endometriosis.	Quantitative Randomised clinical trial	42 women waiting to undergo a video laparoscopy at a hospital. Recruited through hospital/clinic.	Intervention – Five sessions of acupuncture using 19 Dong Bang needles. Control Group – same number of needles but needles inserted 3cm from the original points.	Visual Analog Scale Endometriosis Health Profile-30	The authors state that in the study, acupuncture was found to be beneficial for reducing chronic pelvic pain and dyspareunia and increasing quality of life in women with endometriosis High levels of adherence to treatment were observed in both groups. The absence of side effects and maintenance of improvements were observed two months after therapy in the intervention group. The authors state that data from this study demonstrated that improvement in quality of life was associated with a decrease in pain intensity during the five weeks of treatment. However, it is still not possible to confirm whether the reduction in pain led to improved quality of life or the converse. This study showed a greater increase in EHP-30 score for the subscale of relationship with treatment, demonstrating that acupuncture could be a viable new treatment.	100 %	Randomisation was carried out using Clinical Trails Management System software. Allocation sequence was performed by a lab assistant and hidden to the team conducting the project. No missing outcome data. The study protocol is not available bit it is clear that the published reports include all expected outcomes. Appears to be free of other sources of bias. LOW RISK
Flower et al. (2011) UK	To test the feasibility of a novel methodology for investigating individualised decoctions of Chinese Herbal Medicine rigorously and to gather preliminary data on the treatment effect of CHM for a larger definitive trial.	Quantitative Randomised controlled trial	40 women with laparoscopically diagnosed endometriosis. Recruited through adverts in newspaper and internet.	Intervention - 16 weeks of individualised herbal formulations of between 10 – 15 herbs selected from the Chinese Materia Medica, with a daily dosage	Visual Analog Scale Measure your own medical outcomes profile Endometriosis Health Profile – 30 Liver and renal tests	The EHP-30 Both groups showed an improvement in all domains of the EHP-30. With the exception of social support in the placebo group (0.32), all these changes were clinically important (>0.5 point change) while, in the placebo group, this was the case for control, emotional well-being and self-image. Overall, the VAS, MYMOP and EHP-30 outcome measures favoured the active treatment group. There were no serious adverse reactions reported during the trial or any abnormal liver or renal function test results	50%	A computer generated random numbers table was used for both phases of randomisation. Codes for each group allocation were transferred to sealed opaque envelopes. Opened by an employee at the herbal dispensary. Double

				amounting to between 150g and 250g Intervention 2 – placebo herbs Waitlist control group.		in women taking the active CHM. In the EHP-30, four of five domains favoured the active treatment group. This study had many limitations – selection bias, missing data, high dropout rates. The authors also state that the placebo decoction may have had a therapeutic effect.		blinding was maintained by ensuring that the practitioner did not come into contact with participants herbs. High risk of attrition bias. Increasing missing data throughout trial. Inexperience of the practitioner-researcher conducting the trail is blamed for considerable missing data. Also, high dropout rate. Control group discontinued. Study protocol not available. Appears free from other sources of bias. HIGH RISK
Goncalves et al. (2017) Brazil	To compare chronic pelvic pain, menstrual patterns and quality of life in two groups of women with endometriosis: those who did and those who did not participate in a specific 8-week yoga intervention.	Quantitative Randomised controlled trial	40 women Recruited through hospital/clinic.	Yoga intervention. Control Group	Endometriosis Health Profile-30 Visual Analog Scale Diary	The authors state that the QoL EHP-30 questionnaire, in both groups, the scores decreased from the beginning of the yoga program through the duration of the observation. There was a significant difference between the two groups over time in relation to the EHP-30 central questionnaire's domains (pain, control and powerlessness, emotional well-being and self-image) but not in social support. As for the EHP-30 modular questionnaire's domains, work and treatment were significantly different when comparing the two groups over time. In other domains (relationship with own children and sexual intercourse), both groups had lower scores over time. However, these differences were not significant. A positive association was observed between yoga practice and pain relief and QoL in women with endometriosis. The QoL assessed by the eHP-30 and the evaluation of pain within the 8 weeks of treatment was significantly lower among the women who practiced yoga compared with those who did not.	100 %	The randomisation sequence for was computer generated. No missing data. Study protocol is not available, but it is clear that the published reported included all expected outcomes. LOW RISK

						Furthermore, the women in the yoga group improved their QoL in the domains of pain, control and powerlessness, emotional well-being, self-image and social support. In the modular questionnaire, the domains that were significantly lower in the yoga group were work, relationship with own children, treatment and sexual intercourse. Both groups showed a reduction in daily pain rates. However, women in the yoga group showed a significant reduction, probably because they presented with lower stress levels and greater relaxation. Regarding QoL, it was observed that improving one domain might have affected improvement in other domains in the eHP-30. For example, having more control and feeling less powerless might improve self-image and emotional well-being. Additionally, no improvement in QoL scores were observed in either group in two domains: doctor relationship and infertility. The women who practiced yoga may not have considered it a treatment. This study showed that yoga practice was associated with a reduction in levels of chronic pelvic pain and improvement in QoL on women with endometriosis. Limitation – women in yoga group reported more years of schooling. More women I this group were employed outside the home and were more flexible about being able to attend the sessions.		
Hansen et al. (2017) Denmark Follow up from Kold et al (2012)	To evaluate the long-term effects of a mindfulness-based psychological intervention on chronic pain and quality of life in endometriosis when conducting a six-year follow up on a pilot study.	Quantitative 6 year follow up of pilot study.	Ten women from the pilot study.	Mindfulness-based psychological in the intervention had three types of interaction. A mindfulness training (body scan, sensory training, breathing techniques, music and bio-feedback	Endometriosis Health Profile-30 Short Form Health Survey 36 item	Results showed that all significant improvements from the original study 12 months after the intervention remained during the following five years: pain, control and powerlessness, emotional well-being and social support. Also, the modular scales of work life and relationship with children indicated lasting improvement from 12 months follow up to 6 years follow up. All scales improved further during the 12 months to 6 years follow up, but the improvements did not reach statistical significance.	100 %	Not an RCT. No dropouts from original study. All data presented. Study protocol not available. Small sample size, no control group. Lack of standardised pain measure. Missing non-significant data. MEDIUM RISK

				support. A psych-education and group dialogue. An individual session where themes were adapted to the individual clients' personal goals and challenges.		Six years after completing the intervention, 9 out of 10 participants still used the mindfulness techniques and other mental techniques learned during the intervention. 7 of those 9 women experienced benefits from these techniques to a great or very great extent. The body scan and breathing meditation were the most used mindfulness techniques among the women at follow up. This pilot series represents the first data on the potential long term effects of mindfulness-based psychological intervention for chronic pain in endometriosis. With reservation for the weaknesses, the authors state that their results may suggest a lasting positive effect on health -related QoL for women with endometriosis and endometriosis -related pain.		
Kold et al. (2012) Denmark	To investigate if an intervention based on mindfulness techniques for dealing with pain can improve pain levels, well-being and ability to function in daily life for women with endometriosis.	Quantitative Feasibility prospective observational study.	10 women with endometriosis. Recruited through hospital/clinic.	Mindfulness-based psychological intervention. The intervention had three types of interaction. A mindfulness training (body scan, sensory training, breathing techniques, music and bio-feedback support. A psych-education and group dialogue. An individual session where themes were adapted to the individual clients'	Endometriosis Health Profile-30 Short Form Health Survey-36	Prior to intervention, participants scored below national average on all SF-36 scales, and the scales for bodily pain, role-physical and role-emotion were particularly low. Bottom score on the bodily pain scale indicates very strong pain that causes severe difficulties for daily life. Bottom score on the role-physical scale indicates problems with work or other daily activities for physical reasons and bottom score on the role-emotional scale indicates the problems for psychological reasons. Bodily pain significantly and consistently improved from pre-to post-intervention and follow up measures. Improvement was also seen in the scales for physical functioning, role-physical and role-emotional, although with some fluctuation over time. At its best, physical functioning even approached the national average. In the present prospective, observational pilot study, a questionnaire about general health and a questionnaire with focus on the effects of surgical treatment of endometriosis were used to objectively assess the effects of a 15 hour intervention with mindfulness techniques. The results showed a complex pattern, but positive effects on pain level and associated aspects were achieved. These results need	100 %	Not an RCT. No incomplete data. Study protocol not available. Small sample size, no control group, lack of standardised pain measure. MEDIUM RISK

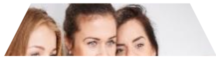
				personal goals and challenges.		confirmation in a RCT study, but some conclusions and suggestions for future research may be justified. In our study, the intervention was mindfulness-based and focused on pain. When effect was measured with the endometriosis specific questionnaire, all five standard scales responded positively, and four of them still indicated improvement at one-year follow up: pain, control and powerlessness, emotional well-being and social support. Only one scale consistently failed to improve – sexual function. The pattern of findings with the general health and well-being questionnaire, points in the same direction. Of the two summary measures, physical health consistently improved, whereas no effect was found for mental health. Four composite scales responded positively, of which three were bodily pain, role-physical and physical functioning. Mental health and vitality showed no effect whereas, unexpectedly, general health and social functioning indicated slightly negative effects., implicating a complex pattern. In summary, the intervention suggested here did, albeit psychological in its form, successfully target physical aspects of the participants problems. Had the origin of their problem been a psychological on or had the effect of the intervention merely been a general psychological effect of being cared about etc. the mental scales of the SF-36 should have improved more than the physical scales. They did not. In conclusion, the present study suggested that use of mindfulness techniques is feasible and might imply positive effects on some aspects of quality of life in patients with chronic pain secondary to endometriosis. Some of these effects might be durable, and our data motivate testing of this principle in randomised controlled studies.		
Mira et al. (2015) Brazil	To evaluate TENS effectiveness as a complementary treatment of chronic pelvic pain and deep dyspareunia in women with deep endometriosis.	Quantitative Randomised controlled trial	22 women with deep endometriosis. Recruited through medical records at hospital/clinic	Acupuncture-like TENNS, frequency 8Hz, pulse duration ~250 us and VIF (variation in intensity and frequency of 1ms). The	Visual Analog Scale Deep Dyspareunia Scale Endometriosis Health Profile – 30	The results demonstrated the effectiveness of acupuncture-like TENS and self-applied TENS as complementary treatment of chronic pelvic pain and deep dyspareunia in women suffering from deep endometriosis with intractable pain, despite the use of hormone therapy. Furthermore, we observed a significant benefit in all considered aspects by the applied questionnaire on quality of life. Both types of TENS were comparable in terms of pain relief and improvement in quality of life.	75%	Randomisation generated by computer program. Allocation concealment – opaque sealed envelopes were used for participants allocation. Performance bias, detection bias not addressed. No missing

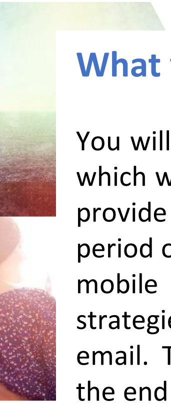
				intensity was adjusted Intervention 2 Self-applied TENS, frequency 85Hz, pulse duration 75us. Intensity was adjustable with 3 options: 10. 20 or 30 mA. Participants were instructed to choose the intensity that was 'strong but comfortable'.		Our study included a small number of women, all with deep endometriosis. In severe cases they had no satisfactory response to hormone therapy and the pain relief caused by TENS determined a relevant outcome. 'Some weaknesses must be cited, such as the follow-up period of these women, sample size and lack of a placebo TENS group serving as control. The positive results obtained regarding such significant complaints justifies further studies to evaluate the use of other electrotherapeutic resources as complementary treatment for endometriosis. In conclusion, TENS was beneficial as a complementary treatment for chronic pelvic pain and deep dyspareunia in women with deep endometriosis with improvement in quality of life. The effectiveness of a non-invasive electrotherapeutic resource in alleviating pelvic pain and improving quality of life justifies its use and prescription.		outcome data. Study protocol not available but all expected outcomes have been published. No other sources of bias. LOW RISK
Petrelluzzi et al. (2012) Brazil	To evaluate the effectives of submitting women with endometriosis and chronic pelvic pain to a therapeutic protocol involving physical and psychological therapy.	Quantitative Observational study	26 women Recruited through hospital/clinic	The treatment consisted of 10 sessions of Physical and psychological therapy (one a week), each session lasted two and a half hours.	Visual Analogy Scale PSQ Salivary cortisol Short Form Health Survey-36	There was no significant difference between the pre and post-treatment SF-36 scores for the following domain: role physical, bodily pain, general health, social functioning, role emotional and mental health. However, there were significant improvements in the vitality and physical functioning domains and vitality. There were no significant correlations between salivary cortisol concentrations and PSI, pain or the SF-36 domains. The data presented here indicate that women with endometriosis and suffering from pain of moderate intensity, present high levels of perceived stress, poor HRQoL and hypercortisolism. Although the proposed treatment alleviated pelvic pain slightly and reduced the PSI significantly, the PSI remained high in comparison with those reported for healthy women, and there was no significant improvement in HRQoL. Nevertheless, there was significant improvement in vitality and physical functioning, together with normalisation of cortisol levels. Moreover, vitality was also positively correlated to role emotional and social functioning and negatively correlated with PSI. The physical therapy and psychological protocol applied in the present study was effective in reducing perceived stress and normalising salivary cortisol levels, as well as improving vitality and physical functioning, although it had only a slight effect on pain	75%	No missing data, small sample size, no control group. LOW RISK

						intensity, probably because in order to alleviate pain a longer treatment is necessary. Therefore, it is concluded that the normalisation of cortisol levels must be considered in any proposed treatment aimed at reducing endometriosis-associated symptoms and improve patients wellbeing.		
Teixeira et al. (2017) Brazil	To evaluate the efficacy and safety of potentizes estrogen compared to placebo in homeopathic treatment of endometriosis-associated pelvic pain.	Quantitative Randomised, double blind, placebo-controlled trial	50 women with DIE Recruited through hospital/clinic	Homeopathy. Potentised estrogen was prepared from 17-beta-estradoil valerate in compliance with the Brazilian Homeopathic Pharmacopeia. Control Group Given vials of hydroalcoholic only. Placebo vials.	Visual Analog Scale Short Form Health Survey 36 item Beck Depression Inventory Beck Anxiety Inventory Electronic questionnaire, physical exam findings, review of medical records.	Adverse event-related withdrawal occurred in only one patient from the potentised estrogen group (spotting). Possible drug-related adverse events occurred in four patients from the potentized estrogen group (nasopharyngitis, leucorrhea and diarrhoea) and 11 patients from the placebo group (headache, nasopharyngitis, canker sores, nausea, stomach pain, leucorrhea, cystitis, constipation, lichen planus and herpes simplex.’ ‘As a function of the need for global treatment of endometriosis, the improvement found in the participants’’ quality of life (SF-36) and depression symptoms (BDI) indicate that potentized estrogen might be beneficial for the treatment of this condition.’ ‘As study limitations, sample size was small and duration of treatment and follow up was short. Another point concerns the inclusion criteria, as they required diagnosis of endometriosis based on imaging methods, namely, TVU after bowel preparation or MRI, which were selected as a function of their high accuracy when performed by experienced radiologists. While the limitations derived from the small sample size might be minimised by replicating the protocol used in larger and /or multicentre studies, the dropout rate (18%) points to the difficulty of keeping patients with severe disease and refractory to treatment in a randomised clinical trial over along period of time. Future observational studies with larger samples and conducted over longer periods of time might consolidate the results found. In addition, imaging methods might also be included in longer lasting studies to quantify the possible reduction of lesions along treatment.’ ‘To conclude, in the present 24-week, randomized, double-blind, placebo-controlled study, potentized estrogen was associated with significant improvement of EAPP, quality of life and depression symptoms among	75%	Incomplete outcome data. Does not report non-significant results of placebo control group. HIGH RISK

						women with endometriosis. Potentized estrogen might represent an effective and well-tolerated complementary treatment for the pain and mental symptoms of endometriosis.’		
Wayne et al. (2008) USA	To assess feasibility and collect preliminary data for a subsequent randomised, sham controlled trail to evaluate Japanese-style acupuncture for reducing chronic pelvic pain and improving quality of life for adolescents with endometriosis.	Quantitative Randomised sham-controlled trial	18 women Recruited through hospital/clinic	A Japanese style of acupuncture. 16 treatments over 8 weeks Sham acupuncture control. 16 treatments over 8 weeks	Endometriosis Health Profile 30 Pediatric Quality of Life Inventory Endometriosis Symptom Severity Scale Perceived Stress Scale Single Question Instrument Blood Test	Preliminary estimates indicate that Japanese-style acupuncture may be an effective, safe3 and well-tolerated adjunct therapy for endometriosis-related pelvic pain in adolescents. A More definitive trial evaluating Japanese-style acupuncture in this population is both feasible and warranted. All HRQoL measures indicated greater improvements in the active acupuncture group compared to the control, however, the majority of these trends were not statistically significant. No serious adverse events were reported. Baseline pain levels in our study population were relatively high. Our results indicate that pain levels declined significantly faster in the active acupuncture group compared to the sham control. Limitations – small sample to due to nature of a pilot study of feasibility. Some of the instruments used to assess outcomes have not been specifically validated in adolescent populations. Nevertheless, our results indicate that Japanese-style acupuncture may be an effective, safe and well-tolerated adjunct therapy for endometriosis-related pelvic pain in adolescents. Further, our findings suggest a more definitive trial evaluating Japanese style acupuncture is both feasible and warranted.	25%	No clear description of randomisation procedure not allocation concealment. Authors state that blinding was not possible. HIGH RISK

Appendix IV Needs Assessment Participant Information Sheet



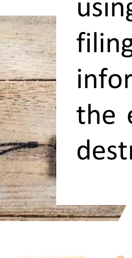



What will happen if I decide to take part?

You will be asked to attend a workshop (2.5 hours) with a small group of others, which will provide you with all of the information about the research process and provide an opportunity to ask any questions you may have. There will then be a period of five weeks where you will be asked to take photographs, using your own mobile phone, of what you consider shows your psychological needs or coping strategies. Each week you will be asked to send five photographs, with captions, by email. This will be done using a password protected Microsoft Word document. At the end of the five weeks you will be asked to attend a second workshop (6 hours) to discuss all the photographs and captions and organise them into groups/themes with the others in the group. Participants will also get to decide how the final outcome will be displayed. The final outcome may be made public in the form of presentations, journal outcomes or other academic material. Participants will be asked to sign a final consent form to say that they are happen for this to happen. Workshops will be scheduled on Saturday's.

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. All electronic data will be stored on a password protected computer file using SharePoint at Coventry University. All paper records will be stored in a locked filing cabinet in Richard Crossman building, Coventry University. Your consent information will be kept separately from your response in order to minimise risk in the event of a data breach. The lead researcher will take responsibility for data destruction and all collected data will be destroyed on or before 31st January 2021.



Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection and data portability. For more details, including the right to lodge a complaint with the information Commissioner's Office, please visit www.ico.org.uk . Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer – enquiry.ipu@coventry.ac.uk

What will happen with the result of this study?

The results of this study may be summarised in published articles, reports and presentation. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Making a Complaint

Content removed on data protection grounds

PHOTOVOICE: A Needs Assessment of those living with Endometriosis and/or Adenomyosis

PARTICIPANT INFORMATION SHEET

What is the purpose of the study?

The aim of this study is to gain insight into the psychological needs, especially the unmet needs of those living with endometriosis and/or adenomyosis. This will be achieved by using Photovoice, a creative research method that using photography to capture the psychological needs and coping strategies of participants from their perspective by asking them to take photographs and adding captions to them. Participants will attend two workshops, one which explains the process and the second one, where participants will analyse and organise the photographs and captions collected. Participants will also have input into the final presentation of the images. Participants will use their own mobile phones to take photographs. Participants may take photographs of themselves or others in their lives, these images may be included in public material such as websites, social media, films and infographics.’

What is my role in this study?

You have responded to an advert to take part in this study and have been invited to participant because you are aged over 18, have endometriosis/adenomyosis, have a mobile phone that can take photographs and access to a computer/laptop.

What are the benefits of taking part?

By sharing your experiences with us, you will be helping researchers at Coventry University to have a better understanding of the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis.

Are there any risks associated with taking part?

This study has been reviewed and approved through Coventry University’s formal research ethics procedure. There are no significant risks associated with participation.

Do I have to agree?

No, it is entirely up to you. If you do decide to be in a photograph and allow it to be used in the study, please keep this information and complete the Consent Form to show that you understand your rights in relation to the research, and that you are happy to have your image included. Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to with draw from the study at a later date. You are free to withdraw your information from the project data set at any time (until INSERT DATE). You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. To withdraw, please contact the lead researcher (details are provided in this document). Please also contact the Research Support Office: ethics.hls@coventry.ac.uk so that your request can be dealt with promptly in the event of the lead researcher’s absence. You do not need to give a reason. A decision to withdraw, or not, will not affect you in any way.

Appendix V Needs Assessment Recruitment Advert

PHOTOVOICE: A needs assessment for those with endometriosis/adenomyosis

RESEARCH PARTICIPANTS NEEDED!

Research has shown that endometriosis and adenomyosis have a negative impact on quality of life.
Living with chronic pain comes with a lot of difficulties, including an impact on mental health.
At Coventry University we want to understand the psychological, emotional and mental health needs of those living with endometriosis and/ or adenomyosis. We also want to understand what coping strategies you use that could help others. We want to use photography to make the invisible visible.

We are looking for voluntary participants who:

- **Are aged 18 or over**
- **Have endometriosis/adenomyosis**
- **Have a mobile phone capable of taking photographs**
- **Interested in taking part in a creative research method involving photography**
- **Can attend two workshops in Coventry city centre (1X 2.5 hours weekday evening 1x 6 hours Saturday)**
- **Would like to meet and work with others with the same condition**

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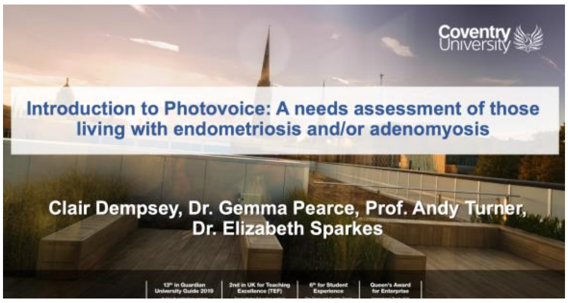
Coventry University

PLEASE NOTE THAT TRAVEL EXPENSES CAN NOT BE REINBURSED

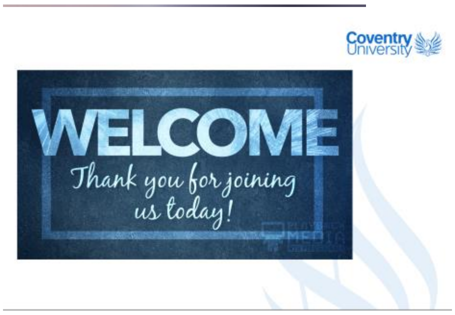
Appendix VI Workshop 1 Presentation



Introduction to Photovoice: A needs assessment of those living with endometriosis and/or adenomyosis

Clair Dempsey, Dr. Gemma Pearce, Prof. Andy Turner, Dr. Elizabeth Sparkes

13th in Guardian University Guide 2019 | 2nd in UK for Teaching Excellence (TEF) | 6th for Student Experience | Queen's Award for Enterprise

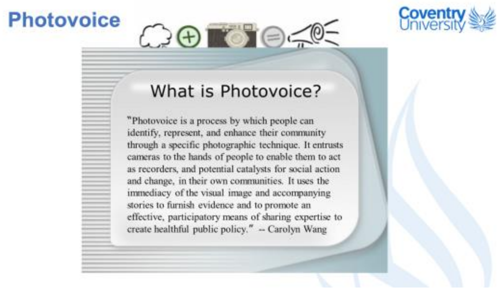


WELCOME

Thank you for joining us today!

Introduction

- Housekeeping – toilets, break time etc
- Introduce ourselves – why are we here?
- What's in your Photovoice Pack?



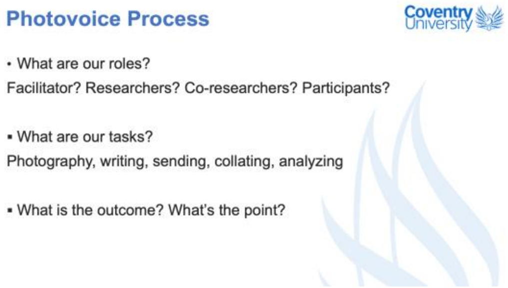
Photovoice

What is Photovoice?

"Photovoice is a process by which people can identify, represent, and enhance their community through a specific photographic technique. It entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for social action and change, in their own communities. It uses the immediacy of the visual image and accompanying stories to furnish evidence and to promote an effective, participatory means of sharing expertise to create healthful public policy." -- Carolyn Wang

Examples of Photovoice

Examples of Photovoice



Photovoice Process

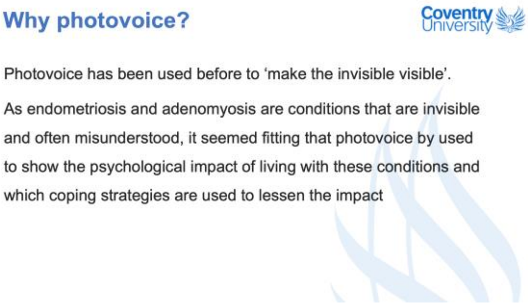
- What are our roles?

Facilitator? Researchers? Co-researchers? Participants?

- What are our tasks?

Photography, writing, sending, collating, analyzing

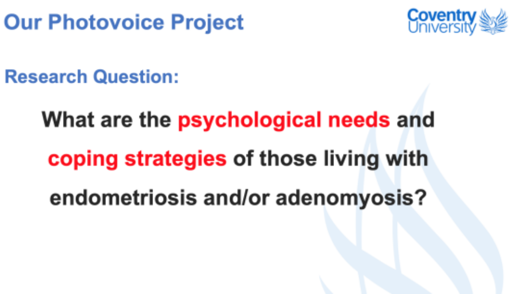
- What is the outcome? What's the point?



Why photovoice?

Photovoice has been used before to 'make the invisible visible'.

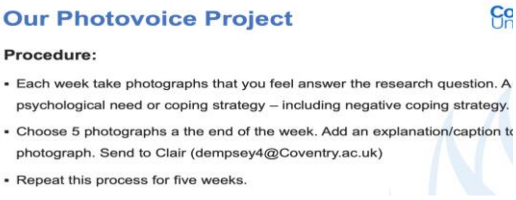
As endometriosis and adenomyosis are conditions that are invisible and often misunderstood, it seemed fitting that photovoice by used to show the psychological impact of living with these conditions and which coping strategies are used to lessen the impact



Our Photovoice Project

Research Question:

What are the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis?



Our Photovoice Project

Procedure:

- Each week take photographs that you feel answer the research question. A psychological need or coping strategy – including negative coping strategy.
- Choose 5 photographs a the end of the week. Add an explanation/caption t photograph. Send to Clair (dempsey4@Coventry.ac.uk)
- Repeat this process for five weeks.

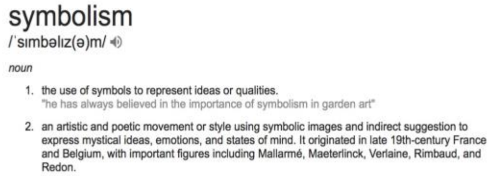
Important Points

INFORMED Consent

- **1st Consent Form – signed prior to this workshop**
- **2nd Consent Form – signed by anyone over the age of 18 that you take a photograph of. Photographs of others will not be included without signed consent forms. No photographs of children.**
- **3rd Consent Form – signed once photography is complete to say you are happy with the inclusion of your photographs and captions in the project. These image/captions may be used in future presentations and published in journal articles.**

Photography

Symbolism in photography:



symbolism
/ˈsɪmbəlɪz(ə)m/

noun

1. the use of symbols to represent ideas or qualities.
   "he has always believed in the importance of symbolism in garden art"
2. an artistic and poetic movement or style using symbolic images and indirect suggestion to express mystical ideas, emotions, and states of mind. It originated in late 19th-century France and Belgium, with important figures including Mallarmé, Maeterlinck, Verlaine, Rimbaud, and Redon.

Photography

Fatigue

Anxiety

Pain

Marriage/relationship

Photography

Technical Information

Photographs will be sent by email and will be password protected for security.

It is important that photographs and captions are matched correctly. Numbering and descriptions will need to be used.

Are you familiar with sending photographs by email from your phone?

Practice run through using photo from break

Q & A

Workshop 2

What needs to be done before the next workshop?

- Take photographs of your psychological needs or coping strategies. Can you identify some?
- Prompt email will be sent each 7 day period asking for 5 photographs and captions. These will be saved securely and collated by participant ID number.
- Think about final presentation. What form should it take? If it's an event, who should be invited?

Any concerns/questions?

If you have any problems, concerns or questions please contact me:
Clair Dempsey dempsey4@Coventry.ac.uk

If you need more consent forms or information sheets please send an email.

If at point you don't want to continue taking part in the photovoice project you don't need to give a reason why. Any images saved will be destroyed and not included in final presentation.

Workshop 2

Date of the next workshop is: xx/xx/2019

Coventry University

Thank you

13th in Guardian University Guide 2019

2nd in UK for Teaching Excellence (TEF)

6th for Student Experience

Queen's Award for Enterprise

Appendix VII Workshop 2 Presentation

Coventry University

Photovoice

Workshop 2

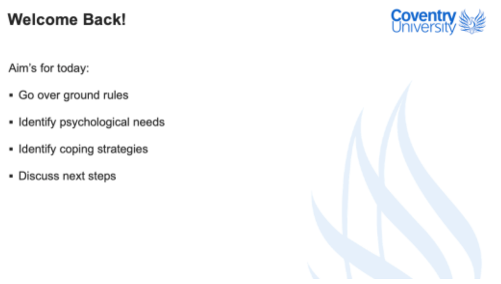
28th July 2019

13th in Guardian University Guide 2019

2nd in UK for Teaching Excellence (TEF)

6th for Student Experience

Queen's Award for Enterprise



Welcome Back!

Coventry University

Aim's for today:

- Go over ground rules
- Identify psychological needs
- Identify coping strategies
- Discuss next steps

Ground Rules

Coventry University

- Confidentiality
- Show respect and compassion for others
- Listen to others
- Try to refer to photos using their numbers
- Make use of stickers – **gold** to include in exhibition, **red** if you decide a photo is too sensitive or person to be publically displayed.
- Feel free to remove any photo/caption you feel uncomfortable about sharing

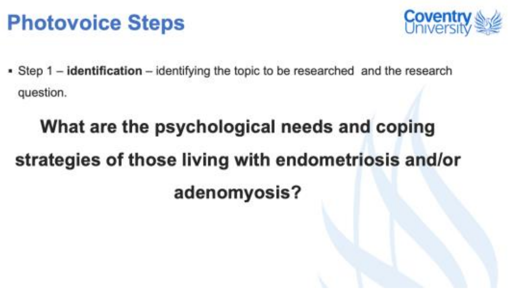
Photovoice

Coventry University

A form of participatory action research. Different from conventional research in 3 ways: shared ownership of research, community-orientated understanding of social problems and propensity for community action (Kemmis and Taggart, 2005)

Photovoice is a process by which people can identify, represent and enhance their community through a specific photographic technique' (Wang and Burris, 1997).

How did it feel being co-researchers in this photovoice study?



Photovoice Steps

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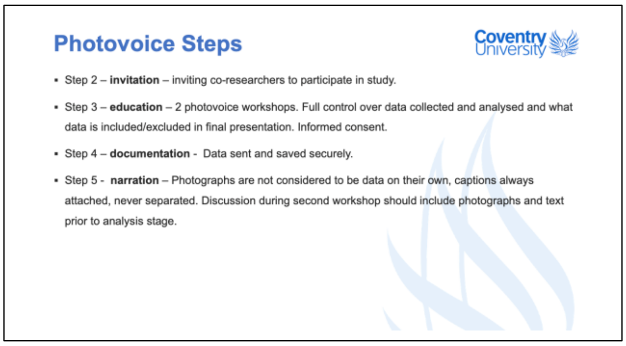
- Step 1 – **identification** – identifying the topic to be researched and the research question.

What are the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis?



Photovoice Steps

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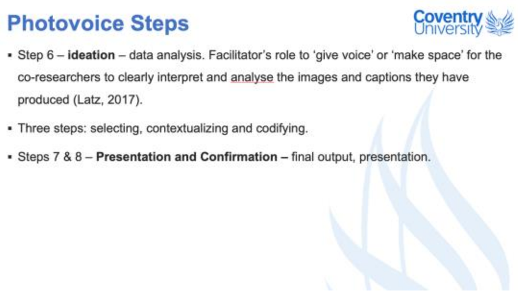
- Step 2 – **invitation** – inviting co-researchers to participate in study.
- Step 3 – **education** – 2 photovoice workshops. Full control over data collected and analysed and what data is included/excluded in final presentation. Informed consent.
- Step 4 – **documentation** - Data sent and saved securely.
- Step 5 - **narration** – Photographs are not considered to be data on their own, captions always attached, never separated. Discussion during second workshop should include photographs and text prior to analysis stage.



Photovoice Steps

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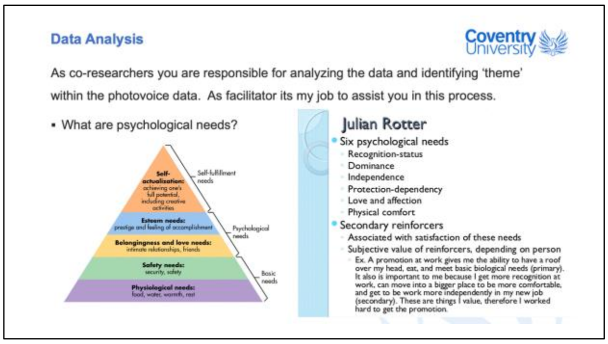
- Step 6 – **ideation** – data analysis. Facilitator's role to 'give voice' or 'make space' for the co-researchers to clearly interpret and analyse the images and captions they have produced (Latz, 2017).
- Three steps: selecting, contextualizing and codifying.
- Steps 7 & 8 – **Presentation and Confirmation –** final output, presentation.



Data Analysis

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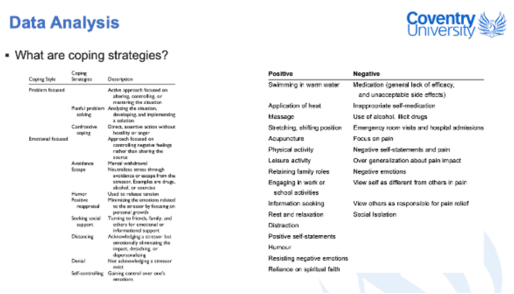
As co-researchers you are responsible for analyzing the data and identifying 'theme' within the photovoice data. As facilitator its my job to assist you in this process.

- What are psychological needs?

Julian Rotter

- Six psychological needs
  - Recognition-status
  - Dominance
  - Independence
  - Protection-dependency
  - Love and affection
  - Physical comfort
- Secondary reinforcers
  - Associated with satisfaction of these needs
  - Subjective value of reinforcers, depending on person
    - Ex. A promotion at work gives me the ability to have a roof over my head, eat, and meet basic biological needs (primary). It also is important to me because I get more recognition at work, can move into a bigger place to be more comfortable, and get to be work more independently in my new job (secondary). These are things I value, therefore I worked hard to get the promotion.

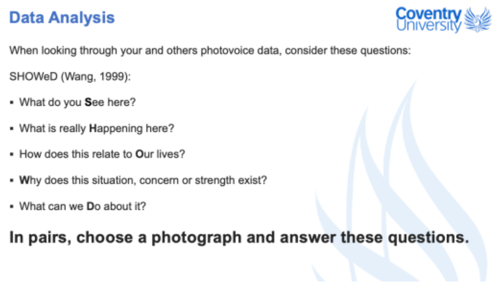


Data Analysis

- What are coping strategies?

Coping Style	Coping Strategies	Description
Problem focused		Active approach focused on altering, controlling, or mastering the situation
	Planful problem solving	Analyzing the situation, developing, and implementing a solution
	Confrontive coping	Direct, assertive action without hostility or anger
Emotional focused		Approach focused on controlling negative feelings rather than altering the source
	Avoidance	Mental withdrawal
	Escape	Neutralizes stress through avoidance or escape from the stressor. Examples are drugs, alcohol, or exercise
	Humor	Used to release tension
	Positive reappraisal	Minimizing the emotions related to the stressor by focusing on personal growth
	Seeking social support	Turning to friends, family, and others for emotional or informational support
	Distancing	Acknowledging a stressor but emotionally eliminating the impact, detaching, or depersonalizing
	Denial	Not acknowledging a stressor exist
	Self-controlling	Gaining control over one's emotions

Positive	Negative
Swimming in warm water	Medication (general lack of efficacy, and unacceptable side effects)
Application of heat	Inappropriate self-medication
Massage	Use of alcohol, illicit drugs
Stretching, shifting position	Emergency room visits and hospital admissions
Acupuncture	Focus on pain
Physical activity	Negative self-statements and pain
Leisure activity	Over generalization about pain impact
Retaining family roles	Negative emotions
Engaging in work or school activities	View self as different from others in pain
Information seeking	View others as responsible for pain relief
Rest and relaxation	Social Isolation
Distraction	
Positive self-statements	
Humour	
Resisting negative emotions	
Reliance on spiritual faith	



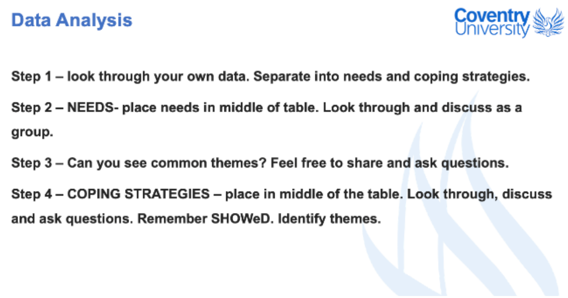
Data Analysis

When looking through your and others photovoice data, consider these questions:

SHOWeD (Wang, 1999):

- What do you **S**ee here?
- What is really **H**appening here?
- How does this relate to **O**ur lives?
- **W**hy does this situation, concern or strength exist?
- What can we **D**o about it?

In pairs, choose a photograph and answer these questions.



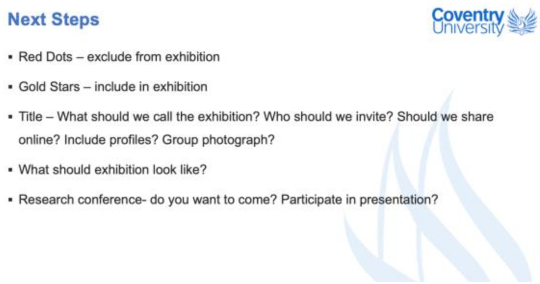
Data Analysis

Step 1 – look through your own data. Separate into needs and coping strategies.

Step 2 – NEEDS- place needs in middle of table. Look through and discuss as a group.

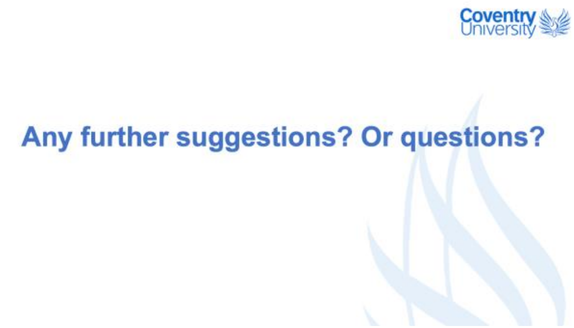
Step 3 – Can you see common themes? Feel free to share and ask questions.

Step 4 – COPING STRATEGIES – place in middle of the table. Look through, discuss and ask questions. Remember SHOWeD. Identify themes.

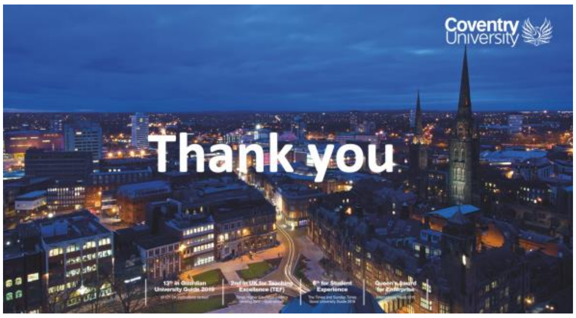


Next Steps

- Red Dots – exclude from exhibition
- Gold Stars – include in exhibition
- Title – What should we call the exhibition? Who should we invite? Should we share online? Include profiles? Group photograph?
- What should exhibition look like?
- Research conference- do you want to come? Participate in presentation?



Any further suggestions? Or questions?



Thank you

Appendix VIII Evidence Statements

Needs

Love & Connection

This was important to co-researchers' and discussed in terms of a basic human need that everyone has and also in reference to Maslow's hierarchy of needs (1943). It's important that people living with endometriosis and/or adenomyosis feel a sense of belonging and connection as their condition and symptoms can lead to isolating behaviour, such resting at home and restricting social activities outside the home.

Evidence

The term 'evidence' refers to actions taken by co-researchers to document or record their symptoms and medical condition such as apps, medical notes, letters, phone calls, recording keeping and providing proof of their painful symptoms and of their diagnosis. The co-researchers had experienced misdiagnosis, being dismissed and not believed and as a result felt that they often have to provide evidence of symptoms and diagnosis.

Work Support

The term 'work support' refers to the co-researchers experience of managing their condition in the workplace and how the symptoms have impacting their employment. This included compromise, understanding, adjustments, empathy and equal opportunity. The co-researchers were grateful for understanding and empathetic employers but worried that they would be seen as problematic for taking time off or asking for adjustments. When looking at things from an employers point of view the co-researchers stated they believed that a more able bodied person would be more likely to have job security, offered promotions or find it easier to find another job. One co-researcher felt her career had stalled as she had found secure employment but worried no one else would employ her.

Professional, Respectful, Empathetic, Educated Care

This theme was developed as the co-researchers discussed what their care should be like. They all had provided examples of negative experiences and that positive experiences were the exception. This term was developed during the group discussion to refer to the type of care people with endometriosis and/or adenomyosis should receive and have access to.

Validation

Validation refers to what co-researchers need from others – healthcare professionals, loved one and others with the conditions. The co-researchers had accepted their diagnosis and symptoms but found it distressing when others did not. This is linked to the theme of 'evidence'. The co-researchers understood that they have a chronic, lifelong medical condition but were frustrated when they weren't believed, their symptoms normalised or observed as weakness or laziness by others.

Lack of Continuity

Lack of continuity refers to the care and treatment received by the co-researchers. They often found it difficult to see the same doctor more than once and had received conflicting information from different healthcare professionals.

Work/Life/Illness Balance

This theme is linked to the 'work support' theme but refers to the juggling work, life and illness. The co-researchers discussed sacrificing household chores, hobbies or social events to preserve energy for work. They also discussed how having a chronic illness was like having a second job and left no room for life outside of work and illness, they had no control over the lack of balance. They also discussed being fearful of losing their jobs, the benefits system (PIP Judgements) but hoped that policies would protect them. They mentioned the Endometriosis UK scheme of Endo Friendly Employers being a step in the right direction. They also discussed that long waiting times for appointments, tests, results and referrals for surgery negatively impacts their ability to work and be productive.

Unmet Needs

Lack of Care

From the beginning of the study the co-researchers wanted to clarify the definition of ‘need’. They suggested the use of the term ‘unmet needs’ as an umbrella term for the aspects of their life that they were not receiving support for. This includes lack of care, being dismissed, having to self-diagnose, being labelled ‘hysterical’, the taboo that surrounds menstruation and unprofessional care. This refers to the lack of physical care, lack of medical treatment.

Pain Belief

The term ‘pain belief’ refers to the co-researchers need for others to believe that they are in pain (physical and emotional) and provide treatment and support, including psychological and emotional support. The co-researchers discussed the lack of psychological and emotional support. Examples shared included lack of counselling pre and post hysterectomy and counselling with a professional that didn’t understand endometriosis.

Sleep

This was discussed as an unmet physiological need. The painful symptoms and anxiety attached to them often led to trouble falling asleep or staying asleep.

Lack of Trust of Healthcare Professionals

This unmet need referred to the need for trust in healthcare professionals providing care and treatment. The co-researchers discussed the need for more collaboration with healthcare professionals and the room to provide input and feedback to those providing care and treatment.

Unrelenting/Relentless/Hard

The term ‘Unrelenting/Relentless/Hard’ is made up of three words present in all the co-researchers data. Due to having a number of unmet needs, they felt that endometriosis and the painful symptoms were relentless, making life difficult. They discussed the recurrent nature of the condition and having to ‘de weed the garden’.

Time’s Against Us

This term refers to the uncertainty around fertility. It also includes the feelings of being left behind, whilst others get married, have families and move on with their lives.

Mental Health

This was a larger theme that developed from the group discussion around the impact that the symptoms of endometriosis and/or adenomyosis have on mental health. Feelings discussed included: loneliness, embarrassment, resentful, being sensitive or fragile and body image. Due to sending so much time at home resting, the co-researchers discussed missing out and cancelling social events, leading to isolation. Living with chronic pain is tiring, the co-researchers discussed the ‘spoon theory’, stating they had to prioritise work and health and had little time or energy of anything else, even when it had a positive impact on mental health.

Lack of Control

This term refers to the co-researchers having no control over their own bodies, symptoms that meant they had to rush to the bathroom and often spend a lot of time there. But also in terms of fertility, having no control over if or when they can have children and having choice taken away from them due to medical treatment, including hysterectomy. The co-researchers also discussed the power imbalance in the relationship between patient and doctor. The healthcare professional has all the power and makes the decision about treatment, often without consideration over fertility, or the patient’s whole life and desires.

Femininity, Sexuality and Motherhood

This term refers to the impact that living with endometriosis and its symptoms have on perceiving oneself as a woman, feeling feminine and whether motherhood will occur or be missed out. This was a more abstract theme than ran through the discussion – the co-researchers coming to terms with their lives taking different turns and dreams and plans changing or disappearing.

SEX (lack of)
This topic was discussed by the co-researchers in a humorous way. The co-researchers talked about the lack of sex in their lives and how this affects their relationships with their partners. They discussed feelings of guilt, blame and feeling like a burden to their partners. They also shared that they often didn't feel sexy and that their partners were fearful of causing them pain.

ENDOBELLY
This is the most visible symptom of both endometriosis and adenomyosis. It can be unpredictable, painful and lead to feelings of shames an embarrassment. It can also be an ironic symptom, women who cannot get pregnant may appear pregnant due to endobelly. It can still occur after hysterectomy.

Financial
There can be a substantial financial impact of living with these medical conditions. There is a risk of circumstances creating a poverty trap. Costs include: low paying positions, sick leave, job loss, prescriptions, using annual leave as sick days to maintain attendance at work, self-management strategies, having a healthy endo friendly diet, having to use public transport and taxis.

Consequence of Pressure (negative strategy)
This term refers to how co-researchers have to pretend to be well and disguise their symptoms around others such as employers family and friends. This behaviour usually happens when they feel pressured by the judgements of others.

Fear of the Future
This term refers to the unpredictability of the conditions, of life changing and not turning out as planned. The future can seem uncertain, particularly around fertility and the ability to get pregnant and have children. The co-researchers discussed how their painful symptoms cause feelings of fear of being scared about what happens if their condition worsens. The co-researchers also expressed concern about not being able to take care of others in the future; elderly relatives and children. They discussed how peer pressure added to this and increased the pressure they felt to be well and have lives similar to those around them.

Coping Strategies

Self-Management (diet, exercise, painkillers)

This was by far the largest theme that was developed during the group discussion and in the secondary analysis. The size of this theme illustrates the effort and burden that the women in the photovoice shared in their data and in the group discussion. Living with and managing endometriosis and/or adenomyosis does seem like a second job when all the aspects of this theme are observed. This theme included: self-advocating, 'another job', medication, 'magic' pill (contraceptive pill), supplements, having and maintaining hope, painkillers, sleep aids, diet, exercise, heat/hot water, taking a break, support group, venting/moaning, research and books, finding inspiration and manging poor mental health.

Comfort

The term comfort refers to turning away from the self for support. This include seeking comfort from loved ones and pets. It also includes finding comfort in nature and food. Sometimes taking comfort in food can mean food prepared by a loved one or eating 'unhealthy' food such as chocolate.

Humour

Humour was often used as a distraction or to lighten the mood, in both the data and the group discussion.

Learning to Appreciate your Body

This term is closely linked to the relentless/unrelenting/hard' theme, the data and discussion and refers to accepting and forgiving the body's 'limitations'. In the group discussion the women recognised that there bodies had been through a lot and fighting against their symptoms, blaming themselves and being critical of their bodies were not helpful and actually impacted negatively on their mental health.

Work Performance

This term refers to how the women behave or act at work. It’s closely related to the ‘work support’ and ‘work/life/illness balance’ theme. During the group discussion a co-researcher shared that she had to use her annual leave for sick days in order not to trigger or alert her employer to her work performance. The others in the group agreed that this was part of working with a chronic illness. They discussed ‘putting on a mask’ at work and pretending to be well, trying to distance themselves from their health condition. The data showed that the women often overcompensated at work, overdoing it, with a negative impact on their symptoms. Their main motivation for this was worry over financial loss.

Pressure

‘Pressure’ refers to a negative coping strategy. Work, finances, daily activities such as social obligations and housework place pressure on those with chronic illness. The co-researchers discussed having to prioritise and letting things like housework go to prioritise saving energy for work. The co-researchers discussed not having a choice but having to perform and meet obligations in order to protect or aim for financial security.

Comparison(negative)

Another negative coping strategy that often has a negative impact on mental health. The co-researchers data and discussion captured a competitive sense of comparison that left them feeling ‘inadequate’ or ‘not enough’ compared with others around them. This strategy is linked to the ‘time is against us’ theme.

Fuel/Caffeine

This coping strategy was established in response to the symptom of fatigue. Some of the co-researchers shared images of coffee and tea, they were attempting to fulfil their obligations, unable to rest or ‘give in’ to their symptoms.

Acceptance

This strategy was present in many of the images and captions as well as the discussion. The co-researchers had work to accept their diagnosis but felt distress when others could not or would not accept their symptoms, experiences or limitations. This led the co-researchers to express frustration about interactions with others, loved ones and healthcare professionals.

Nesting

This strategy was about the relief felt when arriving home, being able to stop pretending to be well and being able to be comfortable.

Responsibility

This strategy refers to the motivation behind the actions taken by the co-researchers. They discussed an increased level of responsibility compared with others without a chronic illness. Their responsibilities include: their health and wellbeing, housework, everyday activities, caring for others, advocating for themselves and researching their condition, meeting financial obligations. Daily activities that may seem ‘normal’ for others could at times feel overwhelming for the women in the photovoice study.

Spirituality

This strategy involves seeking comfort outside of themselves and others, instead looking at the bigger picture or considering a ‘higher power’. This also includes seeking out peaceful moments and environments. During the discussion the co-researchers discussed this as not religious nature but in seeking out solitude, hope and peacefulness.

Creative Outlets as Therapy

This strategy was captured in the images and words of all of the co-researchers. They enjoyed live music events of different sizes, listened to or played music. Two of the co-researchers are employed in artistic careers, art and fashion design. The co-researchers were often willing to attend music events even though they knew it could increase their pain. They always commented that it was worth it but that these events should be more accessible e.g. not standing only. Creative outlets were more than a distraction from pain, they also fulfilled an emotional need to be present, forget about their burden and being with others.

Recognising Good Days

The images and captions that captured this strategy were vibrant and often captured outside. They included holiday photographs, sunshine, gardens and flowers. These images were in contrast to some of those in the need category, which were dark, in doors and muted. One co-researcher expressed that she needed to try to do this more and be less pessimistic. Another said it took practice not to let the negative seep into the good days.

Understanding the Condition and Seeing It

This strategy was a step beyond acceptance. The co-researchers gathered evidence of their condition and symptoms for others but also themselves. They felt that by understanding and learning more about their condition they were then able to make the best decisions for their health and seek out the appropriate care.

Appendix IX The Phoenix Course Outline

Phoenix Course Outline May 2020

Week 1 Overview

Theme	Session Objective and Key Concepts	Material	Home Practice	Resources
Welcome The Mind-Body Connection	Objective: To introduce the course, navigation and the mind-body connection. To introduction awareness of the breath and the five senses. To differentiate between experience and thoughts/feelings about experiences. Key Concepts: • Mindfulness • Why mindfulness is useful for endo/adeno • Awareness of breath • Telling the difference between true experience and thoughts/feelings • Why gratitude?	Introduction Video Acceptance and Chronic Pain Video Vidymala Fist exercise Fadal's pain management video Two arrows video Jon Kabat Zinn mindfulness and chronic pain. Gratitude video	Daily: 1x15 min body scan 1x5 min breathing space Fill in Meditation Diary Mindful activity – one routine action slowed done and done mindfully like the coffee/raisin exercise. Weekly: Coffee/Raisin exercise Post comment on exercise. Share reflection on week 1. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	Link to Endometriosis UK COVID information. Link to Hope 4 the Community website. Audio recording of five minute breathing space and 15 minute Body Scan.

Week 2 Overview

Theme	**Session Objective and Key Concepts**	**Material**	**Home Practice**	**Resources**
Accepting and Being.	Objective: Accepting not avoiding experiences. Letting go of the battle/fight with the body, treating the whole self with compassion. Key Concepts: • Explanation of acceptance • Doing and Being modes • Mindfulness of breathing • Diaphragmatic/Belly breathing • Intro to self-compassion	Video of being and doing modes Video of Kristin Neff talking about self-compassion Video of how self-compassion is good for mental health	Daily: 1x 10 min mindfulness of breathing 1x15 min body scan Fill in meditation diary Optional/As needed: 5 min breathing space Mindful activity – a different routine action slowed done and done mindfully like the coffee/raisin exercise. Weekly: Share reflection on week 2. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	Audio recording of 10 min breathing space, 15 minute Body Scan and 5 min breathing space.

Week 3 Overview

Theme	**Session Objective and Key Concepts**	**Material**	**Home Practice**	**Resources**
Self-Compassion	Objective: Further understanding and use of self-compassion and how to put this in to practice every day. Key Concepts: • Explanation of self-compassion. • Boom and bust cycle. • Intro to pacing • Pacing diary instructions • Shame and self-compassion • Blocking and drowning	Boom and Bust video Pacing videos Shame and self-compassion video by Weiyang Xie Compassionate acceptance video by Adia Groden.	Daily: 1x 10 min Mindfulness of breathing 1x15 min compassionate acceptance Fill in meditation diary Optional/As needed: 5 min breathing space Mindful activity – keep a pacing diary. Weekly: Share reflection on week 3. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	Audio recording of 10 min mindfulness of breathing 15 min compassionate acceptance meditation

Week 4 Overview

Theme	**Session Objective and Key Concepts**	**Material**	**Home Practice**	**Resources**
Mindful Movement	Objective: To begin using applying mindfulness to movement and daily activities. Key Concepts: • Pacing part 2 – 80%/20% split in activity and rest. • Idea of having balance in life • Intro to mindful movement • Conversation with Sundeep • Mindful movement – hard and soft edges • Responding vs reacting	Mindful Movement videos – 3 different levels. Both standing and sitting. Video of Conversation with Sundeep. Video of mindfulness students discussing use of responding vs reacting	Daily: 1 session of mindful movement 1x15 min Compassionate Acceptance Fill in meditation diary Optional/As needed: 5 min breathing space Mindful activity –Continuing pacing diary. Analyse last week's pacing diary. Weekly: Share reflection on week 4. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	You Tube videos of mindful movement exercises 15 minute compassionate acceptance meditation audio recording

Week 5 Overview

Theme	**Session Objective and Key Concepts**	**Material**	**Home Practice**	**Resources**
Dealing with the negative	Objective: To introduce coping strategies for when negative thoughts, feelings and sensations arise during meditation and in everyday life Key Concepts: • Negativity Bias • 3 emotional regulation systems • Acknowledging and letting go of negative thoughts/feelings/sensations • Using self-compassion as a coping strategy		Daily: 1 session of mindful movement Fill in meditation diary Optional/As needed: 5 min breathing space Mindful activity –Continuing pacing diary. Analyse last week's pacing diary. Weekly: Share reflection on week 4. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	15 minute breathing anchor meditation 15 minute compassionate acceptance meditation audio recording

Week 6 Overview

Theme	**Session Objective and Key Concepts**	**Material**	**Home Practice**	**Resources**
Seeking Joy	Objective: To learn how to balance out the negativity bias by seeking out joy. Key Concepts: • Using joy to balance the negativity bias • Why gratitude is important • Spending time tin the green zone/being mode. • Drainers and sustainers		Daily: 1 session of mindful movement Fill in meditation diary Optional/As needed: 5 min breathing space Mindful activity –Continuing pacing diary. Analyse last week's pacing diary. Weekly: Share reflection on week 4. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	15 minute breathing anchor meditation 15 minute treasure pleasure meditation audio recording

Week 7 Overview

Theme	**Session Objective and Key Concepts**	**Material**	**Home Practice**	**Resources**
Connection	Objective: Learning how to nourish and maintain connection with others. Key Concepts:		Daily: 1 session of mindful movement Fill in meditation diary Optional/As needed: 5 min breathing space Mindful activity –Continuing pacing diary. Analyse last week's pacing diary. Weekly: Share reflection on week 4. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	15 minute breathing anchor meditation 15 minute compassionate acceptance meditation audio recording

Week 8 Overview

Theme	Session Objective and Key Concepts	Material	Home Practice	Resources
Setting up independent practice	Objective: To summarise the course and help participants to identify how to maintain their own independent mindfulness practice. Key Concepts:		Daily: 1 session of mindful movement Fill in meditation diary Optional/As needed: 5 min breathing space Mindful activity –Continuing pacing diary. Analyse last week's pacing diary. Weekly: Share reflection on week 4. Connect with others. Share a gratitude. Share a goal regarding mindfulness practice.	15 minute breathing anchor meditation 15 minute compassionate acceptance meditation audio recording

Appendix X TIDieR Checklist

TIDieR (Template for Intervention Description and Replication) Checklist (Hoffmann et al, 2014)

Item No.	Item	Answer/Evidence	Where Located (page/section number)
1.	**Brief Name** Provide the name or a phrase that describes the intervention	The Phoenix course, an online 8 week mindfulness self-management course	Page 191 Table 5.2
2.	**Why?** Describe any rationale, theory or goal of the elements essential to the intervention	The course is an online psychological intervention	Page 164 section 5.3.2
3. **4.**	**What?** Materials: Describe any physical or informational materials used in the intervention including those provided to participants or used in intervention delivery or in training of intervention providers. Please provide information on where the materials can be accessed (e.g., online, appendix, URL). Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	Outcomes chain shows participant progression through the 8 week course. Each week has a different theme. Each week includes a meditation and mindful activity	Page 167 Figure 5.2 Page 172 Section 5.5.1 Appendix IX The Phoenix Course Components and Evidence Base
5.	**Who Provided?** For each category of intervention provider (e.g., psychologists, nursing assistant), describe their expertise, background and any specific training given.	Two facilitators for intervention group. Hollie Vercoe and Clair Dempsey. Specialist Physiotherapist Sundeep Watkins. Health Psychologist and mindfulness teacher Dr Liz Sparkes	Page 167 Figure 5.2 and Appendix IX
6.	**How?** Describe the modes of delivery (e.g., face to face or mu some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	Built on the Hope platform	Page 191 Table 5.2 Image 5.2 and 5.3
7.	**Where?** Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features	Used by participants in participants home	Page 196 Section 5.8.3

8.	**When and How Much?** Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, their duration, intensity or dose.	Intervention group had a session released each week. Control group got all sessions at once.	Page 196 Section 5.8.3
9.	**Tailoring** If the intervention was modified during the course of the study, describe the changes (what, why, when and how).	N/A	
10.	**Modifications** If the intervention was modified during the course of the study, describe the changes (what, why, when and how).	N/A	
11. **12.**	**How well?** Planned: if the intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	Adherence rates were collected through the Hope Platform	Page 197-98 and 206-207

Appendix XI The Phoenix Course Development Guide

Intervention Development and Evidence Base Document V1.0
March 2020

PHOENIX
Course

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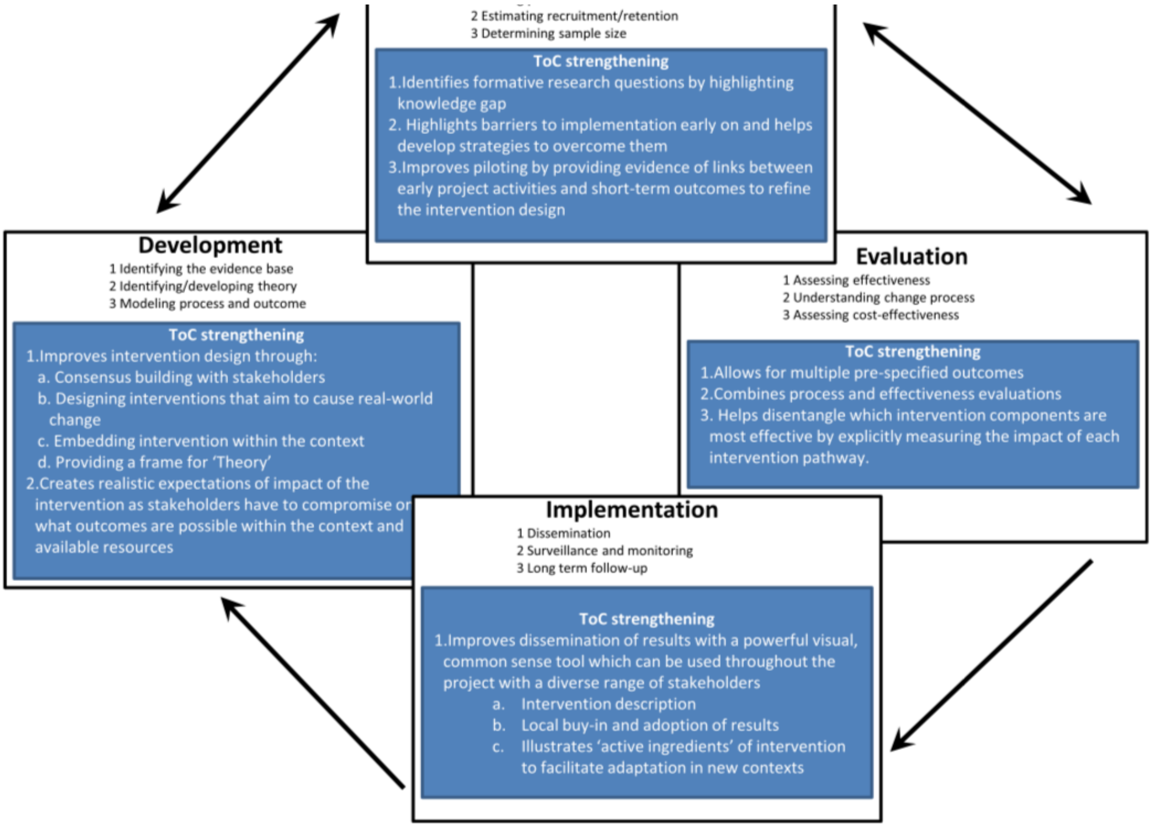
1.0 Background

The Medical Research Council has produced guidelines for the development, evaluation and implementation of complex interventions (Craig et al, 2008, Craig et al, 2019). The guidelines provide researchers with guidance on choosing appropriate methods and the development-evaluation-implementation process. When developing an intervention, the guidelines ask researchers to consider questions like: Are you clear about what you are trying to do: what outcome you are aiming for; and how you will bring about change? Does your intervention have a coherent theoretical basis? Have you used this theory systematically to develop the intervention? Can you describe the intervention fully, so that it can be implemented properly for the purposes of your evaluation, and replicated by others? The guidelines ask further questions and emphasise the importance of the work that goes into developing an intervention prior to the evaluation stage. However, what the guidelines don't include are examples of theories that provide the theoretical basis for the development of interventions. When developing complex interventions that aim to be effective, substantial and scalable researchers need to understand not just if the intervention works but also how and why an intervention has a particular effect and which parts of a complex intervention have the greatest impact on outcomes (De Silva, et al. 2014). De Silva, et al (2014) have proposed a theory-driven approach to the design and evaluation of complex intervention by adapting the integrating the Theory of Change (ToC) into the MRC framework.

Figure 1.



A program theory is a theory of how an intervention contributes to a chain of intermediate results and finally to the intended or observed outcomes (Funnell and Rogers, 2011). Program theory has two components: a theory of change and a theory of action. Theory of change is about the central processes that leads to change for individuals, groups or communities, e.g. psychological processes, social processes, physical process and economic processed (Funnell and Rogers, 2011). Although it may contain psychological or social processes, ToC is not a sociological or psychological theory but a pragmatic framework that describes how the intervention affects change (De Silva, 2014). A strong ToC is powered by reliable and robust theories that provide clear explanation of why change takes place. Theory of Change has a flexible format that clearly describes the pathways through which the outcomes work to achieve the desired impact (De Silva et al, 2014). ToC allows for multiple pathways, levels and feedback loops which reflects the reality of how complex interventions achieve their impact (De Silva et al, 2014). Theory of change incorporates an evidence base for each strand that feeds into the long-term outcome, this allows researchers to understand which components of the intervention have been successful or unsuccessful and how the components of the intervention have contributed to the change in outcomes (Funnell and Rogers, 2011).

Whilst ToC is flexible, it also provides a theory driven, evidence-based framework that leads to the development of a complex intervention. Researchers can follow the steps and describe each stage of intervention development. This allows for tracking of the intervention components and processes but also allows replication.

Table 1. Steps of ToC taken in the development of the Phoenix intervention

ToC STEP	PAGE NO.
SITUATION ANALYSIS	3
Identification/Context of Problem	3
Findings of Systematic Review	4
Evidence statements from Needs Assessment	5
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Intended outcomes	27
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2.0

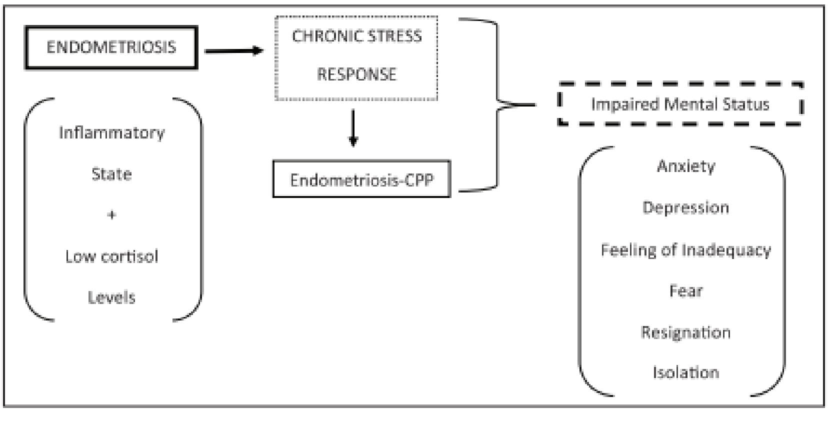
Situational Analysis

2.1 Identification and Context of the Problem

Endometriosis is a complex medical condition that can have a substantial negative affect on quality of life. In the last decade researchers have attempted to understand the full impact of endometriosis and adenomyosis, beyond the symptom of chronic pelvic pain. There are a number of psychosocial consequences of living with endometriosis including: reduced health-related quality of life, impaired educational and professional achievement, perturbed body perception/female identity, difficulties with romantic/intimate relationships, limited engagement in leisure activities, disturbances of role performance/physical functioning, diminished self-esteem, sexual disorders, reduced control over life, limited perspectives for the future, depression and anxiety (Leeners, 2012). It has been difficult for researchers to understand if a diagnosis of endometriosis itself impacts negatively on mental health and quality of life or if it's the symptom of chronic pelvic pain that causes depression and anxiety (Culley, et al, 2013). However, emotional distress has been reported throughout qualitative research into living with endometriosis, this includes feelings of hopelessness, isolation, worthlessness, depressions and suicide ideation (Culley et al, 2013). A recent systematic review of 24 studies concluded that the association between endometriosis and depressive symptoms is largely determined by chronic pain but may also be modulated by individual and context vulnerabilities (Gambadauro, et al 2019).

It has been suggested that the relationship between endometriosis-related chronic pelvic pain and mental health disorders is not unidirectional, that it may have a more cyclical relationship, see Figure2. (Vrekoussis et al, 2020). It has been proposed that chronic stress and inflammation could be one of the explanations for the link between chronic pelvic pain and depression (Vrekoussis et al, 2020). Living with chronic pain may cause chronic stress, which then leads to inflammation, more pain and depression. A biopsychosocial approach to endometriosis diagnosis and management is desired by both healthcare professionals and patients, this approach should combine the physiological, psychological, social, sexual and spiritual (Bertero et al, 2019). The patients want to be seen as more than a 'biomedical defect object', however many physicians have explained that they do not have the ability to adopt a biopsychosocial perspective on their own and suggested the involvement of other physicians to form a multidisciplinary team (Bertero et al, 2019). This finding supports the treatment and care suggestions made by NICE (2017) guidelines, where they state that women with endometriosis can have significant physical, sexual, psychological and social impact and may have complex needs and recommend that women should have access to a multidisciplinary team for treatment. The NICE (2017) guidelines also that healthcare professionals should inform patients of local support groups, online forums and national charities and how to access them. The guidelines also state that research should aim to provide evidence-based options to support self-management of endometriosis (NICE, 2017).

Figure 2. Proposed connection between endometriosis-related chronic pelvic pain and mental health disorders (Vrekoussis et al, 2020).



Self-management plays an important part of managing symptoms of endometriosis and adenomyosis and attempting to limit the impact of symptoms on everyday life, including emotional wellbeing and mental health. In a study of 484 of women with endometriosis aged between 18 and 45, self-managing strategies were found to be common amongst those living with endometriosis (76%). The most common self-management strategy was using heat (70%), rest (68%) and meditation or breathing exercises (47%) (Armour, et al 2019). NICE (2017) added an update to their guidelines in 2019 stating that there was a lack of high quality on the effectiveness of lifestyle interventions such as diet or exercise and other non-medical treatments in reducing pain, fatigue and other symptoms. The guidelines also state that supporting self-management is ‘critical to improving quality of life for those living with endometriosis and adenomyosis.

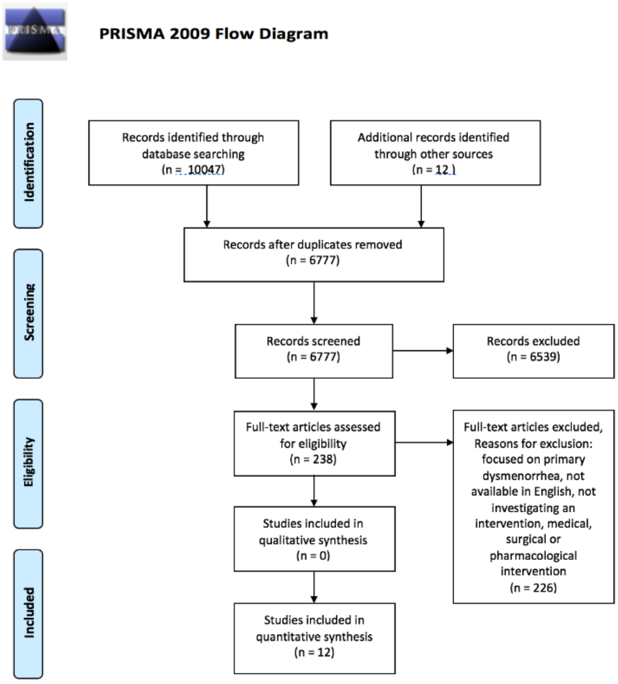
Before a complex intervention could be developed and evaluated, there needed to be a clear understanding of both existing self-management interventions and the quality of those studies. It was also important to evaluate the intervention from the perspective of the participants, to include their experiences in the review. The MRC Framework encourages the use of a systematic review to evaluate the existing evidence when in the early stages of intervention development.

2.2 Findings from Systematic Review

The Medical Research Council Centre for Reproductive health has compiled a list of the top ten priorities for endometriosis in the UK and Ireland. The list includes investigating the most effective way of managing the emotional and/or psychological and/or fatigue impact of living endometriosis (including medical, non-medical and self-management methods (Horne, et al, 2018). This prompt demonstrated that there was a need to understand the effectiveness of existing interventions that aimed to improve the quality of life of those living with endometriosis and/or adenomyosis. A mixed method systematic review was conducted, the research question was: What non-surgical, non-pharmacological interventions are effective at improving quality of life for women with chronic pelvic pain, and what are the experiences of women attending them?

The results of this review echo the statement in the NICE guidelines (2017), there is a need for high-quality studies looking into the effectiveness of non-surgical, non-medical, self-management interventions. The search strategy returned 6777 records, once duplicates were removed, see PRISMA flow diagram below. There were no qualitative records returned. Twelve records were included in the quantitative synthesis. The studies included in the review investigated the effective4ness of the interventions at improving quality of life. The interventions included: Japanese-style acupuncture, Combination of psychotherapy and somatosensory stimulation, acupuncture, Chinese Herbal Medicine, Mindfulness, TENS, combined physiotherapy and psychological therapy, homeopathy and interdisciplinary therapy.

Figure 3. PRISMA flow diagram (Moher et al, 2009).



Unfortunately, due to methodological issues such as missing data, it was not possible to conduct a meta-analysis. Instead the results were synthesised in a critical narrative. There were two promising intervention types, in terms of quality of methodology and effectiveness. Mindfulness interventions and acupuncture showed the potential to be the most effective. The main findings of this systematic review were: 1. There is a huge need for high-quality studies of all types of non-surgical, non-medical, self-management focused interventions that aim to improve quality of life to. 2. There is a need for more qualitative research to be carried out, it is important to capture participants' experiences of these interventions and their evaluations of them.

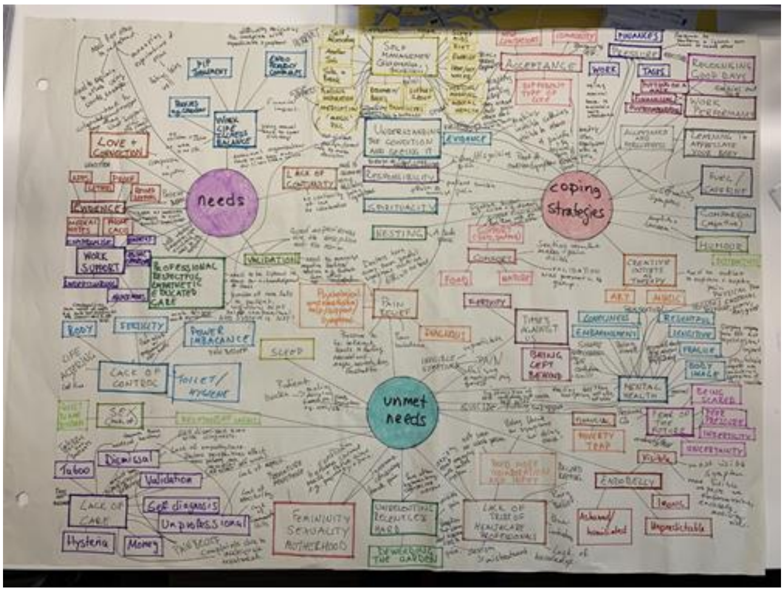
2.3 Evidence statements from Needs Assessment

Due to the lack of qualitative research included in the mixed methods systematic review, when the next step of intervention was being planned, a needs assessment, a qualitative approach was favoured. Photovoice was chosen as the method for the needs assessment as both endometriosis and adenomyosis are invisible illnesses. Qualitative research has made a valuable contribution to understanding how quality of life is impacted by living with the painful symptoms of endometriosis and adenomyosis. Participants have shared their experiences of living with endometriosis: pain restricting or preventing physical functioning, feelings of distress, sadness, self-consciousness and embarrassment in relation to their symptoms as well as depress and suicide ideation (Roomaney and Kagee, 2016). Participants reported using a combination of problem-focused and emotion-focused strategies in order to manage the impact of the disease and its symptoms on their HRQOL (Roomaney and Kagee, 2016). People living with endometriosis put significant effort into maintaining their health and minimising the impact of their symptoms by using self-management techniques. Women have taken steps to become 'expert patients', making use of the internet to educate and help themselves. This work has been described as a 'third shift' performed in addition to paid and unpaid work (Seear, 2009b). The effort to become an expert patient with endometriosis can both reduce and add to existing stress (Rimke, 2000).

The needs assessment conducted as part of the intervention development was done using a Participatory Action Research (PAR) approach called photovoice. The aim of this study was to gain an insight into the specific needs of those living with endometriosis. This work was done in collaboration with women living with endometriosis, who shared ownership of the project and were referred to as co-researchers. The research question was: What are the psychological needs and coping strategies of people living with endometriosis and/or adenomyosis?

A number of needs, unmet needs and coping strategies were identified. Below is a thematic map, which was part of the data analysis procedure. In order to make sense of what the needs and coping strategies are, they were outlined in evidence statements.

Figure 4. Thematic Map.



2.4 Needs

Love & Connection

This was important to co-researchers' and discussed in terms of a basic human need that everyone has and also in reference to Maslow's hierarchy of needs (1943). It's important that people living with endometriosis and/or adenomyosis feel a sense of belonging and connection as their condition and symptoms can lead to isolating behaviour, such resting at home and restricting social activities outside the home.

Evidence

The term 'evidence' refers to actions taken by co-researchers to document or record their symptoms and medical condition such as apps, medical notes, letters, phone calls, recording keeping and providing proof of their painful symptoms and of their diagnosis. The co-researchers had experienced misdiagnosis, being dismissed and not believed and as a result felt that they often have to provide evidence of symptoms and diagnosis.

Work Support

The term ‘work support’ refers to the co-researchers experience of managing their condition in the workplace and how the symptoms have impacting their employment. This included compromise, understanding, adjustments, empathy and equal opportunity. The co-researchers were grateful for understanding and empathetic employers but worried that they would be seen as problematic for taking time off or asking for adjustments. When looking at things from an employers point of view the co-researchers stated they believed that a more able bodied person would be more likely to have job security, offered promotions or find it easier to find another job. One co-researcher felt her career had stalled as she had found secure employment but worried no one else would employ her.

Professional, Respectful, Empathetic, Educated Care

This theme was developed as the co-researchers discussed what their care should be like. They all had provided examples of negative experiences and that positive experiences were the exception. This term was developed during the group discussion to refer to the type of care people with endometriosis and/or adenomyosis should receive and have access to.

Validation

Validation refers to what co-researchers need from others – healthcare professionals, loved one and others with the conditions. The co-researchers had accepted their diagnosis and symptoms but found it distressing when others did not. This is linked to the theme of ‘evidence’. The co-researchers understood that they have a chronic, lifelong medical condition but were frustrated when they weren’t believed, their symptoms normalised or observed as weakness or laziness by others.

Lack of Continuity

Lack of continuity refers to the care and treatment received by the co-researchers. They often found it difficult to see the same doctor more than once and had received conflicting information from different healthcare professionals.

Work/Life/Illness Balance

This theme is linked to the ‘work support’ theme but refers to the juggling work, life and illness. The co-researchers discussed sacrificing household chores, hobbies or social events to preserve energy for work. They also discussed how having a chronic illness was like having a second job and left no room for life outside of work and illness, they had no control over the lack of balance. They also discussed being fearful of losing their jobs, the benefits system (PIP Judgements) but hoped that policies would protect them. They mentioned the Endometriosis UK scheme of Endo Friendly Employers being a step in the right direction. They also discussed that long waiting times for appointments, tests, results and referrals for surgery negatively impacts their ability to work and be productive.

2.5 Unmet Needs

Lack of Care

From the beginning of the study the co-researchers wanted to clarify the definition of ‘need’. They suggested the use of the term ‘unmet needs’ as an umbrella term for the aspects of their life that they were not receiving support for. This includes lack of care, being dismissed, having to self-diagnose, being labelled ‘hysterical’, the taboo that surrounds menstruation and unprofessional care. This refers to the lack of physical care, lack of medical treatment.

Pain Belief

The term ‘pain belief’ refers to the co-researchers need for others to believe that they are in pain (physical and emotional) and provide treatment and support, including psychological and emotional support. The co-researchers discussed the lack of psychological and emotional support. Examples shared included lack of counselling pre and post hysterectomy and counselling with a professional that didn’t understand endometriosis.

Sleep

This was discussed as an unmet physiological need. The painful symptoms and anxiety attached to them often led to trouble falling asleep or staying asleep.

Lack of Trust of Healthcare Professionals

This unmet need referred to the need for trust in healthcare professionals providing care and treatment. The co-researchers discussed the need for more collaboration with healthcare professionals and the room to provide input and feedback to those providing care and treatment.

Unrelenting/Relentless/Hard

The term ‘Unrelenting/Relentless/Hard’ is made up of three words present in all the co-researchers data. Due to having a number of unmet needs, they felt that endometriosis and the painful symptoms were relentless, making life difficult. They discussed the recurrent nature of the condition and having to ‘de weed the garden’.

Time’s Against Us

This term refers to the uncertainty around fertility. It also includes the feelings of being left behind, whilst others get married, have families and move on with their lives.

Mental Health

This was a larger theme that developed from the group discussion around the impact that the symptoms of endometriosis and/or adenomyosis have on mental health. Feelings discussed included: loneliness, embarrassment, resentful, being sensitive or fragile and body image. Due to sending so much time at home resting, the co-researchers discussed missing out and cancelling social events, leading to isolation. Living with chronic pain is tiring, the co-researchers discussed the ‘spoon theory’, stating they had to prioritise work and health and had little time or energy of anything else, even when it had a positive impact on mental health.

Lack of Control

This term refers to the co-researchers having no control over their own bodies, symptoms that meant they had to rush to the bathroom and often spend a lot of time there. But also in terms of fertility, having no control over if or when they can have children and having choice taken away from them due to medical treatment, including hysterectomy. The co-researchers also discussed the power imbalance in the relationship between patient and doctor. The healthcare professional has all the power and makes the decision about treatment, often without consideration over fertility, or the patient's whole life and desires.

Femininity, Sexuality and Motherhood
This term refers to the impact that living with endometriosis and its symptoms have on perceiving oneself as a woman, feeling feminine and whether motherhood will occur or be missed out. This was a more abstract theme than ran through the discussion – the co-researchers coming to terms with their lives taking different turns and dreams and plans changing or disappearing.

SEX (lack of)
This topic was discussed by the co-researchers in a humorous way. The co-researchers talked about the lack of sex in their lives and how this affects their relationships with their partners. They discussed feelings of guilt, blame and feeling like a burden to their partners. They also shared that they often didn't feel sexy and that their partners were fearful of causing them pain.

ENDOBELLY
This is the most visible symptom of both endometriosis and adenomyosis. It can be unpredictable, painful and lead to feelings of shames an embarrassment. It can also be an ironic symptom, women who cannot get pregnant may appear pregnant due to endobelly. It can still occur after hysterectomy.

Financial
There can be a substantial financial impact of living with these medical conditions. There is a risk of circumstances creating a poverty trap. Costs include: low paying positions, sick leave, job loss, prescriptions, using annual leave as sick days to maintain attendance at work, self-management strategies, having a healthy endo friendly diet, having to use public transport and taxis.

Consequence of Pressure (negative strategy)
This term refers to how co-researchers have to pretend to be well and disguise their symptoms around others such as employers family and friends. This behaviour usually happens when they feel pressured by the judgements of others.

Fear of the Future
This term refers to the unpredictability of the conditions, of life changing and not turning out as planned. The future can seem uncertain, particularly around fertility and the ability to get pregnant and have children. The co-researchers discussed how their painful symptoms cause feelings of fear of being scared about what happens if their condition worsens. The co-researchers also expressed concern about not being able to take care of others in the future; elderly relatives and children. They discussed how peer pressure added to this and increased the pressure they felt to be well and have lives similar to those around them.

2.6 Coping Strategies

Self-Management (diet, exercise, painkillers)

This was by far the largest theme that was developed during the group discussion and in the secondary analysis. The size of this theme illustrates the effort and burden that the women in the photovoice shared in their data and in the group discussion. Living with and managing endometriosis and/or adenomyosis does seem like a second job when all the aspects of this theme are observed. This theme included: self-advocating, ‘another job’, medication, ‘magic’ pill (contraceptive pill), supplements, having and maintaining hope, painkillers, sleep aids, diet, exercise, heat/hot water, taking a break, support group, venting/moaning, research and books, finding inspiration and manging poor mental health.

Comfort

The term comfort refers to turning away from the self for support. This include seeking comfort from loved ones and pets. It also includes finding comfort in nature and food. Sometimes taking comfort in food can mean food prepared by a loved one or eating ‘unhealthy’ food such as chocolate.

Humour

Humour was often used as a distraction or to lighten the mood, in both the data and the group discussion.

Learning to Appreciate your Body

This term is closely linked to the relentless/unrelenting/hard’ theme, the data and discussion and refers to accepting and forgiving the body’s ‘limitations’. In the group discussion the women recognised that there bodies had been through a lot and fighting against their symptoms, blaming themselves and being critical of their bodies were not helpful and actually impacted negatively on their mental health.

Work Performance

This term refers to how the women behave or act at work. It’s closely related to the ‘work support’ and ‘work/life/illness balance’ theme. During the group discussion a co-researcher shared that she had to use her annual leave for sick days in order not to trigger or alert her employer to her work performance. The others in the group agreed that this was part of working with a chronic illness. They discussed ‘putting on a mask’ at work and pretending to be well, trying to distance themselves from their health condition. The data showed that the women often overcompensated at work, overdoing it, with a negative impact on their symptoms. Their main motivation for this was worry over financial loss.

Pressure

‘Pressure’ refers to a negative coping strategy. Work, finances, daily activities such as social obligations and housework place pressure on those with chronic illness. The co-researchers discussed having to prioritise and letting things like housework go to prioritise saving energy for work. The co-researchers discussed not having a choice but having to perform and meet obligations in order to protect or aim for financial security.

Comparison(negative)
Another negative coping strategy that often has a negative impact on mental health. The co-researchers data and discussion captured a competitive sense of comparison that left them feeling 'inadequate' or 'not enough' compared with others around them. This strategy is linked to the 'time is against us' theme.

Fuel/Caffeine
This coping strategy was established in response to the symptom of fatigue. Some of the co-researchers shared images of coffee and tea, they were attempting to fulfil their obligations, unable to rest or 'give in' to their symptoms.

Acceptance
This strategy was present in many of the images and captions as well as the discussion. The co-researchers had work to accept their diagnosis but felt distress when others could not or would not accept their symptoms, experiences or limitations. This led the co-researchers to express frustration about interactions with others, loved ones and healthcare professionals.

Nesting
This strategy was about the relief felt when arriving home, being able to stop pretending to be well and being able to be comfortable.

Responsibility
This strategy refers to the motivation behind the actions taken by the co-researchers. They discussed an increased level of responsibility compared with others without a chronic illness. Their responsibilities include: their health and wellbeing, housework, everyday activities, caring for others, advocating for themselves and researching their condition, meeting financial obligations. Daily activities that may seem 'normal' for others could at times feel overwhelming for the women in the photovoice study.

Spirituality
This strategy involves seeking comfort outside of themselves and others, instead looking at the bigger picture or considering a 'higher power'. This also includes seeking out peaceful moments and environments. During the discussion the co-researchers discussed this as not religious nature but in seeking out solitude, hope and peacefulness.

Creative Outlets as Therapy
This strategy was captured in the images and words of all of the co-researchers. They enjoyed live music events of different sizes, listened to or played music. Two of the co-researchers are employed in artistic careers, art and fashion design. The co-researchers were often willing to attend music events even though they knew it could increase their pain. They always commented that it was worth it but that these events should be more accessible e.g. not standing only. Creative outlets were more than a distraction from pain, they also fulfilled an emotional need to be present, forget about their burden and being with others.

Recognising Good Days
The images and captions that captured this strategy were vibrant and often captured outside. They included holiday photographs, sunshine, gardens and flowers. These images were in contrast to some of those in the need category, which were dark, in doors and muted. One co-researcher expressed that she needed to try to do this more and be less pessimistic. Another said it took practice not to let the negative seep into the good days.

Understanding the Condition and Seeing It

This strategy was a step beyond acceptance. The co-researchers gathered evidence of their condition and symptoms for others but also themselves. They felt that by understanding and learning more about their condition they were then able to make the best decisions for their health and seek out the appropriate care.

3.0 Focusing and Scoping

3.1 What is the rationale for the focus?

The needs assessment was thorough and produced rich detail of the psychological needs and coping strategies of those living with endometriosis and/or adenomyosis. It is not possible to include or address all of the needs, unmet needs and coping strategies in one intervention. Focusing and scoping the intervention is about identifying and prioritising the needs to those within the reach and capacity of the intervention. It outlines which needs are within its scope and are beyond it (Funnell and Rogers, 2011).

3.2 What is the feasible scope of the intervention?

The intervention that is being developed:

- will be online and facilitator guided
- will be based in the field of health psychology
- will be mindfulness based
- will address needs that are grounded in psychology or behavioural science.
- Will improve to improve quality of life

Below is a table of the needs and coping strategies that can be included and those that have to be excluded from the intervention because they are beyond the scope of the intervention.

Table 2. Needs and coping strategies include within the scope of the intervention and those excluded for being beyond the scope of the intervention.

INCLUDE	EXCLUDE
Mindfulness – introduction to, evidence-based information, meditations, mindful inquiry an mindful activities/action. Self-Compassion exercises, seeking out the pleasant/joy. Five facets of mindfulness – observing, describing, acting with awareness, non-judging of inner experience and non-reactivity to inner experience.	Financial or legal advice
Social Support – Being able to engage with others living with endometriosis and/or adenomyosis. This will help address feelings of isolation and loneliness.	Medical or Medication advice or recommendations
Pacing – emotional regulation systems, boom and bust cycle, behaviour change, evidence-based guidance. This will help address fatigue, feelings of burnout, negativity strategy of pressure to perform and feelings of guilt and responsibility.	Referral to medical professionals
Gratitude exercises – address the negativity bias.	Diagnosis of health conditions
Physiotherapy input.	Dietary advice
Coping strategies – pain management, establishing a meditation practice, combatting critical messages from healthcare professionals.	Relationship/couples counselling
Reflection, sharing and diary keeping	Raising awareness of the conditions or symptoms, including sharing of misinformation.
	Educating healthcare professionals or others of the conditions.

4.0 Assumptions

The theory of change of an intervention is designed to bring about changes in behaviour, the theory of action clarifies what the intervention will include in terms of outcomes and operations (Funnell and Rogers, 2011). The theory of action adds to the theory of change by clarifying the assumptions and information about the other factors that may affect achievement of outcomes and should be considered during the intervention development stage (Funnell and Rogers, 2011). This section explains what the intervention will do in order to activate the theory of change. This involves providing a detailed statement about each of the outcomes in the outcomes chain.

Below in an outline of the components in the intervention and the evidence base for each component/outcome of the intervention, how this component will operate, any factors that can interfere with achieving the outcome and how these will be addressed within the intervention. Information will be given explaining the outcome chain.

4.1 Rationale for Evidence Base

The findings of the systematic review, which was conducted in 2017, suggests that Mindfulness-Based Interventions (MBIs) have the potential to improve the quality of life of people living with endometriosis and/or adenomyosis. A further, much wider, literature search was conducted in order to update the systematic review and to investigate if there's any evidence suggesting that mindfulness can be a useful and acceptable intervention for patients with other painful, chronic conditions. The systematic review conducted as part of the intervention development examined quality of life measures and outcomes, the wider search included reduction or improvement of symptoms of endometriosis and adenomyosis. Chronic pelvic pain was searched for as well as conditions such as diabetes, IBS and populations such as cancer survivors. Other conditions were included in the search terms as research finding from studies on these conditions could provide useful techniques or strategies that could be applied to the management of endometriosis. Presented below is an exploration of the evidence base, which is summarised in a table in the appendix (Appendix 1).

4.1.1 Psychological Therapy and Mind-Body Interventions

When developing or using an intervention specific factors should be considered, that may lead to positive of negative psychological outcomes: demographic variables, endo-related variables and individual differences (self-esteem, body esteem and emotional self-efficacy) (Facchin et al, 2017). Women, who are newly diagnosed with endometriosis have an increase in anxiety compared with those who have time to understand their diagnosis and those with more severe pelvic pain are more likely to experience poor mental health (Facchin et al, 2017). Teaching and supporting patients ways of managing their physical symptoms and the psychological impact is a fundamental part of multidisciplinary treatment and can help to minimise the devastating impact that endometriosis can have on the sense of self (Facchin et al, 2017). A qualitative study explored what people with chronic illness describe as their strengths related to their health and wellbeing (Krisjansdottir et al, 2018), the findings of this study are similar to those of the photovoice needs assessment conducted as part of the development of this intervention. The study found that personal strengths could be categorised into three domains: internal strengths (being persistent, having a positive outlook, being kind and caring, experiencing positive emotions, being kind towards oneself, reconciling oneself with the situation, having courage and having knowledge and insight), external strengths (support from family and friends) and self-management strategies (being active, planning and prioritising, reducing stress, goal setting and seeking knowledge and help. The authors found that people with conditions who practices self-compassion reported lower stress levels. It's important that participants strengths be identified and incorporating into any psychological intervention. The support of friends and family can be helpful when something new. Maintaining a positive outlook and taking a self-compassionate approach instead of a self-critical approach may also be helpful when living and self-managing symptoms of a chronic illness.

Research into self-management interventions used by people diagnosed with endometriosis has shown that psychological interventions mostly focus on symptoms, especially the primary symptom of chronic pelvic pain (Buggio et al, 2017). An alternative has been suggested:

interventions with distressed endometriosis patients should not exclusively focus on pain but instead facilitate the expression of thoughts and feelings about endometriosis and work to 'empower the female identity' (Buggio et al, 2017). The authors suggest the use of psychotherapy interventions, either group or individual. They argue there is a need for adequately designed trials to investigate the extent of the benefit of psychotherapeutic interventions such as CBT or psychodynamic therapy.

One of the first systematic reviews that evaluated the effectiveness of psychological therapies for treatment of chronic pelvic pain, not endometriosis specifically, demonstrated the scant nature of evidence on the use of psychological therapies and emphasised the need for more robust studies (Champaneria et al, 2012). Since, then more studies have been published, the results of a systematic review examining the evidence for psychological and mind-body interventions to improve endometriosis symptoms and the emotional impact (Evans et al, 2019) support Champaneria et al's (2012) and Buggio et al's (2017) findings that there is a lack of studies that have used the gold standard methodology, meaning definitive conclusions cannot be offered. The authors suggest that there is likely to be a transactional relationship between distress, pain and inflammation in endometriosis patients. The review examined interventions such as hypnosis, psychotherapy, mindfulness and relaxation. The authors found that almost all of 12 studies (89%) reported improved pain, all the studies that looked at anxiety and/or depression reported a reduction in symptoms and one qualitative also looked at sleep and found that the women reported improvement in sleep (Evans et al, 2019). The authors of this study state that yoga can help endometriosis patients to develop greater self-knowledge, autonomy and self-care, causing them to reduce medication (Goncalves et al, 2016). The group environment also provided psychosocial support, women being around others with similar symptoms (Goncalves et al, 2016). The review concluded that there is an issue with low methodological quality but that there are positive findings that suggest psychological and mind-body interventions have the potential to reduce pain and other symptoms. The authors call for better designed RCTs, as it is likely that endometriosis patients will benefit from an MDT setting that includes psychological health and wellbeing (Evans et al, 2019). Another review, conducted the same year aimed to determine the effectiveness of psychological interventions resolving psychological and pain related loss of function associated with endometriosis and to identify gaps in the literature (Van Niekeik et all, 2019). This review supports the Evans et al (2019) review findings: combined mindfulness, psychoeducation and CBT showed significant improvements in pain coping and quality of life. However, there is a substantial need for evidence based psychological interventions and high-quality studies that improve to reduce pain and improve quality of life for those living with endometriosis (Van Niekeik et al, 2019). The results of these reviews are similar to the at systematic review conducted for the development of this intervention, although that review looked at pain reduction and our review looked at quality of life. Some of the same studies were included in both reviews.

A qualitative study of six focus groups evaluated the precepts of women with endometriosis and chronic pelvic pain regarding their social ties (Mellado et al, 2016). The study found social isolation was the main identified theme and was associated with a lack of understanding about endometriosis symptoms and with resignation in the face of recurrent pain. The women in the focus groups reported avoiding partner intimacy and isolation from friends and family as components of social isolation. The authors recommend including rebuilding social ties in the objectives of multidisciplinary management of endometriosis and chronic pelvic pain (Mellado et al, 2016). Group interventions may be more effective for women with endometriosis as women can benefit from the therapeutic element as well as social support from others in the group. A quantitative study reporting the development and feasibility of a group-based yoga program for women with chronic pelvic pain (not endometriosis specifically) found that it was feasible to teach women with chronic pelvic pain to practice yoga to self-manage pain, improve Quality of Life and sexual function (Huang et al, 2017). The findings of the Goncalves et al. (2016a) and the Huang et al. (2017) studies both suggest that group-based interventions are useful because the provide social/peer support as well as the therapeutic element of yoga. In a quantitative study investigating the use of Hatha yoga as a treatment for endometriosis-associated pain, the women in the yoga group showed a significant reduction in pain, lower stress levels and greater relaxation, compared with the control group(Goncalves et al, 2016b). The authors suggest that relaxation used in yoga practice can counteract the negative effects of stress by restoring balance to the autonomic nervous system and the hypothalamic-pituitary-adrenal axis. The authors also found that improving one domain of quality of life may affect improvement in other domains of the EHP-30 (Jones et al, 2001), for example, having control and feeling less powerless might have improved self-image and emotional wellbeing (Goncalves et al, 2016b).

Yoga classes often include elements of mindfulness and meditation practice. It is useful to consider the evidence behind yoga and mindfulness separately but also note that there is an overlap between the two. Yoga is used as a form of exercise, mindful movement but is also used to allow meditators to practice prolong sessions of mediation. Mindfulness has been used and researched as an adjunct treatment for chronic health conditions since the 1970s (Kabat-Zinn, 1979). More recently mindfulness has gained popularity clinically and commercially. A systematic review and meta-analysis of whether mindfulness can improve outcomes in patients with chronic pain (Bawa et al, 2015). The results of the review found 11 studies, conditions included were fibromyalgia, rheumatoid arthritis, chronic MSK pain and failed back surgery syndrome (endometriosis was not included). The review found limited evidence for the effectiveness of mindfulness-based Interventions in chronic pain. Studies were generally small, and results were not always statistically significant. The meta-analysis revealed that mindfulness-based interventions may have a possible impact on perceived pain control, with a moderate effect size.

In the last decade there have been a number of studies published that report the results of using mindfulness-based interventions for improving or reducing symptoms of endometriosis and chronic pain itself. Although systematic reviews have shown studies are often of lower methodological quality and often provide limited evidence, it can be useful to look at the recommendations of the studies themselves. Frequently these studies lack control group as the interventions are run by clinicians for treating patients, in the hopes of improving their quality of life. Endometriosis and adenomyosis symptoms may be lifelong conditions and symptoms can reoccur after surgical and hormonal interventions. Most of the mindfulness-base intervention studies report the complexity of managing or treating symptoms and often call for further, more methodological sound studies. The studies are often preliminary, pilot or feasibility studies. Chronic pelvic pain studies have been included in this section as it takes an average of 7.5 years to be diagnosed with endometriosis, it is possible that undiagnosed endometriosis is the cause of this pain.

A pilot study tested the feasibility of teaching mindfulness meditation to women living with chronic pelvic pain and found it has the potential to improve quality of life (Fox et al, 2011). The results of another pilot study with a 6-year follow up show that there were statistically significant and lasting effects on participants pain level, wellbeing and ability to function in daily life (Kold et al, 2012, Hansen et al, 2017). Most interventions for chronic health conditions use a form of MBSR, developed by Jon Kabat Zinn (1979, 1982) for this very purpose. This study used MBSR and contains three types of interaction: mindfulness training (body scan, sensory training, breathing techniques, music and bi-feedback support), psycho-education and group dialogue and one to one sessions that were adapted for the individuals personal goals and challenges. This intervention trained participants to notice their own breathing and to voluntarily change it from patterns associated with tension toward those of relaxation. The psych-education element included: grief process and emotions associated with adapting healthy habits, social support and mind-body interactions (Kold et al, 2012). The results initially showed a complex pattern, the authors later issued a Corrigendum (2016) stating tan error during data analysis. The results in fact showed statistically significant improvements in all eight SF-36 subscales. They also used the endometriosis specific scale the EHP-30, all five standard scales showed improvements and four of them still showed improvements at the one year follow up: pain, control and powerlessness, emotional wellbeing and social support. The sexual function scale failed to show improvement. The intervention successfully improved physical, psychological and social aspects of the participants problems. The authors concluded that using a mindfulness- based intervention with endometriosis patients experiencing pelvic pain is feasible and may produce positive effects on quality of life (Kold et al, 2012). The six year follow up showed lasting improvements on almost all scales of the EHP-30 and SF-36 (Hansen et al, 2017).

Women serving in the military face unique challenges in treating and managing their chronic pelvic pain. A feasibility study investigated implementing an MBSR program for women serving in the military and experiencing chronic pelvic pain. (Crisp et al, 2016). The authors experienced difficulties regarding availability of classroom space due to permanent change of station for the researchers. They did find that the women in the study found that lifestyle challenges made sustained engagement difficult. Results did show the participation in an MBSR program can reduce pain and promote modulation of select pro-inflammatory cytokines. The authors recommend consideration of the structure and mode of program delivery of MBSR programs (Crisp et al, 2016). This study is important as it raises an issue that doesn’t just affect women in the military. Mindfulness interventions traditionally take place in the evening or weekend and require a 2-2.5 hour commitment of attending sessions face to face for 8 weeks. Participants also have to commit to practicing meditation at home, six out of seven days a week. This can lead to the exclusion of single parents, people who don’t work none to five jobs, people who live in rural areas, those with transport issues, carers, those who travel for work or have other intermittent commitments but mostly it excludes or makes attendance difficult for those the programs were designed for: disabled people. People who live with chronic pain often have many other priorities in their life and may have to prioritise rest over leaving the house in the evening.

An article written about what to do when chronic pelvic pain cannot be resolved or treated by surgery reviewed nonpharmacological therapies (Till et al, 2017). The authors recommend that effective treatment requires a multifaceted approach, they found evidence for the use of: physical therapy and trigger point injections, neuromodulation techniques and TENS, behavioural strategies such as exercise, CBT and mindfulness. CBT and mindfulness were considered to be helpful for chronic pain patients as chronic pain is associated with prop coping skills and maladaptive avoidance behaviours. The authors stated the mindfulness had shown promise in fibromyalgia patients but that, unfortunately CBT therapists that specialise in chronic pain can be difficult to find. Due to this, the authors recommended that web-based CBT and/or mindfulness interventions be used (Till et al, 2017).

Web-based interventions are an obvious solution to challenges with finding face to face therapy or interventions. A recent trial (Ball et al 2020) used Headspace, a pre-existing meditation app for smartphones and a relaxation app (also designed by Headspace) as a control group for women in an outpatient clinical for chronic pelvic pain (not endometriosis specifically). The authors were disappointment by the low level of engagement, even though pre-study PPI focus groups showed that patients were enthusiastic about using an app. There were thirty-one participants in the intervention group, six used the app regardless of and 4 used it when experiencing extreme pain. The authors found that barriers to use included: lack of familiarity and capabilities with technology, failure to establish a routine, busy lives and lack of perceived benefit. Participant feedback included more guidance at the beginning of the study. The authors suggested that there needs to be an understanding of what motivates those with a clinical need to use an app for clinical reasons, appropriate expectations needs to be set from the beginning for participants and that incentivisation (gamification) may improve motivation levels. The authors also suggested that future studies consider unexpected benefits e.g. relieving stress rather than pain. This app was designed to be used individually, it lack the psychosocial element that participants in face to face mindfulness and yoga groups had benefitted from. The authors advised that future studies include social support and a ‘community practice’. This study used a pre-existing app, which did not include input from patients. It could be argued that the main finding from this study is that chronic pelvic pain has many causes and can be complex to treat, assumptions should be made about patient needs, including social support and psychoeducation. It is understandable that chronic pain patients wouldn’t respond to a meditation app, that aims to reduction their pain rather than provide a tool to help them self-manage. One size does not fit all, a mediation app is designed to teach meditation and perhaps can’t be considered a psychological intervention. Nevertheless, the findings of this study hold great value for researchers attempting to provide a self-management online course of many different modalities e.g. mindfulness, ACT, CBT.

In summary, due to a lack of high methodological quality studies, there is limited evidence into the effectiveness of psychological and mind interventions in improving quality of life for people living with endometriosis and or adenomyosis. Both CBT and mindfulness have shown they may have potential for helping patients struggling with the impact of endometriosis on their mental health. The findings of the studies above point highlight that self-compassion and the mind-body link are important qualities to include in an intervention developed for people experiencing chronic pelvic pain, mindful movement and relaxation exercises will be included. A number of studies have shown that psychosocial support is just as important for women’s quality of life as the therapeutic modality used. Face to face group interventions can be difficult to access and attend, therefore an online intervention can be provided as an acceptable solution to these issues. Any intervention developed needs to be developed with the needs of endometriosis patients in mind. Therefore, importance will be placed on the data from the needs assessment and a control group will also be used to determine if an online, group mindfulness intervention is more beneficial than treatment as usual.

4.1.2 Online Resources and Tools

The literature search also included terms related to mHealth apps and online self-management courses for endometriosis, chronic pelvic pain and other chronic conditions. The internet can be a helpful resource for those newly diagnosed with endometriosis and/or adenomyosis. A systematic review investigated the accuracy of information available online when the term endometriosis is Googled (Hirsch et al, 2017). The review found that the internet is 'the source of health information, as patients can access the information quickly, conveniently and privately' (Hirsch et al, 2017). The authors evaluated websites for credibility, quality, readability and accuracy. The found that over a third of web pages did not attribute authorship and almost half did not report sources. Over 750 pages were returned during searches, 54 were included in the review and only one page provided accurate, evidence-based information, clearly communication in plain English. This study shows that the internet can be a useful and easily accessed tool, that women can use privately in the comfort of their own home, however there can be quality and accuracy issues with websites. The review did not include social media posts on Facebook, Instagram or Twitter, which women often use to connect with others experiencing similar symptoms, looking for information or social/emotional support.

Social media is another online resource that can be both helpful but also come with inaccuracies and challenges. Social media can be beneficial for people living with chronic illness, it can provide a connection to others then might not be in contact with otherwise. The therapeutic affordances of social media for people with chronic pain were investigated (Merolli et al, 2014). The authors argued that although research has suggested that social media is well suited to enhance the management of chronic health conditions there is an absence of published studies examining the underlying therapeutic mechanisms of the use of social media. The authors suggested five therapeutic affordances: identity (used to present perceptions regarding disclosure of identity in online social environments), flexibility (the time-space freedom enabled by social media, such as the ability to interact at time suiting the individual and where they choose), structure (the guidance and filtration present in information seeking that social media can provide), narration (encompassed social media's utility to provide a platform to share stories of illness) and adaption (referred to the capacity for one's self-management to evolve through social media to meeting particular needs based on current symptoms). Social media can be useful in a number of ways for those living with chronic pain and health conditions, however, it can be difficult to measure the clinical impact of social media on health outcomes (Merolli et al, 2014). Social media provides more than just a means of communication and contact with others, it allows users to research self-management strategies, to construct an online identity, to share storied of their experiences and to do this at a convenient time for the user.

Women living with endometriosis can access social media to employ the therapeutic affordances explained above, but they can also access online support groups. These can take the form of closed Facebook groups or online forums. The therapeutic affordances of online support groups have been explained as: connection (the ability of connection in order to support each other, exchange advice and try to overcome feelings of loneliness), exploration (the ability to look for information, learn and bolster their knowledge), narration (the ability to share their experience as well as read about the experiences of others) and self-presentation (the ability to manage how they present themselves online (Shoebottom et al, 2016). The authors found that associated outcomes of using online support groups were mostly positive, getting reassurance and improved caring. The negative concerns included concerns about the accuracy of information, arguments between members, overreliance on the groups, becoming upset by negative experiences or good news items and confidentiality. Accuracy of information available about endometriosis online is a real concern as Hirsch et al (2017) have shown above. Online support groups can provide a useful form of support and combat the social isolation often reported by those living with endometriosis and chronic pelvic pain, however, users should use them with an awareness of the issues they may encounter.

Along with the internet, social media and online support groups, mHealth apps have increased in use in recent years. mHealth apps can take different forms, they may contain a self-management tool such as Headspace, they may encourage behaviour change such as smoking cessation or weight loss or they may monitor symptoms or remind a user to take a medication. Incentivising or gamification is often used for health promotion, to encourage users to engage with the app. A systematic review investigated the use of health apps containing gaming elements and analysed the embedded behaviour change techniques (Edwards et al, 2016). The reviewers screened 168- medical, health and wellness or health and fitness apps, of which 64 met inclusion criteria. The apps included aimed to: increase/improve exercise, improve fitness, smoking cessation, encourage oral hygiene, weight loss and blood glucose adherence. The median number of behaviour change techniques was 14. The most common behaviour change techniques were: feedback and monitoring, comparison of behaviour and reward and threat. The most used individual techniques were: self-monitoring of behaviour, non-specific reward, non-specific incentive, social support unspecified and focus on past success. The authors found that smartphone games or apps can provide a potentially cost-effective platform for health promotion and could have a substantial public health impact. A study looked at the use and recommendation of mHealth apps by pharmacists, the public's perceptions of mHealth apps and awareness and use of these app by diabetics in particular (Kayyali et al, 2017). Over half of the pharmacists (56%) that responded were aware of mHealth apps, 60% of which had recommend mHealth apps to patients. Over 76% of individuals in the general public own a smartphone and the most used applications are health and lifestyle (24%), social app (19%) followed by news (18%). The authors concluded that despite the growing number of mHealth apps, the level of awareness and usability of these app by patients and pharmacists is low, although majority who use mHealth apps found them beneficial. (Kayyali et al, 2017). Whilst the term gamification can have negative connotations, associated with gambling, when viewed in terms of behaviour change techniques, they can make an app more successful for both the developer and the user. Gamification in mHealth apps can lead to users developing healthier habits, self-monitoring and self-managing their symptoms and making lifestyle changes.

In summary, an online psychological or mindfulness intervention can be enhanced by importing elements of social media and support groups, enabling users to benefit from their social affordances as well as the therapeutic element of mindfulness. Online mindfulness courses or apps tend to be used by individuals and lack the psychosocial aspect of face to face mindfulness classes. Including an online forum or another way of allowing users to communicate and sharing with each other in a similar way as social media or support groups could provide many therapeutic benefits, in addition to psychosocial support. However, guidelines will need to be provided in order to minimise the risk for over-reliance, sharing of inaccurate information, disagreements between users and to protect confidentiality. Combining the therapeutic affordances found in the use of social media and support groups with gamification, could lead to users encouraging each other to achieve goals or overcome challenges. As the users will be new to an online mindfulness intervention, they will be able to share their reflections on meditating and if they are noticing any changes or improvements. In order to maximise accessibility and usability, the intervention will need to function well on smartphones, tablets and laptops as well as desktop computers. Mediation should be available offline and users should be to use the function of uploading and sharing photographs. Photography proved to be therapeutic for the co-researchers in the photovoice study, but also mimics the functionality of social media platforms such as Facebook, Twitter and Instagram.

4.1.3 Self-Management Strategies and Interventions

Self-management was the largest theme identified in the photovoice needs assessment study. The co-researchers shared the effort and sometimes burden of self-managing symptoms of endometriosis and adenomyosis. An online survey of Australian asked women with endometriosis about their self-management strategies (Armour et al, 2019). Self-management strategies used included: heat (70%), rest (68%) and meditation or breathing exercises (47%). The women also reported using negative strategies with associated adverse events such as: alcohol/hangover (52.8%), exercise/increased pain (34.2%), heat/burns (15.9%). The authors concluded that effective self-management strategies and lifestyle changes can play an important role in managing symptoms and may ‘empower’ women in taking more control over their own health and providing an effective add on to their current treatment, they also stressed that women with endometriosis have unique needs and self-management practices need to be considered in light of potential for flare ups (Armour et al, 2019). As this study shows it is important to consider adverse events of any intervention or self-management strategy, as even helpful strategies such a heat can also have adverse events/effect (burns). Overall self-management courses, both face to face and online have shown benefits to people living with chronic health conditions, including chronic pain. Benefits have included reductions in pain, physical disability, pain self-efficacy, pain intensity, pain interference, pain catastrophising and depression and anxiety and alter patients feelings of empowerment and help prevent medication misuse (Mehlsen et al, 2015, Wilson et al, 2015, Riva et al, 2014, Nicholas et al, 2011). Web-based chronic pain management programs have advantages including: inexpensive to scale to provide services to larger and diverse populations, conveniently accessible about the clock and allow a tailored experience to specific symptoms or needs (Nevedal et al, 2013).

An RCT tested the efficacy of an online chronic pain self-management program (Ruehlman et al, 2012). Participants were recruited online, not from clinical setting, the program was a fully self-directed and self-paced system that integrated social networking features and self-management tools into an interactive learning environment. The results showed significant decreases in pain severity, pain related interference and emotional burden, perceived disability, catastrophising and pain induced fear. The program included four categories: cognitive, behavioural, social and emotional regulation. The authors concluded that a self-paced, interactive pain management training program can achieve measurable effects on pan, mental health and learning outcomes (Ruehlman et al, 2012). Another RCT investigated the outcomes of using internet self-management activities to reduce pain and improve quality of life (Rod et al, 2016). The results showed that internet based self-management activities were useful to those who could not access multidisciplinary pain management and found modest improvements in pain, anxiety, depression and quality of life (Rod et al, 2016).

An online intervention was developed and evaluated for patients with bladder pain syndrome/interstitial cystitis (IC) (Lee et al, 2014). IC symptoms are often confused with endometriosis symptoms, although it is possible to have both conditions. The 8-week intervention included guided imagery/meditation, diet information and exercise advice. The intervention encouraged self-management strategies that were effective at improving quality of life and alleviating symptoms of IC (Lee at el, 2014). An RCT examined the effect on an online self-management curriculum among breast cancer survivors (Smith et al, 2018). The curriculum consisted of web-based content and required activities including attending one online introductory group meeting, viewing videos and completing cognitive reframing and mind-body exercises over an 18-week period. The results showed there was a significant difference in change between the intervention group depression scores and the treatment as usual control group scores. The authors reported reduction in depression and fatigue but not pain severity and concluded that online programs can be a feasible and effective alternative to in person support (Smith et al, 2018).

A report of the results of three separate studies of web-based CBT and ACT interventions that included e-diaries and feedback through smartphones (Nes et al, 2013). The participants in the studies had either IBS, CWP or type 2 diabetes and results showed than there are advantages to using the internet to deliver self-care and behaviour change interventions, interventions with strong theoretical foundations can achieve positive results in short and mid-term time frames. A study that collates the results of ten years of CBT pain self-management outpatient programmes for complex chronic conditions found that symptoms of pain can be greatly reduced as well as depression and anxiety (Boschen et al, 2016). A systematic review investigated the effectiveness of an mHealth self-management intervention of improving sleep, psychological distress, fatigue and sleep in cancer survivors (Silva et al, 2009). The results showed that mHealth interventions that support self-management can improve pain and fatigue in cancer survivors, and some promise for psychological distress and sleep outcomes. The most promising outcomes are the improvements shown in fatigue outcomes. The improvements shown for cancer survivors are promising for an endometriosis population as the level of quality of life for both populations have been found to be impacted in similar ways.

A literature review found that there is a lack of theory driven research and low use of behaviour change techniques in group-based self-management programmes (Keogh et al, 2015). Another review aimed to identify information needs and gaps in chronic pain management as well as technology features to inform the development of an internet-based self-management program (Gogovor et al, 2017). Thirty-nine articles related to twenty patient-orientated internet-based programs. Gaps included lack of knowledge, limited access to health care, suboptimal care and lack of self-management support. Patients considered essential features of an internet-based program as: simple to use, user friendly with a little animation, bilingual, use language that patients can understand with clickable definitions when necessary and be accessible via mobile devices and also include non-medical activities of daily living (Gogovor et al, 2017).

There can be barriers and facilitators to chronic pain self-management (Bair et al, 2009). Barriers to pain self-management may include: lack of support from friends and family, limited resources (e.g. transport, finances), depression, ineffectiveness of pain relief strategies, time constraints, avoiding activity because of fear of pain exacerbation, lack of tailoring strategies to meet person needs and not being able to maintain the use of strategies after study completion. Facilitators may include: encouragement from healthcare professionals, improving depression with treatment supportive friends and family and providing a menu of different self-management strategies to use (Bair et al, 2009). Another facilitator may be encouraging participants to form habits related to self-management strategies. A study into the modelling of habit formation in the real world aimed to investigate the development of automaticity (Lally et al, 2010). Participants were asked to repeat a behaviour of their choice, in response to cue, in an everyday setting without an extrinsic reward. Results showed that for the majority of participants, automaticity increased steadily over the days of the study, supporting the assumption that repeating a behaviour in a consistent setting increasing automaticity (Lally et al, 2010).

Another potential facilitator of a self-management program for a chronic health condition is the concept of 'social identification' (Cameron et al, 2018). Social identification refers to the extent to which group membership shapes self-conception, along with its contribution to self-evaluation and the emotional bond between the individual and group (Tajfel, 1978). Social identification can be a curative mechanism in group interventions, individuals experiencing a sense of belonging to a group. The potential benefits of belonging to a social group is that the members can facilitate goal attainment by lending each other a sense of efficacy in the pursuit of their aims. The results of this study showed that social identification had a bolstering effect on participants confidence in managing various challenges of their chronic disease. Results suggest that social identification – the psychological link of the individual to a contextually meaningful group – can provide an avenue to a number of social processes and resources that promote health related outcomes. These results confirm that group self-management programs can fulfil social needs and be enhance by social identification (Cameron et al, 2018).

Evidence suggests that connectedness is also a protective factor against developing depression or of current depressive symptoms worsen (Cruwys et al, 2013). An RCT that looked at how intersession coping skills practice mediates that relationship between readiness for self-management treatment and goal accomplishment, in a CBT intervention (Heapy et al, 2005). The findings demonstrated that participants practice of pain coping skills and other actions designed to promote behavioural goal accomplishment account for a significant proportion of the variance in a measure of self-reported attainment of behavioural goals. The authors also found that participants beliefs about the relevance of learning and using behavioural and cognitive skills may serve an important role in determining willingness to engage in a self-management programme (Heapy et al, 2005). The message taken from this study is that for participants to feel accomplished by the end of a self-management programme, they need to feel they have attained their goals. Self-management programmes can help participants achieve their goals by explaining the relevance of the skills they are learning and encouraging them to use the skills in between session of the programme.

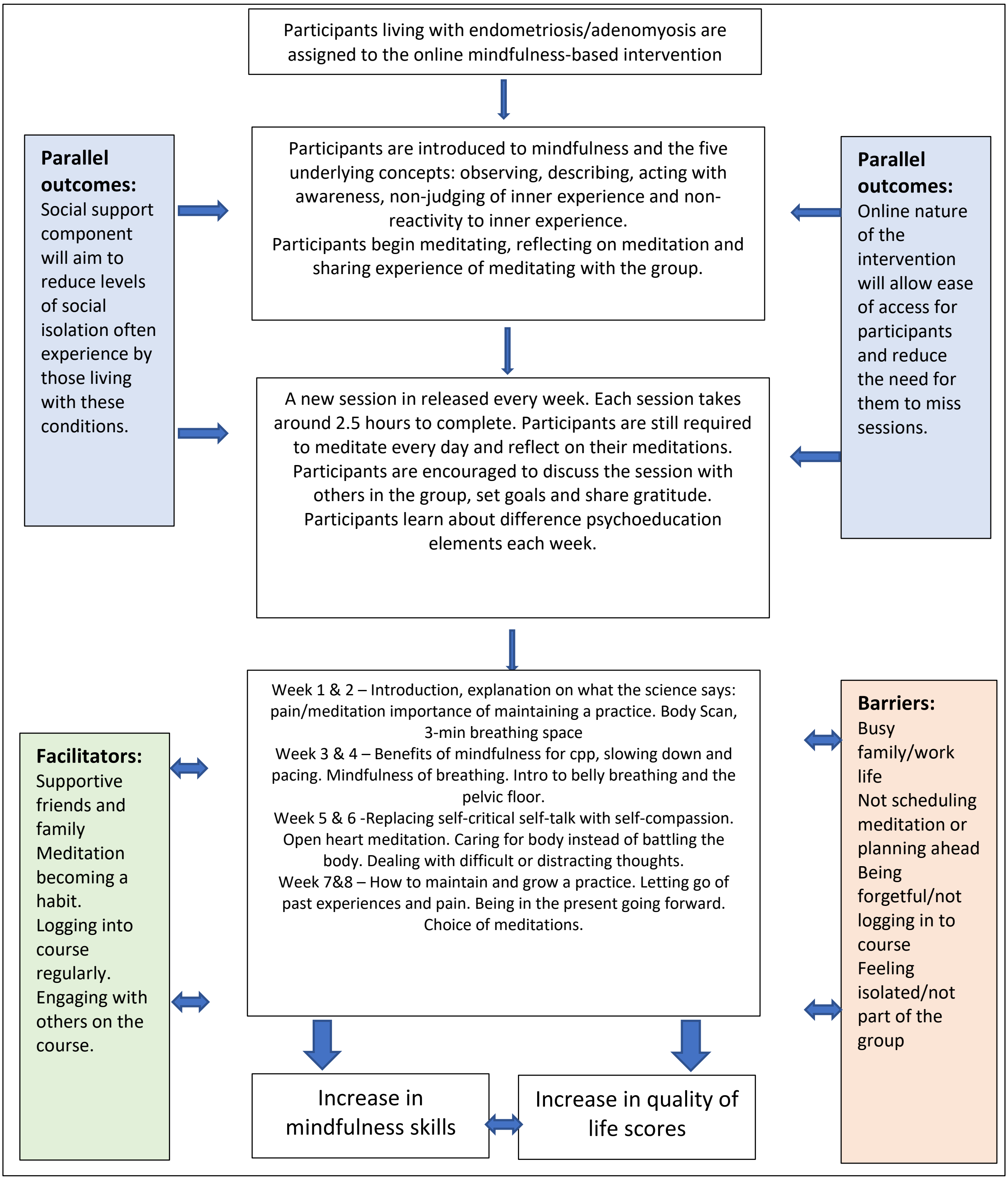
This intervention for people living with endometriosis and/or adenomyosis will be delivered online using the iHOPE digital platform. This platform has produced positive results for face to face and digital, peer delivered self-management courses for cancer survivors (Turner et al, 2012, Martin et al, 2020). The face to face self-management support programme showed statistically significant improvement in general quality of life, cancer specific quality of life and goal planning (Turner et al, 2012). The 6-week digital, peer delivered self-management programme included group curative factors of instilling hope, universality and altruism in the programme, psychosocial factors already mentioned above as being useful for those living with endometriosis. The results of the iHope, digital intervention showed that 61% participated in all 6 sessions, the mean number of session undertaken was five, 45% completed at least 3 sessions and the end outcome measures. Of the participants that completed the satisfaction questionnaire, over 90% found the programme easy to navigate, well-managed by the peer facilitators and the social networking tools useful (Martin at al, 2020). This study found the feasibility evidence promising, showing that the peer delivered digital iHOPE programme is acceptable and practical (Martin et al, 2020). The result of both of these studies show that using the iHOPE platform for an online mindfulness-based intervention with a psychosocial element, has the potential to be considered a feasible and acceptable self-management programme for people living with endometriosis and/or adenomyosis.

In summary, again there is very little published research findings on the use of self-management programmes for people living with endometriosis and/or adenomyosis, although there is some evidence when the net is widened to include chronic pain patients. Self-management programmes have the potential for reducing painful symptoms and improving mental health. They can provide users with coping skills and support them in goal attainment. Online self-management programmes can be useful for those who find it difficult to engage with traditional face to face courses, technology has been developed that now means these programmes can include e-diaries and social media like aspects. The increased use of smartphones now mean that online self-management programmes are more portable and accessible than ever. There are a number of barriers and gaps that are discussed above, avoiding or addressing these can decrease the potential failure of the programme. There are also a number of facilitators to keep in mind and include to encourage participants to engage with a programme.

5.0 Outcomes Chain

An outcomes chain is important as it is the main device for thinking about how the program will function to achieve results and address the situation (Funnell and Rogers et al, 2011). The previous section provides the rationale for why an online mindfulness-based self-management program has been developed, with the aim of improving quality of life for people living endometriosis and/or adenomyosis. This section will show the assumed cause-and-effect relationship between intermediate outcomes and ultimate impact of the programme.

Figure 3. Outcomes Chain



Participants living with endometriosis/adenomyosis are assigned to the online mindfulness-based intervention

Participants are introduced to mindfulness and the five underlying concepts: observing, describing, acting with awareness, non-judging of inner experience and non-reactivity to inner experience.
Participants begin meditating, reflecting on meditation and sharing experience of meditating with the group.

A new session in released every week. Each session takes around 2.5 hours to complete. Participants are still required to meditate every day and reflect on their meditations. Participants are encouraged to discuss the session with others in the group, set goals and share gratitude. Participants learn about difference psychoeducation elements each week.

Week 1 & 2 – Introduction, explanation on what the science says: pain/meditation importance of maintaining a practice. Body Scan, 3-min breathing space
Week 3 & 4 – Benefits of mindfulness for cpp, slowing down and pacing. Mindfulness of breathing. Intro to belly breathing and the pelvic floor.
Week 5 & 6 -Replacing self-critical self-talk with self-compassion. Open heart meditation. Caring for body instead of battling the body. Dealing with difficult or distracting thoughts.
Week 7&8 – How to maintain and grow a practice. Letting go of past experiences and pain. Being in the present going forward. Choice of meditations.

Increase in mindfulness skills

Increase in quality of life scores

Parallel outcomes: Social support component will aim to reduce levels of social isolation often experience by those living with these conditions.

Parallel outcomes: Online nature of the intervention will allow ease of access for participants and reduce the need for them to miss sessions.

Facilitators:
Supportive friends and family
Meditation becoming a habit.
Logging into course regularly.
Engaging with others on the course.

Barriers:
Busy family/work life
Not scheduling meditation or planning ahead
Being forgetful/not logging in to course
Feeling isolated/not part of the group

5.1. Intended Outcomes

The Outcomes chain above shows how participants will progress through the online mindfulness-based course each week for eight weeks In order to achieve the intended outcomes of the intervention . The participants will benefit from the parallel outcomes such as social support and ease of accessibility of the course, these outcomes will strengthen and add to the main components of the course as well as being beneficial themselves. The facilitators and barriers will be discussed with participants as these will either help or hinder the participants progression through the course. It is hypothesised that an increase in mindfulness scores will correlate with an improvement on quality of life scores. It is also hypothesised that participants that spend more time meditating will show a corresponding increase in mindfulness scores, compared with participants that meditated for less time.

This online mindfulness-based course is loosely based on the Mindfulness-Based Stress Reduction course created by Jon Kabat Zinn (1979). The online sessions will following a similar format as the face to face sessions on MBSR, with some elements adapted to an online format and included specific examples of how and why mindfulness formal and informal practices can be used as self-management techniques for managing the impact that endometriosis and/or adenomyosis can have on quality of life. However, just like online support groups and social media there can be unintended outcomes or adverse events when using a mindfulness-based intervention. These are explored in more detail below.

5.1. Unintended Outcomes

When program planning and deciding on intended outcome and the theory behind the outcomes it is important to keep in mind that researchers have an ethical duty of care to their participants, which includes the consideration of unintended outcomes and adverse events of an intervention. The unintended outcomes maybe be a reduction in pain symptoms but not an increase in quality of life scores, or an increase in quality of life scores but no change in the mindfulness scores. Participants may report an increase or decrease in fatigue symptoms. A systematic review on the safety of mindfulness-based interventions found participants reported excessive sleepiness, headache and dizziness and sleep disruption as minor and temporary unintended outcomes (Wong et al, 2018). This systematic review found 36 RCTs met their inclusion criteria, 25 were MBSR trials and 11 were MBCT trials, there were a total of 4031 participants, aged between 12.5 and 74.9 years, in the trials. There were 19 adverse events reported in the mindfulness intervention groups (1%) and 19 adverse events in the control group (0.9%). In the 25 MBSR studies there were no serious adverse events reported, only 3 trials reported at least one intervention related adverse events, including four cases of anger or anxiety in a pain trial, one case of soreness in an anxiety trial and one of a strained neck in a family caregiver trial (Wong et al, 2018). The soreness and strained neck appear to be related to the mindful movement component of the intervention, and this should be taken in consideration when teaching this component, particularly with participants who aren’t often active.

In the same review 2 of the 11 MBCT trials reported serious adverse events, which were unrelated to the intervention. On trial reported 4 cases of hospitalisations due to physical health problems and one case of hospitalisation due to overdose, as well as 9 cases of hospitalisations in the control group. Another trial comparing effectiveness of MBCT with maintenance antidepressant use for prevention of depression relapse reported 10 serious adverse events, but the researchers stated that these events were not connected to the trial itself (Wong et al, 2018). The review concluded that there were very few adverse events in the MBI trials, and even fewer were attributed to MBI's. The authors of the review regarded MBSR and MBCT interventions to be relatively safe but did urge researchers and practitioners to pay attention to temporary negative emotions and increased depression and anxiety, which could be possible when participants are exploring their inner experiences (Wong et al, 2018). This review has implications for researcher, researchers should consider reporting the potential adverse events and continue to take the necessary precautions e.g. screening for vulnerable individuals, having a larger follow up period, recognising the importance of control groups and following trial guidelines and reporting requirements. Indeed, the MBCT implementation resource includes safety advice and caution over health history of participants in groups. The suggested exclusion criteria includes active or recent physical addiction to alcohol or drugs, suicidality, psychosis, PRSD, acute depression, severe social anxiety and physical illness that would prohibit attending a course (Kuyken et al, 2012). The National Center for Complementary and Integrative Health (NCCIH) states that meditation could cause or worsen certain psychiatric problems and urges those with these problems considering trying meditation to contact their doctor. On the same page they say that some research suggests that meditation may physically change the brain and could potentially help to improve many health problems and promote healthy behaviours (NCCIH, 2020).

A critique of mindfulness research has expressed concerns that 'misinformation and poor methodology associated with past studies of mindfulness may lead public consumers to eb harmed, misled and disappointed' (Van Dam et al, 2018). The authors also expressed concern about potential adverse effects from practicing mindfulness, not just taking part in intervention studies. They found more than 20 case studies and observation studies that reported meditation-related experiences that were serious enough to need additional treatment or medical treatment. These studies included reports of meditation related psychosis, mania, depersonalisation, anxiety, pain, traumatic-memory and other forms of 'clinical deterioration' (Van Dam, 2018).The authors also found that whilst 100% of pharmacology trials met the CONSORT requirements, including actively assessing adverse events, only 26% of meditation trials actively assessed adverse events, instead using spontaneous reporting instead.

Conclusion

Any unintended outcomes or adverse events that occur during the feasibility trial of this intervention will be recorded and reported. There is currently a screening information sheet, and a paragraph informing potential participants that the trial is designed to test feasibility and acceptability of the intervention and it is not a replacement for medical advice or psychological therapy. Nevertheless, participants will be given additional advice and signposted to the relevance point of help. Participants will have the option of discussing their experiences: positive or negative during the intervention and at the end of the trail, as some participants from intervention group will be invited to take part in interviews, even if they dropped out of the intervention.

References

Armour, M., Sinclair, J., Chalmers, K.J. and Smith, C.A. (2019) Self-management strategies amongst Australian women with endometriosis: a national online survey, *BMC Complementary and Alternative Medicine,*

Bair, M.J., Matthias, M.S., Nyland, K.A., Huffman, M.A., Stobbs, D., L., Kroenke, K. and Damush, T.M. (2009) Barriers and facilitators to chronic pain self-management a qualitative study of primary care patients with comorbid MSK pain and depression, *Pain Medicine,* 10, 7

Ball, E., Newton, S., Rohricht, F., Steed, L., Birch, J., Dodds, J., Cantalapiedrea-Calvete, C., Taylor, S. and Rivas, C. (2020) mHealth – providing a mindfulness app for women with chronic pelvic pain in gynaecology outpatient clinics: qualitative data analysis of user experience and lesson learnt, *BMJ Open,* 10

Bawa, F.L., Mercer, S.W., Altherton, R.J., Clague, F., Keen, A., Scott, N.W. and Bond, C.M. (2015) Does mindfulness improve outcomes in patients with chronic pain? Systematic Review and Mata-analysis, *British Journal of General Practice,*

Bertero, C., Alehagen, S. and Grundstrom, H. (2019) Striving for a biopsychosocial approach: A secondary analysis of mutual components during healthcare encounters between women with endometriosis and physicians, *Journal of Endometriosis and Pelvic Pain Disorders,* Vol 11(3) 146-151

Boschen, K.A., Robinson, E., Campbell, K.A., Muir, S., Oey, E., Janes, K., Fashler, S.R. and Katz, J. (2016) Results from 10 years of a CBT pain management outpatients program for complex chronic conditions, *Pain Research and Management*

Buggio, L., Giussy, B., Facchin, F., Frattornolo, M.P. and Giorgio, A. (2017) Self-management and psychological-sexological interventions in patients with endometriosis: strategies, outcomes and integration into clinical care, *International Journal of Women's Health,* Vol 19, 281-293

Cameron, J.E., Voth, J., Jaglal, S.B., Guilcher, S.J.T., Hawkes, G. and Salbach, N.M. (2018) "In this together": Social identification predicts health outcomes (via self-efficacy) in a chronic disease self-management program, *Social Science and Medicine,* 28, 172-179

Champaneria, R., Daniels, J.P., Raza, A., Pattison, H.M. and Khan, K.S. (2012) Psychological therapies for chronic pelvic pain: systematic review of randomised controlled trials, *Acta Obstet Gynecology Scand,* 91: 281-286

Craig, P., Dieppe, P., Macintyre, Michie, S., Nazareth, I and Petticrew, M. (2008) Developing and evaluating complex interventions: the new medical research council guidance, *BMJ,* 337

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. and Pettigrew, M. (2019) Developing and evaluating complex interventions: following considerable development in the field since 2006, MRC and NIHR have jointly commissioned an update of this guidance to be published in 2019, Medical Research Council, https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/

Crisp, C. D. (MAJ), Hastings-Tolsma, M. and Jonscher, K.R. (2016) Mindfulness-Based Stress Reduction for military women with chronic pelvic pain: A feasibility study, *Military Medicine,* 181, 9:982

Cruwys, T., Dingle, G.A., Haslam, C., Haslam, S.A., Jetten, J. and Morton, T.A. (2013) Social group memberships protect against future depression, alleviate depression symptoms and prevent depression relapse, *Social Science Medicine,* 98, 179-186

Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M. and Raine-Fenning, N. (2013) The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Human Reproduction Update,* Vol. 19, No.6, 625-639

De Silva, M.J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C. and Patel, V. (2014) Theory of change: a theory-driven approach to enhance the medical research council's framework for complex interventions, *Trials,* 15:267

Edwards, E.A., Lumsden, J., Rivas, C., Steed, L., Edwards, L.A., Thiyagora, A., Sophanpal, R., Caton, H., Griffiths, C.J., Munafo, M.R., Taylor S. and Walton, R.T. (2016) Gamification for health promotion: a systematic review of behaviour change techniques in smartphone apps, *BMJ Open,* 6

Evans, S., Fernandez, S., Olive, L., Payne, L.A. and Mikock-Walus, A. (2019) Psychological and mind-body interventions for endometriosis: a systematic review, *Journal of Psychosomatic Research,* 124

Facchin, F., Barbara, G., Dridi, P., Alberico, D., Buggio, L., Somigliana, E., Saita, E and Vercellini, P. (2017) Mental health in women with endometriosis – searching for predictors of psychological distress, *Human Reproduction,* 32, No.9, 1855-1861

Fox, S.D., Flynn, E and Allen, R.H.C. (2011) Mindfulness meditation for women with chronic pelvic pain: a pilot study, *Journal of Reproductive Medicine,* 56(3-4) 158

Funnell, S. C. and Rogers, P.J. (2011) Purposeful program theory – effective use of theories of change and logic models, San Francisco, CA: Jossey Bass

Gambadauro, P., Carli, V. and Hadiaczky, G. (2019) Depressive symptoms among women with endometriosis: a systematic review and meta-analysis, *American Journal of Obstetrics and Gynecology, Vol 220(3) 230-241*

Gogovor, A., Visca, R., Auger, C., Bouvrett-Leblan, L., Synmeonidis, I., Poissant, L., Ware, M.A., Shir, Y., Viens, N. and Ahmed, S.(2017) Informing the development of an internet-based chronic pain self-management program, *International Journal of Medical Informatics,* 97, 109-119

Goncalves, A.V., Makuch, M.Y., Setubal, M.S., Barras, N.F. and Bahamondes, L. (2016a) A qualitative study on the practice of yoga for women with pain-associated with endometriosis, *The Journal of Alternative and Complementary Medicine,* 00,0

Goncalves, A.V., Barras, N.F., Bahamondes, L. (2016b) The practice of hatha yoga for the treatment of pain associated with endometriosis, *The Journal of Alternative and Complementary Medicine,*

Hansen, K.E., Kesmodel, U.S., Kold, M and Forman, A. (2017) Long-term effects of mindfulness-based psychological intervention for coping with pain in endometriosis: A 6 year follow up on a pilot study, *Nordic Psychology,* 69:2

Heapy, A., Otis, J., Stein Marcus, K., Frantsve, L.M., Janke, E.A., Shulman, M., Bellmore, W. and Kerns, R.D. (2005) Intersession coping skill practice mediates the relationship between readiness for self-management treatment and goal accomplishment, *PAIN,* 118, 360-368

Hirsch, M., Aggarwal, S., Barker, C., Davis, C.J. and Duffy, J.M.N. (2017) Googling endometriosis a systematic review of information available on the internet, *American Journal of Obstetrics and Gynecology*

Horne, A. and Pearson, C. (2018) 'Endometriosis. The experts' guide to treat, manage and live well with your symptoms.' London: Vermilion

Huang, A. J., Rowen, T.S., Abercrombie, P., Subak, L. E., Schembri, M., Plaut, T. and Clao, M.T. (2017) Development and feasibility of a group-based therapeutic yoga program for women with chronic pelvic pain, *Pain Medicine,* 18, 1864-1874

Jones G, Kennedy S, Barnard A, Wong, J and Jenkinson, C. (2001) Development of an endometriosis quality-of-life instrument: The Endometriosis Health Profile-30. Obstetrics and Gynecology, 98, 258–64.

Kayyali, R., Peletidi, A., Ismail, M., Hashim, Z., Banderia, P. and Bonnah, J. (2017) Awareness and use of mhealth apps: a study from England, Pharmacy,

Keogh, A., Tully, M.A., Matthews, J. and Hurley, D.A. (2015) A review of behaviour change theories and techniques used in group based self-management programmes for chronic low back pain and arthritic, *Manual Therapy, 20*

Kold, M., Hansen, T., Vedsted-Hansen, H. and Forman, A. (2012) Mindfulness-based psychological intervention for coping with pain in endometriosis. *Nordic Psychology, 64, 1*

Kristjansdottir, O.B., Stenberg, U., Mirkovic, J., Krogseth, T., Ljosa, T.M., Stange, K.C. and Ruland, C.M. (2018) Personal strengths reported by people with chronic illness: a qualitative study, *Health Expectations,* 21, 787-795

Kuyken, W., Evans, A., Brejch, C., Holmes, L., Wilks, J., Crane, R., Mardula, J., Soulsby, J., Silverton, S., Butler, T, Williams, J., Dymund, M., Fennell, M., Johansson, M. and Suraway, C. (2012) MBCT implementation resources, Exeter University, Bangor University and Oxford

University
https://www.bangor.ac.uk/mindfulness/documents/12MBCTImplementationResources.pdf

Lally, P., Van Jaarsveld, C.H.H.M., Potts, H.W.W. and Wardle, J. (2010) How are habits formed: modelling habit formation in the real world, *European Journal of Social Psychology,* 40, 998-1009

Lee, M.H., Wu, H.C., Tan, T.H., Chan, P.C. and Chen, Y.R. (2014) Development and evaluation of an ehealth system to care for patients with bladder pain syndrome/Interstitial cystitis, *international Journal of Urology,* 21, 62-68

Leeners, B. (2012). 'Psychosomatic Aspects'. In L.C., Guidice, J.L.H, Evers and D.L. Healy, (Eds.), *Endometriosis: Science and Practice* (533-547). Chichester: Blackwell Publishing Ltd.

Martin, F., Wright, H., Moody, L., Whiteman, B., McGillion, M., Clyne, W., Pearce, G. and Turner, A. (2020) Development and evaluation of a digital self-management programme: iHOPE for cancer survivors, *Journal of Medical Internet research,*

Mehlsen, M., Heeguard, L. and Frostholm, L. (2015) A progressive evaluation of the chronic pain self-management programme in a Danish population of chronic pain patients, *Patient Education and Counselling,* 98

Mellado, B.H., Falcone, A.C.M., Pol-Neto, O.H., Rosaesilva, J.C., Nogueira, A.A., Candido-dos-Reis, F.J. (2016) Social isolation in women with endometriosis and chronic pelvic pain. *International Journal of Gynaecology and Obstetrics,* 133, 199-201

Merrolli, M., Gray, K. and Martin-Sanchez, F. (2014) Therapeutic affordances of social media: emergent themes from a global online survey of people with chronic pain, *Journal of Medical Internet Research,* Vol, 16 (12)

Moher, D., Liberati, A., Altman, D.G. (2009) Preferred reporting items for systematic reviews and meta- analyses: The PRISMA statement, *PLoS Med,* 6(7)

National Center for Complementary and Integrative Health (NCCIH) (2020) Meditation in Depth https://www.nccih.nih.gov/health/meditation-in-depth

Nes, A.A.G., van Dulmen, S., Wicksell, R., Fors, E.A. and Eide, H. (2016) Analysing change processes resulting from a smartphone maintenance intervention based on acceptance and commitment therapy for women with chronic widespread pain, *International Journal of Behavioural Medicine,*

Nevedal, D.C., Wang, C., Oberleitner, L., Schwartz, S. and Williams, A.M. (2013) Effects of an individually tailored web-based chronic pain management program on pain severity, psychological health and functioning, *Journal of Medical Internet Research,* Vol 15(9)

NICE Guidelines. ‘Endometriosis: diagnosis and management’. 6th September 2017, http://nice.org.uk/guidance/ng73
Nicholas, M.K., Asghari, A., Corbett, M., Smeets, R.J.E.M., Wood, B.M., Overton, S., Perry, C., Tonkin, L.E. and Beeston, L. (2011) Is adherence to pain self-management strategies associated with improved pain, depression and disability in those with disabling chronic pain? *European Journal of Pain,* 16(1) 93-104

Petrelluzzi, K.F.S, Garcia, M.C., Petta, C.A., Ribeiro, D.A., Monteiro, N.R, Cespedes, I.C. and Spadari, R.C. (2012) Physical therapy and psychological intervention normalise cortisol levels and improve vitality in women with endometriosis, *Journal of Psychosomatic Obstetrics and Gynecology,* 34(4), 191-198

Rimke, H.M. (2000) ‘Governing citizens through self-help literature’. *Cultural Studies,* 14(1) 61-78
Riva, S., Camerini, A.L., Allam, A and Schulz, P.J. (2014) Interactive sections of an internet-based intervention increase empowerment of chronic back pain patients: randomised controlled trial, *Journal of Medical Internet Research,* 16(8), e180

Rod, K. (2016) Finding ways to lift barriers to care for chronic pain patients: outcomes of using internet-based self-management activities to reduce pain and improve quality of life, *Pain Research and Management,* Vol 2016.

Roomaney, R. and Kagee, A. (2016) Salient aspects of quality of life among women diagnosed with endometriosis: A qualitative study, *Journal of Health Psychology, Vol 23(7) 905-016*

Ruehlman, L.S., Karoly, P. and Enders, C. (2012) A randomised controlled evaluation of an online chronic pain self-management program, *PAIN,* 153(2)

Seear K. (2009b) ‘The third shift: health, work and expertise among women with endometriosis’. *Health Sociology Review*, 2, 194–206

Shoebottom, A. and Coulson, N.S. (2016) Therapeutic affordances of online support group use in women with endometriosis, *Journal of Medical Internet Research,* Vol. 18(5)

Silva, E.H., Lawler, S. and Langbecker, D. (2019) The effective of mhealth for self-management in improving pain, psychological distress, fatigue and sleep in cancer survivors: a systematic review, *Journal of Cancer Survivorship,* 13, 97-107

Smith, S.K., MacDermott, K., Amarasekara, S., Pan, W., Mayer, D. and Hockenberry, M. (2018) Reimagine: a randomised controlled trial of an online symptoms self-management curriculum mong breast cancer survivors, *Supportive Care in Cancer*

Till, S.R., Wahl, H.N. and As-Sanie, S. (2017) The role of non-pharmacological therapies in management of chronic pelvic pain: what to do when surgery fails, *Current Opinion Obstetric and Gynecology,* 29, 000-000

Turner, A., Bourne, C., Martin, F., Jessthan, J., McHattie, D., Surendranath, S. and Cooper, L. (2012) HOPE: A positive psychological group self-management support programme for cancer survivors, *Psycho-oncolcogy,* 21

Van Dam, N.T., Van Vugt, M.K., Vago, D.R., Schmalzl, L., Saron, C.D., Olendzki, A., Meissner, T., Lazar, S.W., Kerr, C.E., Gorchor, J., Fox, K.C.R., Field, B.A., Britton, W.B., Bretezynski-Lewis, J.A. and Meyer, D.E. (2018) Mind the hype: a critical evaluation and prescriptive agenda for research on mindfulness and meditation, *Perspectives on Psychological Science,* Vol 13(1) 36-41

Van Niekeik, L., Weaver-Pirie, B. and Matthewson, M. (2019) Psychological interventions for endometriosis related symptoms: a systematic review with narrative data synthesis, *Archives of Women's Mental Health*

Vrekoussis, T., Siafaka, V., Tsitou, A., Tsonis, O., Navrozoglou, I, Makrigiannakis, A. and Paschopoulos, M. (2020) Endometriosis-related chronic pelvic pain: a mini review on pathophysiology and impact on mental health, *Journal of Endometriosis and Pelvic Pain Disorders,*

Wilson, M., Roll, J.M., Corbett, C. and Barbosa-Leiker, C. (2015) Empowering patients with persistent pain using an internet-based self-management program, *Pain Management Nursing,*

Wong, S.Y.S, Chan, J.Y.C., Zhang, D., Lee, E.K.P. and Tsoi, K.K.F (2018) The safety of mindfulness-based interventions: a systematic review of randomised controlled trials, *Mindfulness,* 9: 1344-1357

Appendix XII Consort Statement

CONSORT 2010 checklist of information to include when reporting a pilot or feasibility trial*

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a pilot or feasibility randomised trial in the title	159
	1b	Structured summary of pilot trial design, methods, results, and conclusions (for specific guidance see CONSORT abstract extension for pilot trials)	192
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial	164
	2b	Specific objectives or research questions for pilot trial	194
Methods			
Trial design	3a	Description of pilot trial design (such as parallel, factorial) including allocation ratio	194-195
	3b	Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons	----------
Participants	4a	Eligibility criteria for participants	195
	4b	Settings and locations where the data were collected	195
	4c	How participants were identified and consented	195
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	196
Outcomes	6a	Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed	196-197
	6b	Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons	-------------
	6c	If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial	---------------
Sample size	7a	Rationale for numbers in the pilot trial	201
	7b	When applicable, explanation of any interim analyses and stopping guidelines	201

Randomisation:			201
Sequence generation	8a	Method used to generate the random allocation sequence	201
	8b	Type of randomisation(s); details of any restriction (such as blocking and block size)	201-202
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	201
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	201
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	202
	11b	If relevant, description of the similarity of interventions	---------
Statistical methods	12	Methods used to address each pilot trial objective whether qualitative or quantitative	202
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective	202
	13b	For each group, losses and exclusions after randomisation, together with reasons	---------
Recruitment	14a	Dates defining the periods of recruitment and follow-up	204
	14b	Why the pilot trial ended or was stopped	----------
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	Table 5.6 203
Numbers analysed	16	For each objective, number of participants (denominator) included in each analysis. If relevant, these numbers should be by randomised group	203
Outcomes and estimation	17	For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates. If relevant, these results should be by randomised group	204
Ancillary analyses	18	Results of any other analyses performed that could be used to inform the future definitive trial	208
Harms	19	All-important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	210
	19a	If relevant, other important unintended consequences	---------------
Discussion			
Limitations	20	Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility	211-217

Generalisability	21	Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies	211-217
Interpretation	22	Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence	211-217
	22a	Implications for progression from pilot to future definitive trial, including any proposed amendments	211-217
Other information			
Registration	23	Registration number for pilot trial and name of trial registry	--------
Protocol	24	Where the pilot trial protocol can be accessed, if available	-------
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	6
	26	Ethical approval or approval by research review committee, confirmed with reference number	6

Citation: Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, et al. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. BMJ. 2016;355.

*We strongly recommend reading this statement in conjunction with the CONSORT 2010, extension to randomised pilot and feasibility trials, Explanation and Elaboration for important clarifications on all the items. If relevant, we also recommend reading CONSORT extensions for cluster randomised trials, non-inferiority and equivalence trials, non-pharmacological treatments, herbal interventions, and pragmatic trials. Additional extensions are forthcoming: for those and for up to date references relevant to this checklist, see www.consort-statement.org.

Appendix XIII RCT Participant Information Sheet

Participant Information Sheet - Phoenix Feasibility Study

What is the study about?
The Phoenix online 8-week mindfulness course has been designed by Clair Dempsey, a postgraduate researcher at Coventry University, with lived experience of endometriosis and adenomyosis. It was also designed with input from people living with endometriosis and adenomyosis.

This research study will investigate if it is possible and practical to offer the phoenix course to people with endometriosis and/or adenomyosis as a means of improving quality of life. It will also look at if the course is useful and easy to use.

It is important to note that taking part in this study is not a substitution or replacement for psychological therapy or medical treatment, it is designed to be used alongside existing treatment options. Please contact your GP or another healthcare professional if you feel you would benefit from psychological therapy.

Who is being invited to take part?
People over the age of 18 who have been diagnosed with endometriosis and/or adenomyosis. As this is an online course potential participants will need to have access to a device that can connect to the internet.

What would I be asked to do?
If you decide that you would like to take part, we will ask you to complete a consent form, complete two surveys and provide information about your symptoms, care and treatment at two different time points; one now and one in approximately 8 weeks time. The surveys should take about 20 minutes to complete.

Two versions of the phoenix course will run. There will be two different start dates. We are recruiting 50 people for each group. The first group will be given a start date and be sent a link to the facilitator and peer support version of the phoenix course. The second group will complete the surveys at the same time as the first group and then after the completion of the second group of surveys they will be given access to the self-directed version of the phoenix course. The data collected from each group will be equally important and the researchers have no control over who gets assigned to which group. A software package will be used to randomly assign people to each group. You will find out which group you are assigned to when you complete the surveys. Everyone in both groups will be asked to complete the surveys.

Everyone who takes part in this feasibility study will have access to a version of the phoenix mindfulness course.
This study involves collecting the following personal information from participants: name, email address, gender, age, postcode and the following special categories of data: diagnosis, symptoms, treatment and management of endometriosis/adenomyosis. Participant names and email addresses will not be stored alongside survey responses. We are only collecting postcode data to record the location the course is being accessed in. As there is a possibility that individuals postcodes, in combination with the remaining with the remaining personal data, could be used to identify a person, we will record the location immediately when we download

the data and then delete the postcode straight away. More information on how we will treat your data is provided below under 'how would you process my data?'.

Do I have to take part?
Participation in this study is voluntary and it is up to you, after reading this information, to decide whether you wish to take part or not.

Content removed on data protection grounds

Are there any costs or benefits of taking part?
We are not aware of any costs to you for taking part in this study. You may not feel like you benefit directly from taking part, but when you tell us will contribute to the continued development of the phoenix course.

How will you process my data?
The information you are reading is a page of a survey developed using Qualtrics survey software. Qualtrics is used to manage research projects and collect participant data by using online surveys. Researchers from Coventry University and regulatory organisations may look at the research records to check the accuracy of the research study. The only people at Coventry University who will have access to information that identifies you will be researchers' who will use this information to contact you or to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your right to access, change o move your information are limited, as we need to mange your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained, unless you ask us to delete it. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by following this link to the Qualtrics Privacy Statement

Would everything I say be kept confidential?
We will keep information that we hold about you confidential. When the study is completed, we will write up the findings, but no one will be able to tell who has participated in this study. The findings will be used in scientific publications and presentations.

What will happen with the results of this study?

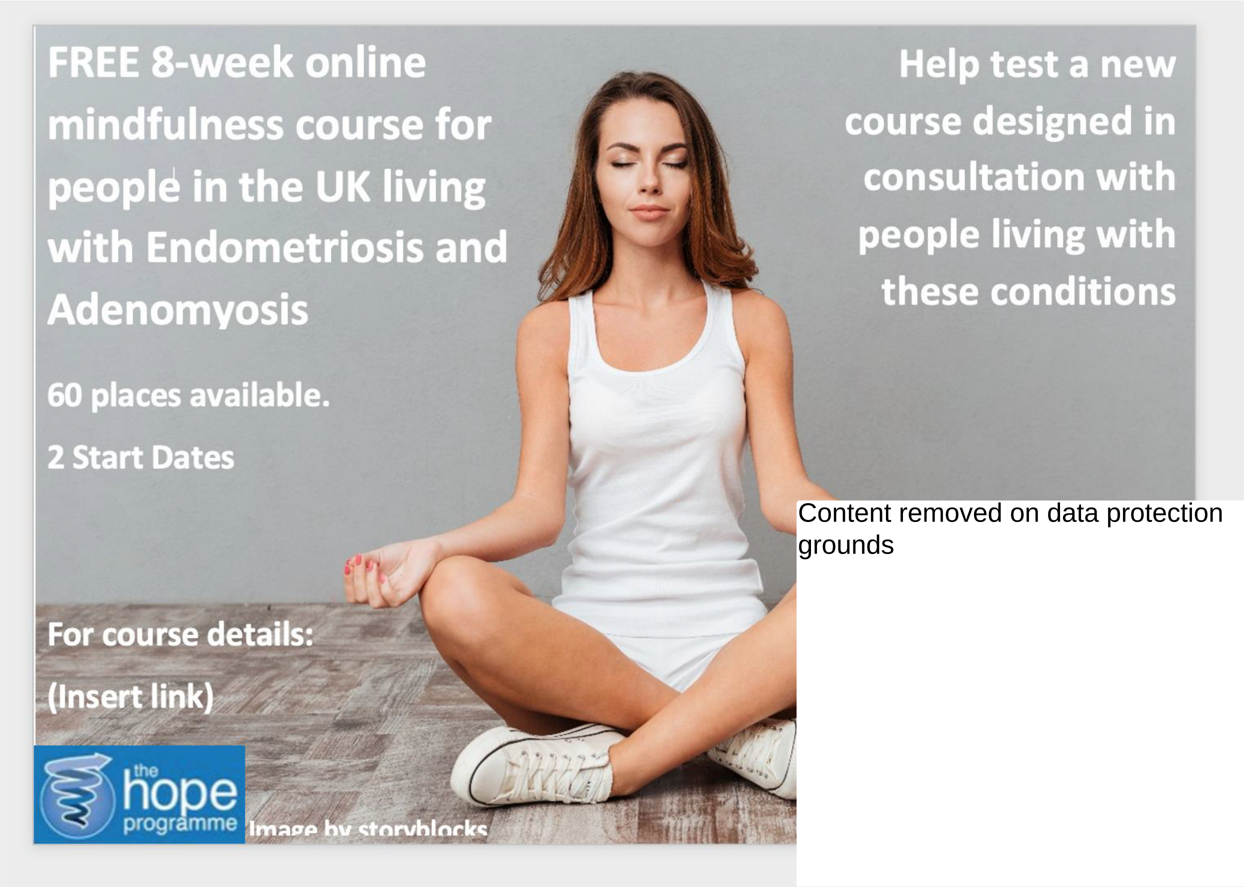
The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

This project has been reviewed and approved by Coventry University Ethics (Project reference: P97545).

Who should I contact if I have a question or complaint?

Content removed on data protection grounds

Appendix XIV RCT Recruitment Advert



FREE 8-week online mindfulness course for people in the UK living with Endometriosis and Adenomyosis

60 places available.

2 Start Dates

For course details:

(Insert link)

Help test a new course designed in consultation with people living with these conditions

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the hope programme

Image by storyblocks

the hope programme

**FREE ONLINE
8-WEEK MINDFULNESS
COURSE**

Coventry University

Are you living with endometriosis or adenomyosis?

Are you over 18 and live in the UK?

60 places available. For information and course details: insert link)

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