Understanding the impact of endometriosis on women's body image: A mixed methods study

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Table of Contents

Abstract

Background

The physical and psychological impact of endometriosis on the individual is considerable, yet there is currently little known about how best to support those if they are negatively impacted by appearance and body image-related issues as a result of the condition. The present study aimed to investigate the impact of endometriosis on body dissatisfaction, functionality appreciation and general wellbeing outcomes, and sought to understand how we can support individuals to improve this.

Methods

Following ethics approval, a mixed methods study was conducted through use of an online survey. Patient and Public Involvement (PPI) from volunteers at Endometriosis UK helped design the study. Participants were recruited from several sources, including social media and through word-of-mouth, and were included if they were over the age of 18 and had been diagnosed with endometriosis. Participants were included from both within and outside the United Kingdom (UK). Data was collected on demographic information, such as age, gender, number of symptoms, length of time experiencing symptoms before diagnosis and length of time *since* diagnosis, number of body locations diagnosed with endometriosis, treatments received, number of surgeries, additional health conditions and geographical differences. Quantitative data was gathered through several standardised measures, including the Endometriosis Health Profile (EHP-30), Short Form Health Survey (SF-36), Body Image Scale (BIS), Functionality Appreciation Scale (FAS) and Self-Compassion scale (SCS-SF). Information was also gathered on support needs, and preferences on support delivery. A thematic analysis was conducted on the qualitative data and correlational analyses, multiple regression and an independent T-test conducted on the quantitative data.

Results

Data cleaning resulted in data from 128 participants (mean age = 31 years; mean length of time experiencing symptoms prior to diagnosis = 10.5 years) that underwent analysis. These participants reported a variety of different symptoms (including menstrual cramps, pelvic pain, fatigue, back pain) and treatments (e.g., painkillers, the pill, laparoscopy, heat) for the

condition. Analysis of the quantitative data showed a number of significant results. First, lower emotional wellbeing, physical functionality, general health perception, self-compassion, positive self-image and control and greater feelings of powerlessness were associated with greater body dissatisfaction. Furthermore, greater emotional wellbeing, physical functionality, general health perception, self-compassion, positive self-image, control and lower feelings of powerlessness were associated with greater functionality appreciation. Finally, following a multiple regression, self-compassion was a significant predictor of body dissatisfaction and functionality appreciation. With regard to qualitative analysis, this revealed that most participants gained information on the condition from other individuals with endometriosis and through social media, but wanted support to improve their body image from trained professionals (e.g., psychologists/counsellors), with a primary focus on improving feelings of control and acceptance of the condition.

Conclusion

This data could support towards guiding policy, practice and theory, as it outlines that there is a desire for support to improve body image in those with endometriosis. The study suggested that to improve body image in those with endometriosis, therapeutic interventions focusing on improving feelings of control and acceptance may be beneficial. These could be delivered through facilitated sessions, as well as being self-led, should participants prefer to work through content this way. Health Psychologists may be well placed to support individuals with managing and improving body image-related issues through such interventions. Future research therefore would benefit from developing and evaluating interventions on body image based upon the Medical Research Council framework for development of complex interventions. These interventions could include techniques from Cognitive Behavioural Therapy, Acceptance and Commitment Therapy and Compassion Focused Therapy, tailored to those with endometriosis.

Chapter 1: Introduction

1.1 Thesis Structure

This thesis has been divided into the following chapters:

- Chapter 1: Outlines the structure of thesis.
- Chapter 2: Provides a literature review of past and current literature to summarise the necessity for the current piece of work.
- Chapter 3: Presents the ontological and epistemological approaches shaping this thesis. Ethics, recruitment, materials and data collection is discussed.
- Chapter 4: Details both the quantitative and qualitative results.
- Chapter 5: Discusses the implications of the results, limitations and conclusions drawn. A reflexive section will also be included here to demonstrate observations and lessons learnt through this process.

1.2 Doctoral Descriptors

The UWE Doctoral Descriptors that the postgraduate researcher is required to meet are as follows:

- Have conducted enquiry leading to the creation and interpretation of new knowledge through original research or other advanced scholarship, shown by satisfying scholarly review by accomplished and recognised scholars in the field;
    - *See Chapter 3 and 4 – Demonstrated through processes outlined in the methodology, detailing the creation of the study, based upon needs identified in the literature review. This new knowledge collected is then presented through quantitative and qualitative findings.*
- Can demonstrate a critical understanding of the current state of knowledge in that field of theory and/or practice;
    - *See Chapter 2 – Demonstrated through review of current literature, and evaluation of challenges that exist in the field presently.*
- Show the ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of the discipline or field of practice including the

capacity to adjust the project design in the light of emergent issues and understandings;
    - *See Chapter 3 – Demonstrated through outlining ethics, recruitment and materials described in the methodology.*
- Can demonstrate a critical understanding of the methodology of enquiry;
    - *See Chapter 3 – Demonstrated through discussion around used of mixed methods approaches and associated challenges with this, and in the discussion section (Chapter 5).*
- Have developed independent judgement of issues and ideas in the field of research and / or practice and are able to communicate and justify that judgement to appropriate audiences;
    - *See Chapter 5 – Demonstrated through presentation of interpreted results and suggestion for future research.*
- Can critically reflect on their work and evaluate its strengths and weaknesses including understanding validation procedures.
    - *See Chapter 5 – Demonstrated through discussion of strengths and weaknesses in approach.*

1.3 Research Context

This topic was chosen due to the researcher's personal and professional interests in the area. The researcher was diagnosed with endometriosis in 2018, following 9 years of symptoms, previously diagnosed as other conditions. Through this time, it became apparent that healthcare provision in this area was scarce, particularly in the realm of psychological support, and the condition was not known, or was misunderstood by most healthcare professionals. As a result, Endometriosis UK became a source of knowledge and support, being one of the few UK based charities/organisations providing information on the condition. The researcher subsequently trained and volunteered as an online support group leader for the charity, to provide the same support that had been so necessary during different stages of their diagnosis journey. Through delivering these sessions, it became apparent that the experience of having endometriosis, and getting a diagnosis or treatment, was very similar for most with the condition; challenging and slow. A common rhetoric was observed by the researcher when listening to attendees, that there was an overriding frustration from attendees towards their bodies ‘not working as they should’. In an attempt to offer advice and support for attendees on this, it transpired that there was no evidence-based resource in the area of body image. There were also only small amounts of published research in the area, highlighting a potential gap in intervention support.

1.4 Endometriosis Background

Endometriosis is a chronic condition, where endometrium-like tissue is found present outside the womb. It affects 10% of individuals assigned female-at-birth worldwide and is the second most common ‘gynaecological’ condition in the UK, after fibroids (Endometriosis UK, 2023; Royal College of Nursing, 2017; World Health Organisation, 2023). Despite this, diagnosis, treatment and management of the condition is not providing effective relief for many individuals, resulting in many suffering both physically and psychologically (De Graaff et al., 2011). It is acknowledged that not every person with endometriosis will identify as a woman, or female, and this thesis aims to represent the diverse female experience, including trans and non-binary individuals.

1.5 Publication

The researcher has an existing piece of research published, demonstrating a methodical approach to understanding the current research in this area.

1.5.1 Paper Summary

What is the evidence of effectiveness of non-pharmaceutical, non-surgical, biopsychosocial interventions for body image and pain management in individuals with endometriosis? A systematic review (Falconer et al., 2022)

This piece was published in the Journal of Endometriosis and Pelvic Pain Disorders (see Appendix 12), and included 6 studies, which concluded that without gold-standard methodology, the evidence of effectiveness cannot be concluded. It highlighted a lack of intervention and standardized measures in body image, highlighting a necessity for further research in this area in this demographic.

Chapter 2: Literature Review

This chapter will explore the epidemiology of endometriosis, describing the diagnostic process, aetiology, and risk factors. It will explain the symptoms observed, both physically and psychologically, and the different treatment pathways currently offered or adopted by individuals with endometriosis to aid in managing the condition. The chapter will then examine body image, and the differences between functionality and appearance and its influence on the sense of self. The chapter will then explore the role of Health Psychology, and how different models/approaches can be used to help in understanding behaviour change and self-perception, and how this can influence physical and mental wellbeing, before assessing the current challenges in treatment approaches, clinician care and the impact of social media on those with endometriosis. A systematic review on the topic, conducted and published by the author (see Appendix 12, Falconer et al, 2022), will then be described, outlining the necessity for the current research, where the research question, aims and objectives will be outlined.

2.1 Epidemiology of Endometriosis

2.1.1 Diagnosis

Providing the true incidence and prevalence of endometriosis is difficult, because to definitively diagnose the presence of endometriosis, surgical visualisation is required (Kuohung et al., 2002). Surgical visualisation is currently considered the 'Gold Standard', and whilst research into alternatives are increasing, the validity of blood tests, ultrasound, MRI and other forms of investigative procedures is not yet clear (Anastasiu et al., 2020; Axelsson et al., 2023; Hsu et al., 2010; Scioscia et al., 2020). Diagnostic delays are common due to the 'trial-and-error' approach often taken by medical professionals to rule out other conditions first, such as Irritable Bowel Syndrome, Diverticulitis, Appendicitis or Crohn's Disease, due to the similar symptoms of the conditions (Nasim et al., 2011). This may lead to a number of consequences, including a decline in reproductive potential (Parasar et al., 2017). Diagnosis is also highly reliant on the patient having access, either physically or financially, to sufficient health care provision, which can result in many individuals suffering for extended periods of time without effective treatment.

Endometriosis can be considered ‘suspected’, from the presence of a fixed, retroverted uterus, or ‘frozen pelvis’, and other pain syndromes, such as painful bladder syndrome, irritable bowel syndrome, fibromyalgia and migraines (Hsu et al., 2010). Some medical teams are trialling new methods to diagnose endometriosis through the presence of antibodies. There is currently a mixed consensus on whether endometriosis can be considered an autoimmune disease, instead being considered a disease associated with chronic local inflammation and antibody self-reactivity (Eisenberg et al., 2012; Shigesi et al., 2019). A review on antibodies found these could be used as a potential diagnostic biomarker (Greenbaum et al., 2021). However, research in this area is still evolving before it can be used more widely.

2.1.2 Aetiology and Risk Factors

The exact *cause* of endometriosis remains unconfirmed (Malvezzi et al., 2020). However, there are several risk factors identified in the pathology of endometriosis. Genetic studies have found approximately 50% of the risk for endometriosis results from genetic factors, with the other 50% resulting from environmental factors (Montgomery et al., 2020). Genetic variations and somatic mutations (alterations in DNA not inherited from parents) have been observed in individuals with endometriosis, suggesting there may be links with the presence of the condition. There are also ethnic differences, with black women having lower rates of the condition compared with white women (Missmer et al., 2004). A systematic review on early life factors for endometriosis identified that women born with low birth weight (<5.5lb), early menarche, shorter menstrual cycle length, alcohol use, red meat intake and high quantities of caffeine intake (>300mg/day) were more likely to be diagnosed with endometriosis (Jurkiewicz-Przondziono et al., 2017; Kechagias et al., 2021; Matalliotakis et al., 2008; Olšarová & Mishra, 2020). Current oral contraceptive use and consumption of fruit, vegetables and fish or omega 3 fatty acids were factors associated with decreased risk, with some inconclusive research on physical exercise and smoking (Bonocher et al., 2014; Hemmert et al., 2019; Jurkiewicz-Przondziono et al., 2017; Tu et al., 2014).

Those with a lean body size in childhood and early adulthood have been found to have an increased risk of endometriosis diagnosis (Vitonis et al., 2010). There may also be a protective effect from having a larger body size at both 8 years old and menarche (Farland et al., 2017). In contrast, women who reported having a larger body size at 10 years had an increased risk of endometriosis diagnosis (Nagle et al., 2009). By adulthood, the research is similar to that in childhood, whereby women diagnosed with endometriosis were taller and thinner, with a significantly lower Body Mass Index (BMI; Hediger et al., 2005). The same study found a higher current BMI to be statistically protective for an endometriosis diagnosis, both at time of diagnosis and historically. A potential reason for the inverse association between BMI and endometriosis is anovulation, where an egg is not released from the ovary during a menstrual cycle, sometimes accompanying those with an increased body size (Shah et al., 2013). However, chronic pain from endometriosis may induce gastrointestinal symptoms or emotional stress, leading to appetite and food intake reductions (Holdsworth-Carson & Rogers, 2018). As a result, it is challenging to advise individuals on the impact of weight and size on endometriosis diagnosis and risk.

2.2 Symptoms

2.2.1 Physical symptoms

Endometriosis has long been considered a gynaecological condition, due to the prior understanding that it was endometrium displaced in other areas of the pelvic cavity (D'Hooghe et al., 2004). This has often lead to the dismissal or misunderstanding of those with symptoms presenting elsewhere, or individuals who were Assigned Female at Birth (AFAB; Jones, 2021). Endometriosis is now understood to be a whole body chronic disease, with some cases of endometriosis tissue being found present in the parietal, visceral, thoracic and central nerve system, extra pelvic muscles or nerves, the kidneys, liver, pancreas, biliary tract, diaphragm, eyes, heart, pleura and lungs (Andres et al., 2020).

The most frequently experienced symptoms leading to diagnosis of endometriosis is dysmenorrhea (painful periods; 79%), pelvic pain (69%), dyspareunia (painful sex; 45%), bowel upset (constipation/diarrhoea; 36%), bowel pain (29%), infertility (26%), ovarian masses/tumours (19.5%), dysuria (painful urination; 9.9%) and other urinary complications (6%; Sinaii et al., 2008). All the above can contribute to distress towards one's physical capability to engage in day-to-day activity, as they are often accompanied with additional physical symptoms, including back and leg pain (76%), dizziness/headaches (69%) and fatigue (45%; Fourquet et al., 2010). Physical deconditioning has also been observed, with reduced strength, balance and functional capacity, and individuals perceiving their overall physical fitness to be poorer, something that is even more pronounced in those with endometriosis-related fatigue (ERF; Álvarez-Salvago et al., 2020). This perceived physical functioning has been significantly associated with pain intensity and acceptance of the illness, suggesting that understanding how to manage and support with both these areas could be beneficial (Bien et al., 2020). General health perception was also significantly lower in those with endometriosis compared with other chronic pain conditions (Verket et al., 2018). Many individuals report the combination of these physical symptoms lead to impairments in their social life, educational attainment, employment/career, family planning, personal relationships, quality of life and mental and/or emotional health across the life course (Missmer et al., 2021).

2.2.1.2 Pain

Pain from endometriosis can become a part of one's salient identity, a prominent part of their identity, as a result of years trying to make meaning of undiagnosed, unexplainable pain (Marschall et al., 2021). When pain becomes a core part of a person's narrative identity, the way in which a person makes meaning of their life, it can lead to further pain, indicating that this altered sense of self can make pain experience worse in those with endometriosis (Marschall et al., 2021). The perceived endless lack of control can negatively influence a person's internal health locus of control, the belief that positive health results from their own doing, which can significantly impact psychological wellbeing, and can cause confusion and self-guilt, as though they are responsible (Ek et al., 2015; Jacox, 1995; Kennedy, 1991). Individuals with endometriosis have described a lack of familiarity they feel towards their body as a result of the increased pain, which may arise as a coping mechanism to detach themselves from the significant amount of bodily pain they are in (Melis et al., 2015). Body image can be distorted in those with pain, in particular, chronic pain, and it is suggested that the pain may contribute to this distortion (Lotze & Moseley, 2007). This is important to consider when exploring the effects of endometriosis on body image, as pain is the most common symptom for those with the condition.

2.2.2 Psychological Symptoms

The pain associated with endometriosis can have a psychological impact, as individuals can experience fear and anxiety from the constant pain (Al Samaraee et al., 2010). They can also experience significantly more symptoms of depression, lower self-esteem and lower emotional self-efficacy compared with healthy controls (Barneveld et al., 2020). In addition to this, because of the way the brain regions interact, a negative emotional state can make pain worse, and cognitive states like attention or memory can increase or decrease pain (Villemure & Bushnell, 2009). It is suggested the psychological modulation of pain can influence a negative-feedback loop, through which impaired pain processing can not only lead to chronic pain, but also emotional and cognitive deficits comorbid with pain, highlighting why physical and psychological outcomes may present together (Bushnell et al., 2013). A systematic review on the psychological aspects of endometriosis found all studies confirmed moderate-to-severe emotional disorders in those with endometriosis (Chaman-Ara et al., 2017). Self and body compassion are both lower in those with endometriosis and the condition has left women feeling powerless, and frustrated at the inability to control their symptoms (Jones et al., 2004; Van Niekerk et al., 2023).

The psychological impact of endometriosis cannot be underestimated, as the persistent symptoms and lack of cure can lead to a reduced quality of life, difficulties in relationships and socialising, and cause feelings of self-doubt (Álvarez-Salvago et al., 2020). This can occur from medical gaslighting, and can lead to cognitive distortions, like catastrophising, which may impact other areas of the person’s life (Kalfas et al., 2022; Lindgren & Richardson, 2023). There may also be feelings of guilt and powerlessness (Ruszała et al., 2022).

2.3 Treatment

Endometriosis causes tissue *similar* to the womb lining to grow in other locations of the body, and classification and staging can be complex due to its highly variable presentation, with pain levels not always concurrent with the amount of endometriosis tissue present (Maharajaa et al., 2019). As a result, treating the condition is often preceded with a series of ‘trial-and-error’ approaches, to rule out other conditions first (Denny et al., 2018). Many people with the condition are treated for abdominal related conditions such as Irritable Bowel Syndrome, Diverticulitis, Appendicitis or Crohn's Disease, due to the similar symptoms of the conditions (Nasim et al., 2011).

2.3.1 Pharmaceutical

Following this trial-and-error approach, even prior to diagnosis, most individuals are then treated with a combination of pharmaceutical treatments, such as hormonal medications, or other types of symptom alleviating medication (NHS, 2017b). Hormonal medications include the different types of pill (Combination and Progesterone Only), the Intra-Uterine Device (IUD), sometimes referred to as the coil, and the Etonogestrel Implant, sometimes referred to as the rod, and all have the potential to reduce pain symptoms and heavy bleeding (NHS, 2017b).

The progestin-only contraceptive pills with desogestrel (DSG) and Combined Oral Contraceptives (COCs) have often been used in the management of symptoms, by stopping the hormone production that leads to ovulation and menstruation (Andrist et al., 2004). After 6 months, both have been found to be effective in reducing endometriosis related-pain, and the DSG pill showed lower levels of dysmenorrhea and dyspareunia (Vannuccini et al., 2022).

The Intrauterine Device, or coil, is a copper device inserted into the uterus, which can help prevent pregnancy if being used as a contraceptive. It also releases progestin, a synthetic hormone with mixed evidence on its effectiveness to reduce painful periods (Lindh & Milsom, 2013). The IUD has been shown to reduce medium-term risk of recurrence of moderate or severe dysmenorrhea following laparoscopic surgery (Vercellini et al., 2003). Another review on its use in endometriosis showed that whilst limited, there is consistent evidence demonstrating that the use of an IUD after surgery can reduce the recurrence of painful periods (Abou-Setta et al., 2013)

The Etonogestrel Implant, or rod, is a small implant placed discreetly underneath the upper arm. It stops the release of an egg by the ovary through slowly releasing progestogen into the body. It also works by preventing the lining of the womb and endometriosis tissue from growing quickly. A multicentre study found that it’s use reduced pelvic pain, improved sexual function and quality of life (Sansone et al., 2018).

2.3.2 Medical and Surgical

Since a diagnostic laparoscopy is currently the gold standard in understanding the presence and extent of the condition, many individuals with endometriosis will undergo surgery to determine the next steps for their treatment (Hsu et al., 2010). In some cases, the surgeon may be able to remove some of the endometriosis tissue, and this may provide some temporary relief. However, most individuals find the tissue grows back, particularly if it has initially been removed by ablation (through destroying the surface tissue), instead of excision (through cutting out the tissue and surrounding area; Pundir et al., 2017). As a result, many individuals with endometriosis will require further tissue removal. In some cases, additional specialist care will be required, for example, if there is the need for a multidisciplinary team, such as bowel or urinary surgeons, individuals may require specialist surgery, which can have longer waiting times (Norton et al., 2020). These waiting times have been further worsened by the Covid-19 pandemic, with a reduction of around 51% of specialist surgeries for endometriosis compared to other elective procedures nationwide (38.6%), suggesting endometriosis has been particularly negatively affected (Lewin et al., 2022). However, a systematic review on the efficacy of surgical and medical intervention for pain in endometriosis found there was no statistically significant difference in pain, suggesting that there may be benefit from less invasive methods of pain management (Mehdizadehkashi, 2017). The reduced effectiveness of surgical interventions may be as a result of ‘Central Sensitisation’ where nerve endings become over-sensitised over time, as a result of the endometriosis, responding to pain stimuli even when there is no stimulus there (Arendt-Nielsen et al., 2018). This pain hypersensitivity, may explain why some patients become less responsive to treatments like surgery, as pain may persist from over-sensitised nerve endings, even after tissue is removed (Nijs et al., 2021).

In the presence of severe endometriosis, a hysterectomy (the surgical removal of the womb/uterus), or an oophorectomy (the surgical removal of the ovaries) may be carried out (Endometriosis News, 2023; NHS, 2017a). This evokes the ‘complete’ shut down of the organs responsible for the hormones thought to amplify the extent of the symptoms experienced.

This can have a significant impact on the individual, both positively and negatively, as many must make this decision, perhaps before they have chosen whether or not to have a family. The decision to choose between pain or fertility is one that many face, which can have a significant impact on the way in which individuals view themselves, as explored below (Melis et al., 2015; Skorupskaite & Bhandari, 2021).

2.3.3 Treatment Challenges

All of these treatment approaches are designed to target the condition as a ‘gynaecological one’, a description that has since been disputed and challenged as one that does not reflect the true scope or manifestation of the disease (Taylor et al., 2021). It is now considered to be a ‘systemic disease’, not one that just affects the pelvic region, which could offer some explanation to why many of these treatments are not always successful long-term. In addition to this, none of the above treatments can ‘cure’ the condition, and as a result, when these treatments are stopped, or if these treatments are unsuccessful, the root cause of the problem has still not been overcome. A review comparing 8 sets of guidelines, including the National Institute for Care and Excellence (NICE) and the European Society of Human Reproduction and Embryology (ESHRE), indicates the unanimous recommendation of the pill and other progestogens for endometriosis-associated *pain* (Kalaitzopoulos et al., 2021). However, there is no clear consensus on the recommended surgical treatment to improve fertility outcomes. There are also discrepancies on second- and third-line treatments, suggesting that for a chronic condition, there is still not currently a unanimous treatment protocol for long term care.

The ESHRE guidelines suggest that progestins are low cost with lower incidence of adverse effects (Dunselman et al., 2014). However, the side effects of many contraceptives, pharmaceuticals, and surgery can be a large deterrent for many (Berlanda et al., 2016). Women using hormonal contraceptives have been associated with worse body image compared to those not using hormonal contraceptives (Nowosielski, 2022). As a result of significant psychological impact already experienced by many with endometriosis (Facchin et al., 2017), targeted multidisciplinary interventions could be considered to improve low self-esteem and self-efficacy that may result from this. Currently, many individuals with endometriosis say they are dissatisfied with ‘conventional’ treatments they are receiving for their endometriosis, owing to persisting symptoms and lack of satisfaction with medical support (Schwartz et al., 2019), with 61.5% of women (*n* = 133) reporting seeking naturopathic and/or complementary procedures instead (Grzanna et al., 2017). Providing options for self-management are also important, given the value these provide in increasing autonomy and self-esteem (Ould Brahim, 2019), often damaged through dismissal or disbelief by health professionals (Cox et al., 2003).

2.4 Complementary Therapies

Most of the above pharmaceutical and surgical treatments for endometriosis focus on alleviating physical symptoms, as opposed to psychological symptoms. Complementary therapies offer the opportunity for treatment of both. Physical complementary therapies include the use of acupuncture, Transcutaneous Electrical Nerve Stimulation (TENS), heat, exercise, manual physiotherapy, Chinese Herbal Medicine (CHM), Yoga and diet (Armour et al., 2021; Flower et al., 2011; Gonçalves et al., 2017; Leonardi, Horne, Vincent, et al., 2020; Mira et al., 2018; Mira et al., 2020; Nirgianakis et al., 2022; Wójcik et al., 2022). Psychological complementary therapies include Cognitive Behavioural Therapy (CBT), psychotherapy, psychoeducation with a focus on self-compassion, and newer approaches well documented for their success in other chronic pain conditions, like Acceptance and Commitment Therapy (ACT; Donatti et al., 2022; Hughes et al., 2017; Meissner et al., 2016; Van Niekerk et al., 2022a).

Psychological therapies to manage the non-physical side effects of the condition are not usually the main area of focus for treatment (NICE, 2017). Endometriosis UK, one of the largest charitable organisations for the condition in the UK, make little to no mention of psychological therapies that may be supportive in managing the condition, other than suggesting GPs could refer to counselling services (Endometriosis UK, 2023a). There is no guidance on what this would involve, or how it could help, and no indication of associated cost, which many patients have to pay for privately. Although the focus is more on navigating how to manage *physical* pain, as opposed to potential psychological distress, including impacts to body image; pain clinics can offer holistic psychological support for pain-related conditions. Referral to pain clinics can be obtained via a GP, however, many GPs will try other treatment approaches first. There is currently a target wait time of around 18 weeks in England for accessing pain treatment (Connelly, 2020), with a wait time of 6 months or longer considered ‘medically unacceptable’, as deterioration in health related quality of life occurs from as little as 5 weeks (Lynch et al., 2008). However, post-pandemic, waiting time for some specialist pain services has risen to more than two years (Connelly, 2020). Some NHS services offer Pain Management Programmes (PMPs), which can be a way of accessing treatments like CBT, Mindfulness Based Stress Reduction (MBSR) and ACT, in relation to pain, but these also require referral from a GP. The British Pain Society, the oldest and largest multidisciplinary professional organisation in the field of pain in the UK, only provide an informational guide on PMPs, and this guide is currently 10 years out of date (The British Pain Society, 2013). In summary, there is little to no provision for psychological therapies in the UK for Endometriosis in general, particularly with regard to managing potential body image distress.

Complementary and Alternative medicine (CAM) is often popular amongst those with endometriosis as it is often more easily accessible, with little to no waiting times and reduced associated costs (Maxion-Bergemann et al., 2006). There are also less side effects, making them a favoured choice amongst many (Guo et al., 2021). Similarly to pharmaceutical and hormonal treatments, CAM therapies can help with symptom management, and due to their reduced side effects, can often be used long term with no negative repercussions (Guo et al., 2021). However, without a comprehensive treatment path identified by professionals, or even a unanimous definition of what ‘self-management’ is (O’Hara et al., 2019), and limited literature with gold standard methodology, the ability to discern between the effectiveness and use of some treatments over others still remains with the individual, adding additional responsibility in the hands of the patient.

2.5. 1 Self-Management

As a result of the often-long waiting times for treatment, and medical care that does not always provide relief, many individuals with endometriosis have turned to self-management methods to improve the impact of their symptoms. Many begin their search for self-management approaches through information seeking on the internet, support groups and endometriosis associations (O’Hara R. et al., 2019). This has supported in the empowerment of these individuals, enabling them to take charge of their health (Cox et al., 2003). However, many can also feel overwhelmed, and conflicting information can make it hard for individuals to make evidence based decisions about the approach they should take (Seear, 2009).

Self-management tasks and complementary therapies are often tried within the endometriosis community, however there has been mixed results into whether any health benefits have been had from implementing such practices, with some strategies being no more effective at reducing symptoms compared to placebo (Mardon et al., 2023; Seear, 2009). The challenge with so many self-management options is that whilst they have shown benefits in other conditions, or contexts, and in some case in endometriosis, there is less tailored approaches to endometriosis specifically, and as the needs of these individuals are unique compared to other conditions, some of the benefits of these self-management approaches could be missed (Armour et al., 2019). With so many advocating for themselves, there is less opportunity to understand from individuals the barriers and facilitators to accessing self-management tools, what they would benefit from, and how they would like this information made accessible to them. It is also less clear whether individuals actually want to receive tools and techniques for self-management, or if there are other approaches that would be preferred, such as more tailored input from medical professionals.

2.5 Telehealth Interventions

There can be some challenges in physically attending appointments as a consequence of chronic pain or fatigue resulting from endometriosis (Leonardi et al., 2020). This barrier became more apparent when the Covid-19 pandemic occurred, and the entire public health system changed radically overnight, with many face-to-face appointments having to be conducted differently. There was an increased acceptability towards telehealth interventions as a result of the pandemic, including Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT) and Group Psychotherapy, many of which were used to great success (Cuthbert et al., 2022; Lichiello et al., 2022). For example, “empowered relief” interventions, an intervention that equips patients with pain relief skills, saw clinically significant improvements when delivered virtually during the pandemic (Ziadni et al., 2021). This uses mindfulness principles, combined with neuroscience and cognitive behavioural therapy (CBT) techniques, an intervention successful in improving perceived pain in individuals with endometriosis (Donatti et al., 2022). This suggests home-based treatments can be used successfully in symptom management, and could minimise geographical barriers accessing healthcare provision, that may result from limited physical accessibility due to their endometriosis symptoms and pain (Leonardi et al., 2020). A mixed methods study using an SMS text message intervention for endometriosis found high acceptability and suitability of these messages, providing clear, useful and appropriate information for endometriosis (Sherman et al., 2022). However, there remains potential barriers in digital literacy and accessibility for interventions such as these, so alternatives must be considered.

2.6 Body image

Body image is defined as a person's perception, feelings and thoughts about their body (Grogan, 2016). When those with endometriosis perceive themselves to have a 'sick body' associated with their chronic pain, it can cause negative body image and general body dissatisfaction (Melis et al., 2015). Satisfaction with both bodily appearance and appreciation of bodily functionality is comparatively lower in those with endometriosis compared with non-clinical women (Volker & Mills, 2022). Appreciating the 'self' and what it can do has been supportive of individuals 'de-emphasising' physical appearance as a source of esteem, which may improve body image (Alleva & Tylka, 2021). Therefore, functionality, appearance and the sense of self are considered in more detail below, due to the fractured sense of self reported in those with endometriosis (Aerts et al., 2018).

2.6.1 Functionality

Bodily functionality refers to all the things the body is able to do or is capable of doing in different domains (Alleva & Tylka, 2021). This could include one's ability to function internally (e.g., digestion), move physically (e.g., walk), experience senses and sensations, be creative, communicate and look after oneself through self-care (e.g., sleeping or showering). The 'Body Conceptualisation Theory' suggests women have been socialised to pay more attention to their body's appearance over its functionality, focusing more on their body-as-an-object compared to men (Franzoi, 1995). Objectification Theory supports this concept, suggesting that women are often sexually objectified and evaluated and valued based primarily on their physical appearance (Fredrickson & Roberts, 1997). This can lead women's ability to be attuned to their bodily functionality to be reduced, which may lead to feelings of shame when it is not 'functioning' (Alleva & Tylka, 2021).

Research on how women with endometriosis feel about their level of body functioning is scarce, but the available qualitative evidence in this area shows that the body and sense of self is particularly negatively impacted in women with endometriosis (Mills et al., 2023). Individuals with endometriosis have described feeling as though their body is 'broken', 'defective' or 'damaged', which may result from several of the symptoms experienced with the condition. When women's bodies have been described in the Objectification Theory as being there to serve for sexual pleasure (Fredrickson & Roberts, 1997), or valued based on their level of fertility (Bovet, 2018), the painful sex and infertility often experienced with endometriosis may explain why many feel as though their body is not functioning as it 'should', and may contribute to how a woman perceives their value as a 'heteronormative woman' (Mills et al., 2023). The frustration towards body functionality can be further compounded when some research has shown the negative symptoms experienced with endometriosis to be relieved during and after pregnancy, yet for many, getting pregnant in the first place can be challenging (Alberico et al., 2018). Individuals who are infertile have described their feminine identity as defective, because society considers parenthood an experience that makes a person 'complete' (Alamin et al., 2020).

However, this does not explain why individuals with endometriosis who do not want children or do not identify as female still struggle with the challenges that the symptoms associated with this condition can bring. Women who are childless by choice are often socially defined with negative stigma, however, there are differences observed between cultures (Culley et al., 2011), and it has been observed that some of this pressure for parenthood comes from doctors as opposed to the individual themselves (Facchin et al., 2018). In addition, the extent to which childlessness is viewed negatively is dependent on the individual, and the value they place on the identity of becoming a parent, highlighting a potential area for psychological intervention in individuals struggling with the reduced functional ability to conceive (Facchin et al., 2021). The challenge of endometriosis-related symptoms in transmasculine individuals (those assigned female at birth but identifying as male) can also be particularly challenging due to the implications this can have on their bodily perception during transition, and the potential gender dysphoria experienced if waiting for a hysterectomy (Ferrando, 2022).

2.6.2 Appearance

Bodily appearance also has associated norms and ideals around weight, shape and specific body parts and features, such as skin tone and hair texture (Cash & Pruzinsky, 2002; Jarry et al., 2019). This includes the internalisation of 'White beauty ideals' across many cultures, including skin bleaching for lighter skin, smooth straight hair, and thinness (Harper & Choma, 2019). Another study examining differences between 10 world regions found within cultures, there were significant differences in 'ideal body weight' between rural and urban areas in places like South Africa and Malaysia. They concluded less socioeconomically developed societies idealized heavier figures and body dissatisfaction was greater in higher economic status sites, like North America (Swami et al., 2010).

Many with endometriosis describe feeling 'less attractive' (Mills et al., 2021), with 34% feeling their general appearance is affected by having endometriosis (Ghorbani & Yashmaie, 2009), negatively affecting their self-esteem (González-Echevarría et al., 2019). They may also have negative body image distortions and general body dissatisfaction (Melis et al., 2015), potentially due to feeling "overweight" as a result of hormonal therapy, or having scars following surgical interventions (Facchin et al., 2018). Another symptom often experienced is severe bloating, often described as 'Endo belly', where individuals feel they need to conceal how they look, and minimise discomfort, often feeling as though they 'look pregnant', a challenging paradox when being able to conceive is something some struggle with (Sayer-Jones & Sherman, 2022). The perception of their physical appearance also becomes more negative when experiencing a 'flare-up' (Sayer-Jones & Sherman, 2022), indicating the negative impact on body image these various symptoms can have on the individual.

In addition to this, as a woman generally, body image perception changes across the menstrual cycle, with body dissatisfaction being significantly greater during the premenstrual and menstrual phases, despite no anthropomorphic changes occurring, with an additional expressed desire for a small body size in all phases of the cycle (Jappe & Gardner, 2009; Teixeira et al., 2013). Body dissatisfaction is worsened with the water retention, negative affect, and impaired concentration also experienced during the premenstrual phase (Carr-Nangle et al., 1994). This water retention and bloating may cause deviation from the 'thin ideals' of Western culture, causing further distress towards one's self (Luscombe et al., 2009; Swami, 2015). When combining these experiences in individuals with a condition exacerbated throughout the menstrual cycle, this may worsen appearance and body image perception in individuals with endometriosis.

2.6.3 The Tripartite Model of Influence

The Tripartite Model of Influence proposes there to be three core sources of influence to body dissatisfaction; parents, peers and media (Hardit & Hannum, 2012). Peers and the use of social media (such as platforms like Facebook and Instagram) can be common avenues for individuals to seek knowledge and support for their endometriosis (Sbaffi & King, 2020; Holowka, 2022), due to the challenges many face with clinician care and concerns towards the interests of the pharmaceutical industry (Neal & McKenzie, 2011). Whilst social media is associated with the risk of misinformation and contradiction, it can be a useful space for people to seek tips for the ways in which endometriosis may present, and advocacy to manage it (Holowka, 2022). However, social media can have negative consequences for body image. Specifically in the case of appearance-focused use, certain platforms like 'Instagram' and 'Snapchat' were more detrimental to a person's body image than 'Facebook', due to their higher emphasis on 'visual' content and subsequent appearance comparisons compared to the more 'text-based' content of 'Facebook' (Vandenbosch et al., 2022). Exposure to 'Fitspiration' content (images that aim to promote a 'healthy' lifestyle') can also risk increases in body dissatisfaction, with only body positivity (BoPo) content (images promoting body acceptance and diversity) having the potential to improve body image (Vandenbosch et al., 2022). Exposure to idealised female figures has led to reduced body satisfaction (Durkin & Paxton, 2002), and psychoeducation can be supportive in reducing body image disturbance too (De Valle et al., 2021); something to be considered by clinicians supporting those with endometriosis. Interventions targeting mediators such as internalisation and comparisons in the context of social media use have also been found to improve body satisfaction and subjective well-being (Jarman et al., 2021).

2.6.4 Sense of self

The sense of self is significantly impacted with endometriosis, with individuals feeling shame and inadequacy alongside their body image concerns, creating a fractured sense of self (Aerts et al., 2018). This dissatisfaction with one's body has been linked with disruptions to a sense of wellbeing and self-compassion (Cash & Smolak, 2012), with some seeing their relationship with their body as a constant struggle for control (Mills et al., 2021). It is described as a disease of multiple losses: relationships, career and sense of self-worth, and bodily appreciation can be more challenging when their body is a source of such chronic pain (Cox et al., 2003; Markey et al., 2020). This can also have an effect on partners of those with endometriosis, with a systematic review finding that partners may experience emotional distress, lack of support, isolation and poor sexuality (Facchin et al., 2020). As a result, psychosocial support and couples therapy may be beneficial to reduce the negative impact the condition can have on domains like intimacy and the relationship in general (Norinho et al., 2020). This may also reduce the negative impact of the changes to a person's identity as a result of their endometriosis, so that in the context of women's roles and societal expectations, women feel like less of a burden to their loved ones (Cole et al., 2021).

It has been suggested that interventions to promote optimal treatment of endometriosis need to have a multi-dimensional focus to target the multiple facets of the condition (Cole et al., 2021). It is also suggested that promoting empowerment, pain acceptance and body acceptance (feeling comfortable in one's body despite not being satisfied with all of it, or focusing on assets rather than flaws) could elicit positive outcomes (Bullo, 2018; Cash & Smolak, 2012; Markey et al., 2020). Acceptance towards having endometriosis has helped women create a better sense of understanding towards their body (Mills et al., 2021a), suggesting that Acceptance and Commitment Therapy and other self-compassion-based interventions could support in improving body image (Fogelkvist et al., 2016; Wetherell et al., 2011).

2.6.5 Positive Body Image

Supporting participants to view their body and their experience of having a chronic condition like endometriosis more positively could encourage individuals to reframe their experience of having the condition to a perspective that is more optimistic. Individuals have been found to feel some level of gratitude at what their body was able to achieve, despite the condition (Mills et al., 2021). It was noted however, that this was only after time had passed, or they had achieved something initially considered ‘unlikely or ‘impossible’, such as bearing a child. Some viewed their endometriosis journey as one that enabled them to reconnect with their body (Mills et al., 2021). For others, it provided an opportunity to re-evaluate and reappraise the foundations of their relationships, with partners putting the health and wellbeing of the individual with endometriosis above their own needs and desires (Hudson et al., 2016). Research into appearance, functionality, and sense of self in endometriosis is still limited, and although these previous studies demonstrate initial value in building more body image related interventions in this patient demographic, it is still less clear which elements of body functionality and appearance individuals feel they would benefit from interventions to target.

Body image has also previously been understood to be on a continuum, with negative body image representing low levels of positive body image (Tylka, 2011). Positive body image has since been identified as distinct from negative body image, and is defined as a multifaceted construct, including “body appreciation, body acceptance/love, broadly conceptualising beauty, adaptative investment in appearance and inner positivity” (Tylka & Wood-Barcalow, 2015, p. 127). It is not just appreciating appearance or how it aligns with cultural appearance ideals, but praising what the body can do and it’s ‘unique features’ (Tylka & Wood-Barcalow, 2015). There may be benefit from supporting individuals to reach a place of body ‘neutrality’, where there is more emphasis on accepting the body as it is, instead of feeling as though they have to ‘love’ their body (Clark, 2022). However, developing interventions that are supportive in targeting areas of positive body image may be beneficial in an endometriosis population as professionals not sufficiently focusing on ‘positive’ body image may leave their patients less able to connect with how their body feels and functions (Daniels et al., 2018). Placing more focus on encouraging individuals to appreciate, respect, celebrate and honour their bodies may lead to longer lasting treatment effects and gains (Tylka & Wood-Barcalow, 2015).

2.7 Health Psychology

Health Psychology literature can help with understanding the biological, social, and psychological factors influencing health, through the use of models and theories. In this context, it can provide a framework from which to understand the impact of endometriosis on the individual, and understand the influence of their health behaviours and self-efficacy (Holloway & Watson, 2002). It can also provide some explanation into why an individual may choose one treatment option over another.

2.7.1 COM-B Model

The COM-B model provides an explanation for three core components contributing to health behaviours. These are Capability, Opportunity and Motivation (West & Michie, 2020). The COM-B model can support in understanding and tailoring the support for individuals with endometriosis. For example, some individuals with the condition lack the knowledge and understanding of the approaches that can be adopted to manage the condition (Roomaney & Kagee, 2016; *Psychological Capability*), or in some cases, they experience such severe symptoms, they are unable to implement self-management strategies, such as exercise (Seear, 2009), and therefore may need extra provision with physically carrying out a behaviour (*Physical Capability*). In other cases, individuals have been unable to make changes, or manage their symptoms, because the products/services were too costly (Cox et al., 2003; *Physical Opportunity*), or the place they lived made it harder to access the care they need, something that became particularly prevalent during the Covid-19 pandemic (Waters et al., 2022; *Physical Opportunity*). For many, social and familial norms have shaped the narrative, management and endurance of endometriosis (Markovic et al., 2008; *Social Opportunity*). Lastly, a person's motivation to make change may often the biggest driver as to whether health behaviour change will occur. Motivation can be reflective, (planning and evaluating), something that may be challenging in the context of a chronic condition like endometriosis, where there is little ability to plan in advance due to the unpredictability of the condition's symptoms. Motivation can also be automatic (habits and impulses; West & Michie, 2020), an approach or thinking style, that some with the condition may take when managing the condition, through familiarity. The PRIME Theory of Motivation is linked to the COM-B model and provides a framework for understanding these diverse factors influencing these motivational processes and how they interact.

The COM-B model can help with understanding the parameters in which change may or may not occur and can guide intervention delivery and policy makers in supporting individuals to make health behaviour change. However, in the context of chronic illness such as endometriosis, this model may be too simplified. It does not take into account the lack of control experienced by many with a chronic illness (Aujoulat et al., 2008), and the way in which this lack of control can cross over across all three components making change particularly challenging. Chronic illness may be supported by intervention, however, to do this, there must first be an understanding of the sense of self and beliefs surrounding one's health, and a readiness to change, before change can be considered. Interventions to manage pain and improve body image need to take into account the many individual, personal challenges that come with a condition like endometriosis, reiterating the importance of treating the condition in an individualised, biopsychosocial way (Aerts et al., 2018).

2.7.2 Stages of Change

To determine the readiness to change, the 'Stages of Change', or the Transtheoretical Model (TTM) can help with understanding where a patient is in their health journey, as the model suggests that to make change, individuals must be in the right place to do so. In the context of endometriosis, change might include an openness to change treatment method, when others prior have failed, and a readiness to change or challenge the thoughts or beliefs one has towards the condition. The TTM outlines six stages; precontemplation, contemplation, preparation, action, maintenance and termination. It suggests that individuals progress through from one to the next, and helps conceptualise the process of behaviour change in each stage (Prochaska & Norcross, 2001). In endometriosis, this may include changing to a new treatment regime that there is evidence for and they have been recommended to follow, such as a change in diet. However, despite knowing that it may be beneficial, a person may be reluctant to make the change because it requires time and adopting a new routine. Understanding this reluctance to change, and how ready one is to change can help with delivering an intervention at a time where a person may be more ready to receive it, and therefore more successful when making change.

However, there are cases when someone with endometriosis may have tried most treatment options and are instead in the process of navigating acceptance towards having a chronic condition. In this case, the TTM may be less applicable, as they may not want or need to change a behaviour into a new one, and instead these individuals should be supported in understanding, *controlling,* and managing their endometriosis. Chronic pain, as experienced in endometriosis, can also influence readiness to adopt new beliefs and coping responses, and it is suggested there are limitations to the applicability of the TTM in patients with chronic pain (Jensen et al., 2000). It has been proposed that to understand readiness for change in pain, more consideration should be made on the stability and speed of transitioning between the stages, and learning more about the cause and their perceived control of their pain (Dijkstra, 2005).

2.7.3 Health Locus of Control

Health Locus of Control can be used to understand the extent to which an individual believes they have control. Preventative health behaviours may be possible to put in place to manage symptoms (ZindIer-Wernet et al., 1987), but as a condition with no cure, and poor understanding into its origin, it is challenging to identify specific health behaviours that can truly 'prevent' the genesis of endometriosis. Having a perceived internal locus of control, where an individual feels they are in control of their health, can support individuals to become more likely to engage in information seeking, or medication adherence, maintaining healthy lifestyle habits or regularly attending medical appointments (Strudler Wallston & Wallston, 1978). External locus of control on the other hand, the belief that one's health is in the hands of fate, or others, has been more strongly associated with wellbeing than internal control (Gore et al., 2016), suggesting that feelings of control in the context of health varies. Having higher internal locus of control has been linked with reduced depression symptoms in chronic pain patients, compared with those who felt their health was down to 'chance' (Wong & Anitescu, 2017), suggesting the perception of self and behaviours engaged in following diagnosis may offer opportunity for intervention to improve outcomes. It also indicates the potential benefits for increasing patient involvement in the decision-making process when it comes to their health management. It has been suggested that promoting resilience, emotional support and good health can promote healing and reduced chronicity of pain, and supports in managing expectations of eradicating pain towards controlling it instead (Cohen et al., 2021). This may encourage individuals to perceive the level of control they have over their condition differently and may subsequently have beneficial outcomes for the way in which individuals perceive their body. Increasing an internal locus of control may be beneficial in the context of endometriosis, where despite feeling out of control of the condition itself, individuals may feel more control over how they navigate day-to-day tasks and activities, which may consequently result in improved feelings of control. The Health Locus of Control will be considered in more detail below due to the framework it provides in understanding the perceived control over the condition.

2.7.4 Common-Sense Model of Self-Regulation

Supporting patients to navigate their health condition and associated threats and treatments is a core focus of the Common-Sense Model (CSM) - a model that outlines how illness can be conceptualised (Leventhal et al., 2016). It can be a good way to examine variables that may influence future or current health, perceived personal vulnerability and illness severity, and therefore can be a useful tool to support those with endometriosis. It can help with reframing the causes, consequences, coping strategies and identity surrounding chronic illness (McAndrew et al., 2008). This indicates that the way in which illness is conceptualised, or the cognitive representation of illness is down to personal perspective and experience (Weinman et al., 1996). Supporting patients to conceptualise their endometriosis in a way that makes them feel less vulnerable, and more in control, may improve outcomes.

2.8 What are the current challenges facing patients in understanding their condition and provision of care?

2.8.1 Treatment approaches

The current economic burden associated with endometriosis is around £8.4 billion in the UK, a cost which has been found to increase again in those with higher pain presence (All-Party Parliamentary Group on Endometriosis, 2020; Simoens et al., 2012), yet the research funding into endometriosis is still very limited. Individuals with the condition are often treated with pharmaceuticals as a first point of treatment, yet women are more likely to suffer adverse side effects from medications, as clinical trials on their effectiveness have been predominantly conducted on men (Anwar, 2020). Despite being as common as diabetes (Diabetes UK, 2023), there is currently no comparable financial or research investment, highlighting a wider issue into the lack of investment into women's health generally. In 2021, the UK Government launched a press release, calling for evidence aimed at improving healthcare for women, as they identified less is known about women’s health conditions, including endometriosis, recognising that the impact of the condition is often overlooked (GOV.UK, 2021). The government later released an updated sexual and reproductive health strategy, with suggested changes following their call for information in 2021 (GOV.UK, 2022). They received 110,123 responses, with respondents reporting that they were often ‘not listened to’, or told their heavy painful periods were ‘normal’ and they would ‘grow out of them’. There was also a consensus that there are difficulties accessing high quality information on women’s health issues, and the challenges their health can bring in participating in the workplace or daily life.

The Government set out a 6-point long-term plan, outlining how they hope to address some of the issues raised, which include improved access to services, prioritising services for conditions like endometriosis. This is suggested to be achieved through increased shared decision making between health professionals, and increased guidance on surgical treatment options so patients are better informed. They also recommend that employers introduce or improve workplace provision and policies for endometriosis and have now begun a review of the NICE guidelines on endometriosis care to consider the necessity for an update to these guidelines. They now more readily promote the ‘Menstrual Wellbeing Toolkit’ available to GPs should they choose to access it (Royal College of General Practitioners, 2018). However, this is again mainly focused on upskilling of understanding relating to how endometriosis can be managed in primary care, as opposed to tangible resources for patients.

2.8.2 Clinician care

Clinician care also presents another challenge in endometriosis care, as it has been said that ‘one doctor’ can transform a patient’s experience, and create more positive diagnostic pathways towards endometriosis (Fernley, 2021). However, a negative doctor patient alliance can have negative physical and psychological consequences (Fernley, 2021). Dismissal of the patient experience, or lack of understanding from clinicians, is a big factor in the management and feelings of control surrounding endometriosis. Health professionals dismissing the pelvic pain experience of women has left many struggling to convey the severity of their symptoms (Grace, 1995). Despite reporting higher pain prevalence, and greater post-surgical pain, women are less likely, or wait longer, to receive pain relief compared to men (Chen et al., 2008; Fillingim et al., 2009; Gerdle et al., 2008). The lack of resource placed in understanding endometriosis treatments has resulted in 82% of physicians believing there is a need for psychosocial care in this patient group, yet only 15% are routinely referring patients for support with this, and 72% do not feel adequately trained to provide care for this in endometriosis (Reddy et al., 2020). In addition to this, when patients reach a point of surgery, they can then be faced with the challenge of receiving a diagnosis, or specialist surgery conducted by clinicians who are less qualified in offering such surgical interventions. There are only 63 specialist endometriosis centres accredited by the British Society of Gynaecological Endoscopy (BSGE, 2023), which means that the number of clinicians able to offer excision surgery (i.e., surgery to cut out endometriosis tissue) is minimal, with many opting to deliver ablation surgery (i.e., the burning or destroying of surface tissue) instead. Laparascopic excision has significantly greater improvements to dysmenorrhea (painful periods), dyschezia (painful bowel movements) and chronic pelvic pain compared with ablation, suggesting that upskilling clinicians in this area will also improve patient outcomes (Pundir et al., 2017).

As a result of the reduced confidence in treating endometriosis, women have reported that they feel they need to “be their own doctor” and have to strongly advocate for themselves (Young et al., 2020), creating a negative power dynamic in the patient-provider relationship, as women become wary of the power of their doctors due to them reducing their needs down to a medical label. Some have found their doctors to be sympathetic and understanding, with staff at dedicated Endometriosis Centres being reported as caring, supportive and accessible (Moradi et al., 2014). However, the majority of experiences have been reported to be negative, with symptoms being dismissed as ‘normal’ or ‘not serious’, with difficulties accessing specialists who understand endometriosis, and many younger patients reporting that their physicians have thought they were making it up for attention (Moradi et al., 2014). The main barrier to effective endometriosis management appears to be a lack of knowledge, empathy and communication skills (Kundu et al., 2015), suggesting that the inclusion of more tools that can support self-management may be beneficial.

2.9 Systematic review

A systematic review examining the evidence of effectiveness of non-pharmaceutical, non-surgical, biopsychosocial interventions for body image and pain management in individuals with endometriosis was conducted to understand what care provision currently exists (Falconer et al., 2022; Appendix 12). Nine databases were searched, with inclusion/exclusion criteria applied. Participants were females, aged over 18, with laparoscopically confirmed endometriosis, due to the high validity this has compared to medical records alone, and wide variety of symptoms presenting with the condition. Cisgender females were included due to the complex body image and identity related concerns potentially arising from the condition presenting in someone with female organs but identifying as male (Simbar et al., 2018).

A total of 6 publications were identified from 9,101 records, which included five randomised control trials and one controlled clinical trial. There were 323 participants, recruited through medical records or self-referral, and treatments were largely administered by specialist practitioners. The interventions delivered in these publications included acupuncture, Chinese Herbal Medicine (CHM), dietary supplementation, yoga and psychotherapy and somatosensory stimulation. Study quality was assessed using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool, which found 2 weak quality papers, and four moderate quality papers showing improvements to pain, with large effect sizes in four papers. However, no studies used established body image measures to examine intervention effects on body image, and all lacked a health psychology theoretical basis. There were common issues in selection bias, confounders, and blinding, and without gold-standard methodology, evidence of effectiveness cannot be concluded. The absence of interventions on body image may be due to there not being enough yet known about how body image is influenced and impacted in those with endometriosis. Therefore, further research is needed to help identify what components of body image individuals with the condition would find useful to have further intervention on, and building understanding into how this could be delivered.

2.10 Current Research

As concluded in the systematic review, to increase the understanding of the influence of endometriosis on body image, and how individuals would benefit from support for this, further research is required. Currently, the number of publications on endometriosis and body image are limited, with the majority of published articles in this area being qualitative pieces (Volker & Mills, 2022; Mills et al., 2023). These have been important in building understanding of the subjective experience of individuals with endometriosis. However, there has been very little quantitative research, which would enable a more generalised understanding of body image perception in endometriosis, including how it relates to other constructs. The few quantitative pieces in this area have identified that there is reduced satisfaction with appearance and reduced appreciation for bodily functionality compared to those without endometriosis (Volker & Mills, 2022). A systematic review identified psychological interventions can be beneficial in addressing body image concerns in other gynaecological conditions like Polycystic Ovarian Syndrome (PCOS), but psychological interventions for endometriosis have so far only focused primarily on improving pain and quality of life (Pehlivan et al., 2023). Another mixed methods study aiming to identify the overall needs and preferences of those living with endometriosis (for an SMS text message intervention) identified a desire for psychological and emotional support, including tips and strategies for looking after and caring for their body (Sherman et al., 2022). However, there is not yet any mixed methods research on whether there is a preference for different types of intervention approach, e.g. acceptance-based approaches, or in-person vs. online and individual vs. group approaches for *body image* specifically. Body image concerns may be best addressed in a group setting (Pehlivan et al., 2023), however, this has not yet been examined. There are also no comparisons that have been made between body dissatisfaction and functionality appreciation against general wellbeing outcomes. Therefore, we do not yet know if general wellbeing is impacted by body image in those with endometriosis, or vice versa.

This thesis has so far outlined the way in which endometriosis presents and described a number of treatment options available in the UK. These treatment methods primarily target physical symptom management, with a necessity for psychological support being recognised, but not readily delivered. The impact of endometriosis on body image has been acknowledged, with the existing studies identifying the varied impact the condition has on both functionality and appearance appreciation and satisfaction. The social influence of peers and social media, and current challenges have also been considered, and Health Psychology models have been discussed, to demonstrate how they conceptualise the influence of endometriosis on body image, and thus, how this could be targeted. However, it is currently unclear if there are certain body image needs that individuals with endometriosis would like further input on. It is also unclear how individuals would prefer to understand and receive information and support on this, for example, via one-to-one therapy or self-led materials.

Therefore, this mixed methods study intended to answer the following research question:
What is the impact of endometriosis on body dissatisfaction, functionality appreciation and general wellbeing outcomes, and how can we support individuals to improve this?

To do this, the study addressed the following aims:

1. To understand if there were differences in body dissatisfaction (BD) and functionality appreciation (FA) depending upon the number of symptoms, number of body locations diagnosed with endometriosis, length of time experiencing symptoms before diagnosis and length of time *since* diagnosis, treatments received, number of surgeries, additional health conditions and geographical differences between participants in and outside the UK.
2. To understand the relationship between both body dissatisfaction and functionality appreciation *and* general wellbeing outcomes among people with endometriosis (emotional wellbeing, physical functioning perception, general health perception, self-compassion, perceived control and powerlessness and self-image).
3. To understand if individuals with endometriosis felt they would benefit from support to improve their body image; and if so, which areas they would like support in, and how they would like this delivered.

These aims were achieved via the following objectives:

- Create an online survey, supported with feedback from PPI.
- Disseminate survey and gather data.
- Analyse both qualitative and quantitative data from the survey.

- Identify demographic differences between participants.
- Identify body dissatisfaction, functionality appreciation and general wellbeing differences between participants.
- Identify which areas individuals would benefit from support in and how they would like this delivered.

Previous research has identified that body image can be negatively influenced by endometriosis (Mills et al., 2023; Pehlivan et al., 2023; Sherman et al., 2022; Volker & Mills, 2022), but it is unclear if there are factors influencing this more than others, and therefore support needs are unclear.

Therefore, the hypotheses related to the quantitative data analyses (Aims 1 and 2) were as follows:

1. Body dissatisfaction (BD) scores will be significantly positively correlated with the number of symptoms, number of body locations diagnosed with endometriosis, length of time experiencing symptoms before diagnosis and length of time *since* diagnosis, number of treatments tried, number of surgeries, and number of additional health conditions.
2. Body dissatisfaction (BD) scores will be significantly negatively correlated with scores relating to emotional wellbeing, physical functioning perception, general health perception, self-compassion, perceived control and powerlessness, and self-image scores.
3. Functionality appreciation (FA) scores will be significantly negatively correlated with the number of body locations diagnosed with endometriosis, length of time experiencing symptoms before diagnosis and length of time *since* diagnosis, number of treatments tried, number of surgeries, number of additional health conditions.
4. Functionality appreciation (FA) scores will be significantly positively correlated with scores relating to emotional wellbeing, physical functioning perception, general health perception, self-compassion, perceived control and powerlessness and self-image scores.
5. Participants from the UK will have greater BD scores/lower FA scores than those from outside the UK.

Chapter 3: Methodology

This chapter will explore the ontological and epistemological approaches used to frame the study and data collection, and the challenges presented with the use of mixed methods research. The ethical considerations are then discussed, highlighting the areas of consideration in endometriosis research specifically, as well as general ethical considerations. The recruitment process will then be outlined, before describing the subsequent participant sample and materials used to gather both quantitative and qualitative data. The data collection procedure is also outlined.

3.1 Ontology and Epistemology

To understand personal perspective and experience, it can be useful to first understand how a person may understand their reality (Ontology) and how this is developed, through conceptualising what they know through logic, reason and intuition (Epistemology; Al-Ababneh, 2020).

There are many paradigms through which reality and knowledge are described, with some considered a more appropriate approach for framing mixed methods research, like this study, than others. For example, an interpretivist ontology suggests that there is more than one reality, therefore the researcher remains open to new ideas, with a belief that reality is constructed socially and experientially (Cassar & Bezzina, 2015). Another ontology is constructivist, and it is important to consider that the researcher, having been diagnosed with endometriosis (see 5.9 Reflexivity section), may have approached the research from such a perspective, through which the impact of their own background and experience with the condition may have had influence.

Epistemology, on the other hand, has had much debate, with researchers questioning the appropriateness of adopting a singular epistemological stance and how this aligns with mixed methods approaches (Uprichard & Dawney, 2019). In some cases, it can lead researchers to either embrace or reject a whole viewpoint (Thomas et al., 2020), whereas instead, there could be focus on smaller concepts from several stances. The stance chosen to frame the research can define the intent, motivation and expectations of the outcomes, and therefore, it is important to consider this when developing and interpreting results (Cassar & Bezzina, 2015). For example, a positivist approach would see the researcher focusing on facts that are observable and measurable, looking for causal relationships between the data (Park et al., 2020). Empiricism on the other hand suggests that experiences and observations are the most important way to gather knowledge or data (Hjørland, 2005).

3.1.1 Advantages and Challenges associated with using Mixed Methods

In chronic illness, the way in which individuals understand and develop their reality is ever changing, in an attempt to make meaning from the evolution of their condition (Paterson, 2001). How they perceive their reality may change over time, based upon their recalled reality (a life prior to their illness) and their current reality (a life with the illness; Trento, 2019). This ontological complexity is another example of why aligning to a singular paradigm may not capture the extent of the personal experience. It is also an advantage to using mixed methods, as it can be a useful way to approach capturing the patient experience, to gain a better understanding of the nuances of living with a chronic condition, as it considers both fact and opinion. An interpretivist epistemological approach may enable the researcher to understand patterns in thoughts, feelings and behaviours, and build understanding of the contextual environments from which these may develop, giving participants space to explore their views, opinions and values on a more personal level. A positivist epistemological approach would enable the research to gather quantitative measurable data that may enable an understanding of how one influences the other and offers participants impartiality and anonymity.

Quantitative and qualitative research may also attract different audiences, with quantitative research promoting data collection that is emotionally detached, with reduced bias, and high scientific replicability, due to its consistent approach, potentially appealing to academics in medical sciences. Whereas qualitative research potentially holds more appeal to academics in healthcare, where researchers can further their understanding of lived experience, and healthcare needs, leading to more in depth tailored interventions (Renjith et al., 2021). In a field like Health Psychology, which brings science, evidence, and healthcare intervention together, mixed methods are a good way to combine both forms of data collection. The quantitative data demonstrates statistical significance to increase the replicability and comparison between the endometriosis population and other clinical populations, whilst the qualitative findings facilitates insights into the contexts and experiences of the participants, helping gain a holistic perspective on treating and managing long term conditions like endometriosis (Dures et al., 2011). Incorporating qualitative elements into other quantitative study designs may provide more rigor (Cassar & Bezzina, 2015).

Gathering mixed methods data can also be useful in the context of chronic pain conditions like endometriosis, as quantitative measures can be critiqued for not being ‘patient centred’ enough (Carr, 2001), whilst qualitative methods (like identifying research themes) are not always practical in clinical practice (Hadi et al., 2019). However, combining them can provide a wider picture of the pain experience of endometriosis patients, to understand its influence both physically and psychologically.

Mixed methods are also a good way of capturing the terminology through which a person may describe themselves with, potentially influencing bodily perception and identity further. For example, some prefer using the terminology ‘people who menstruate’ when describing those who endometriosis effects, as it may be considered that this is more inclusive of the community (Bell, 2017). Yet, there is debate that this may be considered dehumanising, ‘othering’ and excluding of those in the menopause or trans individuals who no longer bleed (Bobel, 2020). Therefore, using mixed methods may give individuals the freedom to perceive and define themselves in a way that represents them.

However, the challenge with bringing two epistemological approaches together (i.e., using mixed methods) is the complexity of social phenomena, that encourages researchers to use mixed methods in the first place: to better capture different methods of data collection and subsequent data exploration. This same rationale is why bringing two approaches together can be challenging, as social phenomena is complex (Uprichard & Dawney, 2019). Trying to bring this into a cohesive conclusion may not capture the differences intended through using two different methodological approaches to examine outcomes. Quantitative data aims to gather representative samples that can later be generalised or compared against other samples, whereas qualitative data aims to gather in-depth personal experiences, with deeper detail, but less generalisability. There are also few mixed methods studies in endometriosis, with researchers choosing to conduct each component of their research separately, choosing to first gather qualitative data and complementing it with quantitative data, for example, in the form of acceptability scales (Sherman et al., 2022). Alternatively, researchers are gathering quantitative data and complementing it with qualitative data to build meaning (Zarbo et al., 2019). The present study adopts a similar approach, gathering data from the same sample, at the same time, collecting quantitative data, and embedding these results with qualitative data, to provide rationale and explanation for choices made, collating these against each of the study's aims. This is often referred to in text as 'QUANT + qual', as the capitalised component indicates this data carries more weight, and is supplemented by the lowercase component (Schoonenboom & Johnson, 2017).

3.1.2 How have these challenges been overcome?

It is suggested that Pragmatism may be a way of resolving some of the challenges around data integration in mixed methods research (Uprichard & Dawney, 2019). Pragmatism addresses considerations from both qualitative and quantitative researchers as it suggests individuals can have single or multiple realities. It involves interpretation, as it proposes that no two people have exactly identical experiences, but recognises there are varying degrees of shared experiences between two people (Baum, 2017)**.** A major similarity in this approach to this research is that it suggests knowledge and reality are based on beliefs and habits that are socially constructed (Yefimov, 2004). Pragmatists generally agree that all knowledge in the world is socially constructed but some versions match individuals' experiences more than others. Pragmatism believes humans are free to believe what they want, and human action cannot be separated from past experience (Kaushik & Walsh, 2019). Therefore, approaching it from the perspective that someone's knowledge is based on their experience, is well aligned to endometriosis, as it further aids understanding in a research area that is still emerging.

By framing this piece of research from a pragmatist approach, it provides an opportunity for participants to share their experience openly and without parameters. Health professionals often discredit the experiences of those with endometriosis, labelling their pain as psychosomatic instead of pathological (Markovic et al., 2008). In addition to this, medical students can be influenced into thinking that what a patient reports may be unreliable, to preserve their authority as a physician (Trento, 2019). By dismissing patient experience, it reduces the likelihood of capturing a relativistic epistemology, that would support the stance that no one person's knowledge is superior to another's. Therefore, by conducting a mixed methods piece of research, it provides the opportunity to gather both measurable quantitative data, and its qualitative context.

3.2 Ethics

The ethical approval for this study was received on 19th October 2022 (Appendix 14) and was approved by the School of Social Sciences Research Ethics Committee at the University of West of England (UWE). The ethics application (Appendix 13) outlined the collection of the questionnaire data via Qualtrics, a secure online UWE approved platform. Other than being asked to provide consent, all questions in the questionnaire were voluntary, with participants not required to answer questions they felt uncomfortable with. All sources of recruitment shared a link that took participants directly to the Qualtrics survey, where they were then shown the informed consent and information sheet.

Participants demonstrating an interest in participating were asked to consent, by advising them their participation was voluntary and they would have the right to withdraw from the study at any time during data collection, and up to 4 weeks after completing the survey. They were provided with the information sheet, with additional detail, providing context for the need for the research, the aims of the research itself, and how their participation will help develop this. The sheet provided enough information so that participants were informed with what they were signing up to, including detail on data management and publication information. The lead researcher also added their contact details (UWE Student email address) so if there were any additional questions prior to the study, these could be asked, so participants were as informed as possible before consenting. It was recognised that answering questions on this topic may bring up discomfort in some participants. Whilst the aim of this study was not to deliver an intervention, the risk of thinking about this topic in detail may evoke some negative feelings. Therefore, participants were reminded at the start that if they felt they required additional support, there were a selection of organizations and charities they could be signposted to from the information sheet.

Participants were asked to set up their own participant identifier via Qualtrics, to enable easy subtraction of their data if they wanted to withdraw. By conducting all data collection online, it enabled wider participation across geographical locations, particularly in a population suffering from chronic pain, where face to face contact may be more physically challenging. Once collected, data was downloaded onto excel and stored on a password protected laptop on a restricted folder on the UWE OneDrive.

3.3 Procedure

Following ethics approval, the draft version of the questionnaire was sent to five women diagnosed with endometriosis, volunteering for Endometriosis UK, as part of ascertaining its acceptability. The National Institute for Health and Care Research (NIHR) suggests that having Patient and Public Involvement (PPI) can improve the quality and relevance of research, provides different perspectives, and empowers those affected by the research, with lived experience of the condition, by giving them a say in it (National Institute for Heath and Care Research, 2021). By using individuals with the condition to provide feedback, it enabled 'Patient-Oriented Research', making it a more pragmatic approach to data collection, as it seeks to make individuals with the condition 'expert' as opposed to 'subject', addressing a potential power imbalance between researcher and participant (Allemang et al., 2022).

The PPI group were not asked specifically whether they thought an online survey was appropriate, however, feedback suggested that they felt the survey was a 'perfect length' and allowed them to 'express themselves freely', which they felt 'unable to do with healthcare professionals' (See Appendix 1). Having a PPI group provide feedback on the questionnaire enabled those with the condition to express their thoughts and opinions, to ensure the questions captured everything they felt they would want to discuss on the topic. Other amendments were made in response to this PPI feedback, with most of the suggestions incorporated into the questionnaire, and rationale for comments made that were not incorporated, justified in Appendix 1. Once finalised, the study was promoted via several sources (see below).

3.4 Recruitment

Recruitment for the study was carried out online through opportunity sampling, to increase the reach to potential participants. Endometriosis UK (Endometriosis UK, 2023), the UK's leading charity for those with endometriosis, agreed to publicize the research within their volunteer monthly email. Endometriosis UK published the research in their national volunteer newsletter, and also asked volunteers to disseminate the link to their groups. The Centre for Appearance Research also agreed to publicize recruitment on their social media platforms and sent it to the 'CAR Participant Pool' of over 900 people, who have consented to receiving information about ethics-approved studies. In addition to this, the research was advertised on the researcher's own social media platforms, in addition to a number of other contacts who agreed to share (see Appendix 2). This included some 'influencers' in the endometriosis and body image space, e.g. 'The Fanny Diaries' (11.2k followers) who, following a series of screening questions to ascertain the ethical boundaries of the research, agreed to publicize it across their social media platforms (Instagram and Facebook) and websites. Lastly, to reduce bias, the research was advertised on a series of 'general' Facebook groups, used primarily for lifestyle-based conversation and event planning. For a full list of organizations and users contacted for recruitment, see Appendix 2.

3.5 Participants

A total of 245 participants started the survey. Inclusion criteria outlined participants needed to be aged over 18 years old, and have been laparoscopically diagnosed with endometriosis, due to the high validity this has compared to medical records alone, and wide variety of symptoms presenting with the condition. Participants were also included from both the UK and beyond, to determine if there were differences observed, and therefore potential considerations for treatment based on location of the participant. After 117 participants' data were removed, for reasons outlined below, this left a sample size of 128 participants. G*Power was used to determine sample size, using Cohen's large effect size criteria $f^2 \geq 0.35$ (Selya et al., 2012), and a significance criterion of $\alpha = .05$ and power = .95, the minimum sample size needed was 40, suggesting the sample size of 128 participants was more than sufficient.

Participants' ages ranged from 19 years to 54 years old (M=31.28, SD = 6.839), with an average 10 year wait for a diagnosis, and 4.9 years since confirmed diagnosis. Further details are outlined below, in Table 1.

	N	%
Sex-assigned-at-birth		
Female	126	98.4
Transgender male	1	0.8
Gender variant/non-conforming	1	0.8
Location		
United Kingdom	100	78.1
East Midlands	6	4.7
East of England	4	3.1
Greater London	5	3.9
Ireland	1	0.8
North East	1	0.8
North West	8	6.3
Scotland	7	5.5
South East	16	12.5
South West	15	11.7
Wales	8	6.3
West Midlands	10	7.8
Yorkshire and the Humber	12	9.4
Outside United Kingdom	28	21.9
Asia	2	1.6
Australia	2	1.6
Canada	4	3.1
Europe	5	3.9
North America	14	10.9
South America	1	0.8

Table 1 – Number of Participants based upon demographics

3.6 Materials

A mixed methods investigative study was conducted via an online survey (Appendix 3). The quantitative measures included validated scales. This was complemented by open questions to gather qualitative data. This decision was made because incorporating qualitative elements into other quantitative study designs may provide more rigor (Cassar & Bezzina, 2015).

3.6.1 Quantitative Measures

The quantitative questions (see Appendix 9) included the collection of demographic data, and diagnosis-related data, including the number of symptoms, the number of body locations diagnosed with endometriosis, length of time experiencing symptoms before diagnosis and length of time since diagnosis, number of surgeries, number of additional health conditions and geographical location. The quantitative findings increased confidence in the generalisability of the results and provided an option for participants to answer more sensitive topics, without providing additional detail if they did not feel comfortable. It also provided a better understanding into how the complexities within endometriosis compare against those of other conditions, by using scales previously used in other long-term conditions.

3.6.1.1 Endometriosis Health Profile - EHP-30

The EHP-30 (Appendix 4) has been found to be a valid, reliable disease specific measure (Jones et al., 2001), with excellent test-retest reliability (Hansen et al., 2022). It consists of 30 questions, with five core subscales: pain, control/powerlessness, emotional well-being, social support and self-image. Scores were rated using a Likert scale, ranging from 0 (never), to 4 (always). Each subscale directly translated into a 0-100 scale, as it assumes each subscale carries equal weight. The greater the total score, the poorer the overall health related quality of life. For the purposes of this questionnaire, only the control/powerlessness (poorer control/greater powerlessness) (Questions 12-17, e.g. During the last 4 weeks, have you felt frustrated because your symptoms were not getting better?), and self-image (poorer self-image) subscales (Questions 28-30; e.g. During the last 4 weeks, have you felt frustrated as you cannot always wear the clothes you would choose?) were used, and analysed using the EHP-30 User Manual (Jenkinson et al., 2016). The EHP-30 demonstrated excellent internal consistency for the control/powerlessness subscale (Cronbach's alpha ≥ 0.94) and reliable internal consistency for the self-image subscale (Cronbach's alpha ≥ 0.88; Jones et al., 2006).

3.6.1.2 The 36-Item Short Form Health Survey (SF-36)

The SF-36 (Appendix 5) is a self-reported measure of health, found to be a reliable, valid and responsive measure for endometriosis (Stull et al., 2014), with excellent test-retest reliability (Brazier et al., 1992). It consists of 36 questions covering 8 domains of health; limitations in physical, social and usual activities, bodily pain, general mental health, emotional difficulties, vitality and general health perceptions. Scores were rated using a Likert scale, with scale ratings differing between subscales. Each subscale is directly translated into a 0-100 scale, as it assumes each subscale carries equal weight. Some subscale questions required recoding to form an average for the subscale, so that all items were scored in a way that a high score defined a more favourable health state. The greater the total score, the greater the perceived health state. For the purposes of this questionnaire, the physical functioning section (poorer physical functioning) (Questions 3-12; e.g. During a typical day, does your health limited you in these activities; bending, kneeling or stooping?), the emotional wellbeing section (greater emotional wellbeing) (Questions 24-26, 28 and 30; e.g. during the past 4 weeks, how much of the time have you been a happy person?) and the general health section (greater general health) (Questions 33-36; e.g. How true or false are the following statements for you; my health is excellent) were used, and analysed using the SF-36 Scoring Instructions (RAND, 2019). The SF-36 demonstrated reliable internal consistency (Cronbach's alpha ≥ 0.85; Brazier et al., 1992).

3.6.1.3 Body Image Scale (BIS)

The Body Image Scale (Appendix 6) is a 10-item scale, ranging from 0 (not at all), to 3 (very much), created for the use of understanding the body image perceptions of cancer patients, used in other studies on endometriosis (Sullivan-Myers et al., 2023). The Body Image Scale is a highly reliable, clinically valid Likert scale, with good test-retest reliability and excellent internal consistency (Cronbach's alpha ≥ 0.93; Hopwood et al., 2001), and has been shown to be a reliable, valid tool for assessing body image in women with benign gynaecological conditions, including endometriosis (Stead et al., 2004). The scale supports with understanding the affective, e.g. ‘Have you been feeling less feminine?’, behavioural, e.g. ‘Do you find it difficult to look at yourself naked?’ and cognitive, e.g. ‘Have you been dissatisfied with the appearance of your scar(s)?’, outcomes of the individual (Hopwood et al., 2001). All 10 questions were used within this survey. Five questions are presented positively, e.g. “Have you been feeling feminine?” and five questions are presented negatively, e.g. “Did you find it difficult to look at yourself naked?”. Participants were asked to consider the questions in the context of the past week to keep the answers sensitive to any ongoing treatments. The greater the total score, the greater the level of body dissatisfaction. Scores can range from 0 to a maximum of 30.

3.6.1.4 Functionality Appreciation Scale (FAS)

The Functionality Appreciation Scale (Appendix 7) is a reliable, valid 7-question Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree), used to determine the appreciation, respect and honour the individual has towards their body (Alleva et al., 2017). The scale is used to not only recognise what the body is capable of doing, but acknowledging feelings of gratitude the individual may have towards this (Alleva et al., 2017), e.g. “I respect my body for the functions that it performs”. The FAS demonstrated reliable internal consistency (Cronbach’s alpha ≥ 0.86; Alleva et al., 2017) and has been used in other studies on endometriosis (Volker & Mills, 2022). By using the FAS, the results help inform whether an intervention should focus on fostering body functionality appreciation, in addition to, or instead of aesthetic bodily appreciation. The scores from the questions are averaged, with greater scores reflecting greater levels of functionality appreciation. Scores can range from 7 to 35.

3.6.1.5 Self-Compassion Scale – Short Form (SCS-SF)

The Self Compassion Scale (Appendix 8) is a 12-question Likert scale, ranging from 1 (almost never) to 5 (almost always), that measures an individual’s capacity for self-compassion. The scale is split into two areas: self-disparagement (e.g. “When I fail at something important to me, I become consumed by feelings of inadequacy”) and self-care (e.g. “When I’m going through a very hard time, I give myself the caring and tenderness I need”). The SCS–SF demonstrated reliable internal consistency (Cronbach’s alpha ≥ 0.86; Raes et al., 2011), and test–retest reliability was found to be .71 (Raes, 2011). The greater the total score, the greater the self-compassion. Using this scale will support in communicating the importance of targeting body image concerns amongst individuals with endometriosis. Scores can range from 0 to 60.

3.6.2 Quantitative Data Analysis

A correlational analysis was conducted to measure the strength of the relationship between body dissatisfaction (BD) scores and the number of symptoms, the number of body locations diagnosed with endometriosis, length of time experiencing symptoms before diagnosis, length of time since diagnosis, number of treatments used, number of surgeries, and number of additional health conditions. This correlation was then repeated against functionality appreciation (FA) scores. An independent T-test was conducted to explore whether the geographical location of the participant impacted body dissatisfaction and functionality appreciation.

A multiple regression was run to gain insight into whether the general wellbeing outcomes (defined in this research as the mental, physical and emotional health of the individual) related to having endometriosis, predicted body image outcomes. This examined the strength of the relationship between the dependent variable (body dissatisfaction (BD) or functionality appreciation (FA)), against the predictor variables (the number of symptoms reported [a significant demographic related variable], emotional wellbeing, physical functioning, general health perception, self-compassion, control/powerlessness and self-image).

3.6.3 Qualitative Data

To gather qualitative data, there were 10 open-ended questions (See Appendix 10), which provided participants the opportunity to share their experience in more detail or provide further context to some of the quantitative questions. These questions also provided an opportunity to understand more on what these participants would find useful to better support their body image. Participants were asked if they had received support to improve their body image, to determine if support had been accessed for this, and for those that had, or had not received support, participants were asked to provide their rationale for this.

3.6.4 Qualitative Data Analysis

3.6.4.1 Thematic Analysis

Conducting a thematic analysis is a process that involves familiarising with the qualitative data gathered, then coding and identifying themes from this data (Braun & Clarke, 2006). This approach offers a detailed, exploratory approach to finding patterns in the data, compared with content analysis, which is often used more with analysing visual data. As the analysis was conducted on qualitative data from the online survey, it was more appropriate to use thematic analysis instead of content analysis. Furthermore, thematic analysis is often the approach chosen when collating qualitative data in endometriosis (Mills et al., 2021; Grogan et al., 2018), because of its ability to capture the broad experience of those with endometriosis (Fernley, 2021) and the way it covers the epistemological spectrum (Braun & Clarke, 2014). This study was a reflexive thematic analysis, as this allowed for familiarisation with the data, generating initial themes and codes, then developing and reviewing these themes and codes to ensure they still closely aligned with the data gathered (Braun & Clarke, 2006). To do this, inductive coding was used to gather and organise the data, because of its ability to condense extensive, varied raw data, and establish links between the data collected and the research aims and objectives (Thomas, 2006). It is also a useful approach when evaluating less researched topics, as it avoids using pre-defined codes, and enables codes to be created from the data itself (Humble & Mozelius, 2022). A deductive approach involves the use of pre-existing theory to interpret data, and as there is currently little data on body image perception in endometriosis, inductive coding felt better able to capture the range of experiences in this topic (Braun & Clarke, 2022).

3.6.4.2 Inductive Coding

Samples of data from each question were first read, and codes created, which were then evaluated and reviewed as the rest of the data was analysed. As a result of this inductive coding 6 themes and 26 codes were initially identified (Appendix 11). There are a variety of frameworks that can be used to ensure quality in this qualitative analysis (Treharne & Riggs, 2015). The editors of the British Journal of Health Psychology (BJHP) set up a working group with expertise in qualitative research to establish guidance on assessing the quality of qualitative data reporting (Shaw et al., 2019), which concluded that researchers should be following the APA journal standards of reporting to robustly assess the quality of qualitative research (American Psychological Association, 2018). This outlines that data should '*adequately*' capture diversity relevant to the research question, '*manage researchers' perspectives*', be '*grounded in evidence*', be '*insightful and meaningful*' to current literature, gather '*contextual*' information relating to participants and present these findings '*coherently*'.

3.7 Methodology Reflection

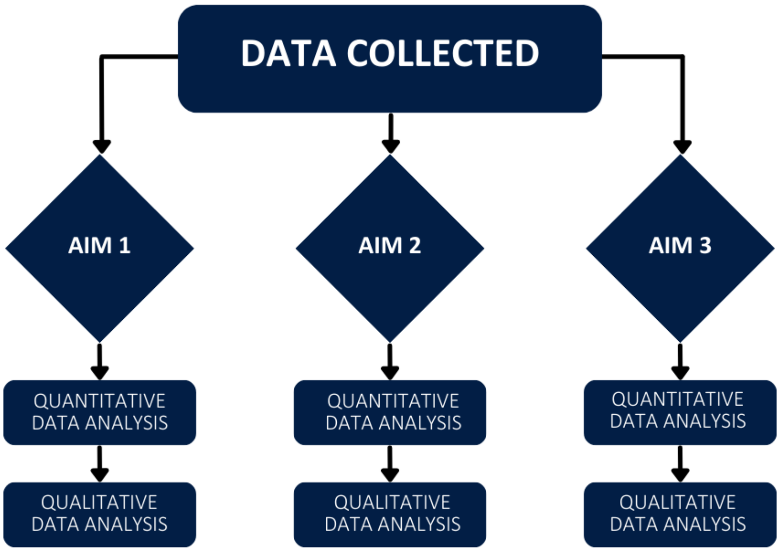
Reflecting on this piece of research, balancing being a pragmatist researcher and the desire to be a fair researcher was challenging at times. Being a pragmatist researcher is based on the assumption that the methodological approach being used is the one that is best for the particular research problem (Tashakkori & Teddlie, 1998). Pragmatists also believe knowledge is experience (Kaushik & Walsh, 2019), but the researcher's own worldview cannot be separated from the research, which may risk influencing the way in which the research is conducted. For example, the choice of questions used to ask participants may be influenced by the researcher's own personal history with having endometriosis, and the associated belief system as a result. Therefore, questions were based upon feedback from volunteers and the review of existing literature in this field, or lack thereof, in addition to the researcher's personal experience with having endometriosis, to shape the research question examined.

Chapter 4: Results

This chapter will explore the data screening processes following data collection. It then presents the quantitative and qualitative data collected for each of the three aims, which will then be compared, contrasted, and collated during the discussion.

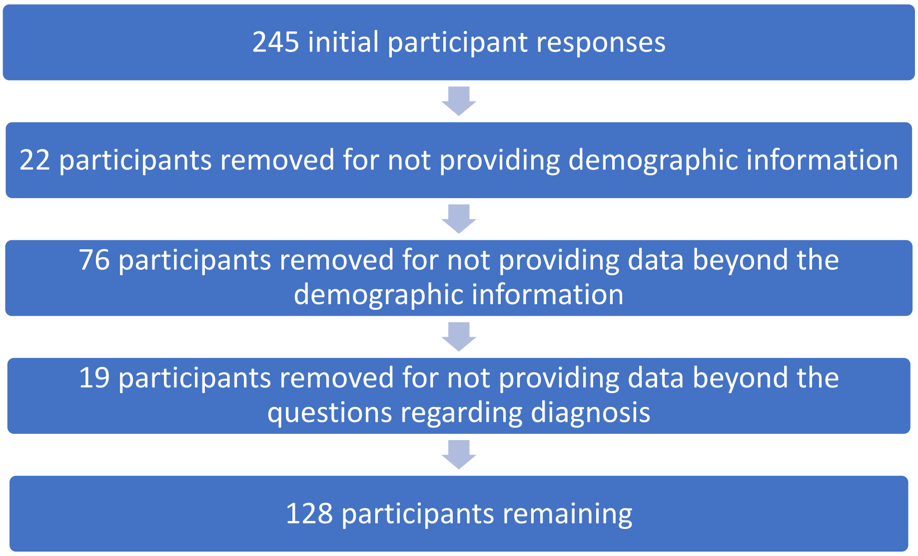
4.1 Data Collection

As outlined in section 3.1.1, the present study gathers data from the same sample, at the same time, collecting quantitative data, and embeds these results with qualitative data, to provide rationale and explanation for the choices made, collating these against each of the study’s aims (QUANT + qual). The quantitative data collected helped provide a wider understanding of the impact of endometriosis on the collective body image perception of the participants, and the qualitative data contributed towards providing context to the quantitative data. Therefore, to review and analyse the data, the following process was carried out:



4.2 Data Screening

Prior to analysis, quantitative data was cleaned to remove any incomplete, or invalid data and ensure all answers were correctly formatted. Prior to screening, there were 245 responses. After the screening process, outlined below, this resulted in a sample of 128 participants.



Participants who did not complete the survey ranged from 17-68 years old (M = 26 years old). The time experiencing symptoms prior to diagnosis ranged from 2 years to 25 years (M = 1.3 years), and the time since diagnosis ranged from 6 months to 38 years (M = 2 years). The average age of the 'completers' was 31 years old, with an average time experiencing symptoms prior to diagnosis around 10.5 years, and average time since diagnosis around 4.9 years. Therefore, the completers may be more motivated to complete the survey due to the potential increased impact the condition has had on their lives. This may therefore have some influence on the data gathered, as it may only be capturing the experiences of individuals who are experiencing increased repercussions from the condition, and therefore may not be representative of 'milder' cases, or those without a diagnosis.

4.2.1 Normality Testing

To test for the normality of data distribution, values of skewness and kurtosis, plus histograms, were examined for all variables. The normal distribution of variables was based on a range for skewness or kurtosis below +1.5 and above -1.5 (Tabachnick et al., 2019). This is outlined in table 2 below.

Measure	**Skewness**	**Kurtosis**
Body Image Scale (BIS)	-.44**	-.89**
Functionality Appreciation Scale (FAS)	-.20**	-.49**
Length of time experiencing Symptoms before Diagnosis (Years)	1.19**	1.57
Length of time since Diagnosis (Months)	2.47	9.07
Number of Surgeries	1.35**	1.49**
Emotional Wellbeing (SF-36)	.003**	-.573**
Physical Functioning (SF-36)	-.283**	-.879**
General Health (SF-36)	.675**	.459**
Self-Compassion (SCS-SF)	.296**	.154**
Control/Powerlessness (EHP-30)	-.954**	.593**
Self-Image (EHP-30)	-.920**	.011**

Table 2 – Skewness and kurtosis values of quantitative measures

*** Indicates that score is normally distributed*

Following the preliminary analyses to assess normality of distribution, and excluding missing cases (exclude cases pairwise), data was analysed. If all variables were normally distributed, Pearson's r correlation was conducted. If only part of the variables were normally distributed, Spearman's Rho correlation was conducted (Pallant, 2016).

4.2.2 Internal Consistency

Cronbach's Alpha was evaluated for each variable, as outlined in table 3 below. Scores were rated from reliable to excellent based on the following parameters: Reliable (.84-.90), Strong (.91-.93), Excellent (.93-.94; Taber, 2018).

Measure	**Cronbach's Alpha**
Body Image Scale (BIS)	α = .93
Functionality Appreciation Scale (FAS)	α = .86
Endometriosis Health Profile (EHP-30) – Control/ Powerlessness Subscale	α = .94
Endometriosis Health Profile (EHP-30) – Self Image Subscale	α = .88
The 36-Item Short Form Health Survey (SF-36)	α = .85
Self-Compassion Scale – Short Form (SCS-SF)	α = .86

Table 3 – Chronbach's Alpha values of quantitative measures

*** Indicates that score is normally distributed*

4.3 Aim 1

To understand if there were differences in body dissatisfaction (BD) and functionality appreciation (FA) depending upon the number of symptoms, number of body locations diagnosed with endometriosis, length of time experiencing symptoms before diagnosis and length of time since diagnosis, treatments received, number of surgeries, additional health conditions and geographical differences, and between participants in and outside the UK.

4.3.1 Quantitative Data

*4.3.1.1 **Body Image and Endometriosis** Symptoms*

Symptoms varied between participants; however, a large number were experienced by all (see Table 4 below). The 128 participants reported 27 different symptoms, described below. Menstrual cramps were the most reported symptom, experienced by almost all participants (*n* = 125, 97.7%). Pelvic pain, fatigue and back pain were also highly common across participants (88-3% - 95.3%). There were also fifteen additional 'other' symptoms experienced, noted by participants. This included bloating, migraines, chronic cystitis, sweats, mood swings, difficulty breathing, fainting (due to the pain), right shoulder pain, pudendal neuralgia, weight loss/gain, coughing blood, dizziness, brain fog and limb numbness.

Symptoms	**Number of Participants**	**Percentage of Cases**
Menstrual Cramps	125	97.7%
Pelvic Pain	122	95.3%
Fatigue	119	93%
Back Pain	113	88.3%
Abnormal or Heavy Periods	105	82%
Constipation and/or Diarrhoea	102	79.7%
Painful Bowel Movements	101	78.9%
Painful Intercourse	101	78.9%
Leg Pain	95	74.2%
Nausea	84	65.6%
Painful Urination	77	60.2%
Infertility	38	29.7%
Other (15)	27	21.2%

Table 4 – Percentage of cases of symptoms, reported by participants

Due to the nature of a chronic illness like endometriosis, as there were so many concurrent symptoms experienced by participants, it was not possible to compare between specific symptoms and the body image variables. Instead, correlations were examined between the total number of symptoms experienced and the body image variables.

On average, women experienced 9 out of the 13 pre-defined symptoms listed (excluding other symptoms identified; *N* = 128, *M* = 9.45, *SD* = 2.40). As per the hypothesis, results revealed a significant positive correlation between the number of symptoms experienced and body dissatisfaction (R = .28, *n* = 120, *p* = .002; see Table 5 below), indicating that participants who report more symptoms also experience greater body dissatisfaction. Contrary to the hypothesis, there was no significant correlation between the number of symptoms experienced and functionality appreciation (R = -.04, *n* = 123, *p* = .634; see Table 5 below). This suggests that participants' level of functionality appreciation is not influenced by the number of symptoms they experience.

Aim 1					
Individual Characteristics	**M**	**SD**	**Range**	**Correlation with body dissatisfaction**	**Correlation with functionality appreciation**
Number of symptoms	9.45	2.40	1-12	R = *.28* *p* = .002**	R = -*.04* *p* = .634
Number of body locations diagnosed with endometriosis	3.81	2.62	1-10	R = *.19* *p* = .033	R = -*.10* *p* = .269
Length of time experiencing symptoms, prior to diagnosis (years)	10.55	6.46	1-37	R = -*.001* *p* = .989	R = -*.049* *p* = .494
Length of time since diagnosis (months)	58.98	59.49	1-394	R = .10 *p* = .263	R = .20 *p* = .026
Number of treatments	6.28	2.65	1-12	R = .16	R = -.11

				p = .077	*p* = .246
Number of surgeries	1.87	1.07	1-4	R = .17 *p* = .086	R = -.05 *p* = .635

***. Correlation is significant at the 0.01 level (2-tailed)*

Table 5 – Correlation Matrix to show Mean, Standard Deviation and Range of Individual Characteristics

4.3.1.2 Body Image and the Number of Body Locations Diagnosed with Endometriosis

The number of body locations in which endometriosis was diagnosed varied between participants (see Table 6 below). Out of 128 participants, endometriosis was described to have been diagnosed in 22 different locations, described below. The most common location for endometriosis to be diagnosed was the ovaries (n = 83, 64.8%). The uterosacral ligaments and posterior cul-de-sac were also common locations for endometriosis to be diagnosed. There were also ten additional ‘other’ locations identified by participants. This included the ureters, pelvic lining, abdominal wall, appendix, perineum, diaphragm, kidneys, womb, bowel, and sciatic nerves.

Location of the Diagnosis of Endometriosis	**Number of Participants**	**Percentage of Cases**
Ovaries	83	64.8%
Uterosacral Ligaments	71	55.5%
Posterior cul-de-sac (space between uterus and rectum)	64	50%
Fallopian Tubes	43	33.6%
Rectum	41	32%
Anterior cul-de-sac (space between uterus and bladder)	38	29.7%
Other (10)	38	29.7%
Bladder	32	25%
Cervix	22	17.2%
Intestines	21	16.4%

Abdominal Surgical Scars	19	14.8%
Vagina	15	11.7%
Vulva	1	0.8%

Table 6 — Percentage of cases of diagnosed endometriosis locations, reported by participants

The location of the diagnosis of endometriosis varied across participants, with many having it diagnosed in multiple locations. Therefore, it was not possible to make comparisons between the effects of endometriosis in certain locations, against body dissatisfaction and functionality appreciation. Instead, the frequency of the number of body locations diagnosed with endometriosis was calculated, and subsequently compared to the body image variables.

On average, women were diagnosed with endometriosis in 3 out of the 11 locations listed (*N* = 128, *M* = 3.81, *SD* = 2.62). Contrary to the hypothesis, there was no significant correlations between the number of body locations in which endometriosis was diagnosed and body dissatisfaction, R = .19, n = 120, p = .033 (see Table 5 above). Results also showed that there was also no significant correlation between the number of body locations in which endometriosis was diagnosed and functionality appreciation (R = -.10, *n* = 123, *p* = .269; see Table 5 above). This suggests that participants' level of body dissatisfaction and functionality appreciation is not influenced by the number of body locations in which endometriosis was diagnosed.

4.3.1.3 Body Image and Length of time experiencing Symptoms before Diagnosis (Years)

The length of time experiencing symptoms before diagnosis varied, therefore, it was not possible to make comparisons between the effects of length of time experiencing symptoms, against body dissatisfaction and functionality appreciation. Instead, the mean length of time a participant's experienced symptoms was calculated, and subsequently compared to the body image variables.

On average, women had experienced symptoms for 10.5 years before getting diagnosed (*n* = 127, *M* = 10.55, *SD* = 6.46). Participants' level of body dissatisfaction and functionality appreciation was not influenced by the length of time experiencing symptoms before diagnosis. Contrary to the hypothesis, there was no significant correlations between the length of time experiencing symptoms and body dissatisfaction, R = -.001, *n* = 119, *p* = .989 (see Table 5 above). Results also showed that there were no significant correlations between the length of time experiencing symptoms, and functionality appreciation R = -.049, *n* = 122, *p* = .494 (see Table 5 above).

4.3.1.4 Body Image and Length of time since Diagnosis (Months)

The length of time since diagnosis varied, therefore, it was not possible to make comparisons between the effects of length of time since diagnosis, against body dissatisfaction and functionality appreciation. Instead, the mean length of a participant's time since diagnosis was calculated, and subsequently compared to the body image variables.

On average, women had been diagnosed with endometriosis for 59 months (*N* = 128, *M* = 58.98, *SD* = 59.49). Participants' level of body dissatisfaction and functionality appreciation was not influenced by the length of time since diagnosis. Contrary to the hypothesis, there was no significant correlations between the length of time since diagnosis and body dissatisfaction, R = .10, *n* = 120, *p* = .263 (see Table 5 above). Results also showed that there was also no significant correlations between the length of time since diagnosis, and functionality appreciation R = .20, *n* = 123, *p* = .026 (see Table 5 above).

4.3.1.5 Body Image and Number of Treatments tried

The treatment received for the participants' endometriosis varied between participants (see Table 7 below). Out of 128 participants, there were 19 treatments reported to manage their endometriosis. The most common treatment received was painkillers (*n* = 117, 91.4%). The pill and a laparoscopy were also common treatments tried. There were also four additional 'other' treatments tried, identified by participants. This included cannabis, herbal supplements and anti-depressants or other medications specifically used for mental health.

Treatment Received (Number of Treatments tried)	**Number of Participants**	**Percentage of Cases**
Painkillers (Pharmaceutical)	117	91.4%
The Pill (Hormonal)	103	80.5%
Keyhole/Laparoscopy (Surgery)	102	79.7%
Heat (Complementary Therapy)	91	71.1%
Dietary Changes (Complementary Therapy)	78	60.9%
TENS Machine (Complementary Therapy)	60	46.9%
The Coil, e.g. the Mirena (Hormonal)	58	45.3%
Injection (Hormonal)	34	26.6%
Acupuncture (Complementary Therapy)	33	25.8%
Pelvic Physiotherapy (Complementary Therapy)	28	21.9%
Multidisciplinary Surgical Intervention, e.g. colorectal surgeon, gynaecologist urologist (Surgery)	28	21.9%
Other Medications	27	21.1%
Other (4)	20	15.6%
Other Physiotherapy (Complementary Therapy)	15	11.7%
Hysterectomy (Surgery)	5	3.9%
Hysterectomy and Oophorectomy (Surgery)	5	3.9%

Table 7 – Percentage of cases of treatments received, reported by participants

With so many treatment types available and used, it was not possible to make comparisons between the effects of a specific treatment, against body dissatisfaction and functionality appreciation. Instead, the total number of treatments used to manage their endometriosis was calculated, and subsequently compared to the body image variables. It was also recognised that there may be crossover between participants recording keyhole surgery and hysterectomy as types of treatments they had received, which is acknowledged in the limitations section.

On average, women had tried 6 different treatments for their endometriosis (*N* = 128, *M* = 6.28, *SD* = 2.65). Contrary to the hypothesis, there was no significant correlation between the number of treatments tried and body dissatisfaction, R = .16, *n* = 120, *p* = .77 (see Table 5 above). Results also showed that there were no significant correlations between the number of treatments tried and functionality appreciation R = -.11, *n* = 123, *p* = .246 (see Table 5 above). This suggests that participants' level of body dissatisfaction and functionality appreciation is not influenced by the number of treatments tried.

4.3.1.6 Body Image and Number of surgeries

The number of surgeries varied, therefore, it was not possible to make comparisons between the number of surgeries, and subsequent body dissatisfaction and functionality appreciation. Instead, the total number of surgeries participants had was calculated, and subsequently compared to the body image variables.

On average, women had received 2 surgeries (*n* = 101, *M* = 1.87, *SD* = 1.07). Participants' level of body dissatisfaction and functionality appreciation was not influenced by the number of surgeries received. Contrary to the hypothesis, there was no significant correlations between number of surgeries and body dissatisfaction, R = .17, *n* = 120, *p* = .086 (see Table 5 above). Results also showed that there was also no significant correlations between the number of surgeries and functionality appreciation R = -.05, *n* = 123, *p* = .635 (see Table 5 above).

4.3.1.7 Body Image and Additional Health Conditions

Almost two thirds (64.8%) of participants had also been diagnosed with an additional health condition on top of endometriosis (*n* = 83, *M* = 1.35, *SD* = .479). This included diagnoses of adenomyosis, fibroids, migraines, irritable bowel syndrome (IBS), fibromyalgia, Polycystic Ovary Syndrome (PCOS) and mental health conditions such as anxiety, depression and borderline personality disorder.

Although not the focus of this thesis, an independent T-test analysis on whether additional health conditions impacted body dissatisfaction and functionality appreciation was conducted. However, contrary to the hypothesis this also showed there was no significant differences between the groups for body dissatisfaction in those who had an endometriosis diagnosis only (*M* = 16.41, *SD* = 8.57), or additional health condition diagnosis as well (*M* = 18.39, *SD* = 8.23); *t*(118) = 1.23, *p* = .221. This was also the case with functionality appreciation, with no significant differences between those with endometriosis only (*M* = 3.73, *SD* = 0.79), or those with an additional health condition diagnosis as well (*M* = 3.47, *SD* = 0.88); *t*(121) = -1.64, *p* = .104. This suggests that participants' level of body dissatisfaction and functionality appreciation is not influenced by the number of additional health conditions. Despite not being significant, there was a trend with both, that having an additional health condition lead to higher body dissatisfaction and lower functionality appreciation, indicating that this could warrant further investigation in future studies.

4.3.1.8 Geographical location (UK vs Outside UK)

Of the 128 participants, 78.1% (*n* = 100) resided within the UK and 21.9% (*n* = 28) resided outside the UK, including in Europe, Australia and the United States of America (USA). Although not the focus of this thesis, an independent *T*-test explored whether the geographical location of the participant impacted body dissatisfaction and functionality appreciation.

As per the hypothesis, there were statistically significant differences between the groups for their body dissatisfaction in those outside the UK (M=12.30 SD = 8.39), or those from the UK (*M* = 19.21, *SD* = 7.76); *t*(118) = -3.95, *p* = <.001, CI [-1.32, -.42] indicating that participants from the UK experience greater body dissatisfaction. However, contrary to the hypothesis, there were no significant differences in functionality appreciation between those outside the UK (*M* = 3.69, *SD* = 0.89), or those from the UK (*M* = 3.52, *SD* = 0.84); *t*(121) = .93, *p* = .357. This suggests that participants' level of functionality appreciation is not influenced by their geographical location. Furthermore, due to the difference in group sizes, these results should be treated with caution, but suggest there could be differences that warrant further investigation.

4.3.1.9 Desire for children

Comparisons between those who were currently pregnant and non-pregnant participants, against the body image variables were not conducted due to the significant differences in group size. However, it is worth noting that there were differences in the number of participants who were currently trying to conceive, wanting children in future, or did not want children at all (see Table 8). The differences between these groups could warrant further investigation in future, larger studies.

Participant's desire for children	**Number of Participants**	**Percentage of Cases**
Do not want children	28	21.9%
No children, but would like children in future	53	41.4%
No children, but currently trying to conceive	19	14.8%
Have children and do not wish for anymore	17	13.3%
Have children, and trying to conceive another	9	7%
Currently pregnant	1	0.8%

Table 8 – Percentage of cases of participant's desire for children, reported by participants

4.3.2 Qualitative Findings

Following the initial 6 themes and 26 codes identified, the themes and codes were then refined further, to improve coherence, whilst still adequately capturing the patient experience. This was therefore reduced to 4 themes, with 15 codes, as outlined below.

Theme	Codes	Subcode
Functionality	Gynaecological Symptoms	Bleeding Difficulties surrounding Sex Fertility
	Gastrointestinal Symptoms	Bowel and Urinary Issues Digestive Issues
	Pain-related Symptoms	Exhaustion Pain
	Less able to participate	Less able to participate Lack of control Planning in advance
Appearance	Adapting clothing	Adapting clothing
	Inferior as a woman	Inferior as a woman Lack of confidence
	Body image changes	Body image changes
Perception of Self	Feeling like a failure/body given up or broken	Feeling like a failure/body given up or broken
	Lack of connection to self	Lack of connection to self Fear for the future Grieving previous self Feel negative towards self
	Mental health difficulties	Mental health difficulties
	Sense of power/empowerment /strength/confidence	Sense of power/empowerment /strength/confidence Gratitude
Social Support	Breakdown of relationships	Breakdown of relationships
	Feeling lonely/less lonely	Feeling lonely/less lonely
	Attitude towards clinicians and care	Attitude towards clinicians and care
	Self-care	Self-care

Table 9 – Themes, codes and subcodes identified from inductive coding

It is acknowledged that future research would benefit from using a PPI group to gain feedback on the defined themes and codes, and ascertain whether it was felt these themes and codes were representative of the data collected. There were some qualitative findings that did not directly map against the quantitative research questions. This included findings from codes such as: gastrointestinal symptoms and pain-related symptoms. Whilst this data provided additional context on the endometriosis experience of the current participant sample, this was not included in the results as they did not answer any of the research questions.

4.3.3 Qualitative Findings regarding experiences of endometriosis diagnosis and treatment

Qualitative findings showed that the impact of diagnosis on bodily perception left many participants feeling as though symptoms "*ruled their lives*", and although diagnosis helped some with accepting the condition and the symptoms their body experienced, for others, it left them feeling like "*it would never end*". The perception of their current treatment methods were mixed, with many feeling as though it had "*not helped as hoped*", but some feeling the treatment made them "*appreciate*" what their body had gone through. This section includes themes of functionality (codes - less able to participate), perception of self (codes - feeling like a failure, lack of connection to self) and social support (codes - attitude towards clinicians and care) (See Table 9).

To increase understanding of the impact of the symptoms, the participant's perception of their body pre and post diagnosis, and how the treatments made them feel about their body was examined through the qualitative component of the survey. When describing the impact of symptoms, many felt they were dominating their lives, resulting in feelings of grief:

> "*They have ravaged my body, I grieve my old life before I got super unwell (around 23) and my symptoms ruled every aspect of my life. I hate my body sometimes as I feel like it's working against me and the plans I have for my life & things I wish to achieve*" (ID: Participant #5, age 30, Australia, 10 years of symptoms prior to diagnosis).

Others acknowledged how it had impacted their view of their body and how they feel unable to "*trust*" their body anymore:

> "*They [symptoms] have made me feel like I can't trust my body to be there for me when I need it to be. It makes my life feel very unbalanced and unsafe*" (ID: Participant #11, age 20, USA, 5 years of symptoms prior to diagnosis),

The attempts at managing the symptoms were not always successful, which had a negative impact on their lifestyle and perception of control:

> "*The pain flares are unbearable, you can do everything right with diet, exercise, taking meds on time and nothing stops it. It makes you dissociate with your body, it doesn't feel real. Time seems to stop as you have to cancel plans, yet again because you're not feeling well… The worst part is that there is no help, just gaslighting from the medical profession*" (ID: Participant #99, age 53, Canada, 37 years of symptoms prior to diagnosis)

The participants' perception of their body pre and post diagnosis also indicated that in some cases, having a diagnosis was helpful, but for others, it did not change anything. For some, pre-diagnosis, they felt confusion at the lack of understanding into the cause of the pain:

> "*Confused, as I found my body couldn't be relied upon, I basically hated my body, but not for the way it looked, how it would constantly cause me pain, but I couldn't figure out what was causing it"* (ID: Participant #26, age 27, UK, 8 years of symptoms prior to diagnosis).

There were also common mentions of "*dissociation from my body*" and "*losing trust in my body*". Many explained feeling that they were led to believe what they were experiencing was their "*fault*". Following a diagnosis there was frequent mention of feeling "*less dramatic*", "*having a reason for how they felt*" and therefore being a "*little kinder*" to themselves. But for many, the diagnosis did not change anything, as they felt the pain and the symptoms would still continue, despite the diagnosis:

> "*I feel like it's never going to end until I have a hysterectomy. Although I understand my pain and feel more believed. It still controls every aspect of my life, from my career, my sex life, the clothes I wear and my social life"* (ID: Participant #22, age 28, UK, 5 years of symptoms prior to diagnosis).

Others felt that knowing the cause of their symptoms, but also learning there was no cure caused more anxiety:

> "*Since diagnosis my endo has actually gotten worse over time. I kind of wish I didn't know I had it because knowing there's no cure, that it can cause so many issues is a worry*" (ID: Participant #64, age 37, UK, 15 years of symptoms prior to diagnosis).

Participants were also asked how the various treatment approaches they had tried made them feel about their body, and there was again, a mixed response for how they perceived their body. The overriding perception was negative, with mentions of feeling like "*damaged goods*", "*violated*", "*embarrassed*" and "*flawed*". There were common themes amongst participants of feeling "*less like a woman*" and "*lacking in connection*" with themselves. Many feared the lack of control the condition caused, and did not feel supported by doctors in understanding what was happening with their body, instead being encouraged to trial different treatment approaches:

> "*I did not know what was happening only that something was really wrong. I was being gaslighted by numerous doctors and I felt like a guinea pig trying multiple different "treatments*" (ID: Participant #83, age 41, UK, 20 years of symptoms prior to diagnosis).

Others felt the treatments did not provide the relief they had hoped:

> "*Treatment makes it seem there is something to help my body. However, the simpler ones only alleviate the pain and do not 'fix'. I still deal with some frustration with my*

> *body due to treatments not fixing and just helping symptoms*" (ID: Participant #21, age 27, UK, 7 years of symptoms prior to diagnosis).

Some felt that the treatment they had been offered had made their symptoms worse:

> "*Most contraceptive treatments caused me to gain weight and also to become quite depressed so I have learnt to avoid those… This has made me feel worse about my body because it has further affected my relationship with my partner. I am constantly in pain since switching to a 12-week course and taking even more medication than ever which leads me to feel useless and hopeless*" (ID: Participant #46, age 34, UK, 12 years of symptoms prior to diagnosis).

However, a few participants reported that having treatment provided them with a level of appreciation for their body:

> "*I appreciate her more now. She has been through so much and I appreciate and respect her for this*" (ID: Participant #58, age 34, Germany, 3 years of symptoms prior to diagnosis)

Whilst others described feeling more at peace with themselves as a result of treatment:

> "*Surgery has been the best treatment for me. I've felt a lot better in myself since having an excision laparoscopy. I feel healthier which has made me feel more at peace with my body*" (ID: Participant #74, age 23, UK, 8 years of symptoms prior to diagnosis).

These results again indicate that the experience of having endometriosis, and the diagnosis and treatment protocols for it cannot be a 'one-size-fits-all' approach, and therefore, person-centred care should be considered throughout.

4.4 Aim 2

To understand the relationship between body image (as measured by body dissatisfaction (BD) and functionality appreciation (FA)) and general wellbeing outcomes (as measured by greater emotional wellbeing [SF-36], poorer physical functioning perception [SF-36], greater general health perception [SF-36], greater self-compassion [SCS-SF], poorer perceived control and greater powerlessness [EHP-30] and poorer self-image [EHP-30])

4.4.1 Quantitative Data

Aim 2					
Scales	**M**	**SD**	**Range**	**Correlation with body dissatisfaction**	**Correlation with functionality appreciation**
Body Image Scale (BIS)	17.72	8.37	0-30	N/A	N/A
Functionality Appreciation Scale (FAS)	3.56	.85	7-35	N/A	N/A
Emotional Wellbeing (SF-36) Scores	45.59	20.37	0-100	R = -.63 *p* = <.001**	R = .37 *p* = <.001**
Physical Functioning (SF-36) Scores	60.48	26.72	0-100	R = -.49 *p* = <.001**	R = .43 *p* = <.001**
General Health (SF-36) Scores	31.25	21.17	0-100	R = -.51 *p* = <.001**	R = .44 *p* = <.001**
Self-Compassion (SCS-SF) Scores	2.68	.70	1-5	R = -.50 *p* = <.001**	R = .40 *p* = <.001**
Control/Powerlessness (EHP-30) Scores	73.11	23.36	0-100	R = .58 *p* = <.001**	R = -.33 *p* = <.001**
Self-Image (EHP-30) Scores	70.64	26.76	0-100	R = .73 *p* = <.001**	R = -.28 *p* = .002**

***. Correlation is significant at the 0.01 level (2-tailed)*

Table 10 – Correlation Matrix to show Mean, Standard Deviation and Range of Scales

The general trend of the *means* of the wellbeing measures indicated that in this sample, there was poorer perceived control, self-image, general health, and emotional wellbeing and greater powerlessness, indicating a generally poorer perceived health state and health related quality of life. Perceived self-compassion was neither great nor poor and perceived physical functioning means indicated a slightly greater perceived health state.

4.4.1.1 Examination of the relationship between Body Image and Emotional Wellbeing

As per the hypothesis, there was a significant negative correlation between the emotional wellbeing scores and body dissatisfaction, R = -.63, *n* = 120, *p* = <.001 (See Table 10 above). Results also revealed a significant positive correlation between the emotional wellbeing scores, and functionality appreciation R = .37, *n* = 123, *p* = <.001 (See Table 10 above). This indicates that participants with lower emotional wellbeing experience greater body dissatisfaction and lower functionality appreciation.

4.4.1.2 Examination of the relationship between Body Image and Physical Functioning

As per the hypothesis, there was a significant negative correlation between physical functioning scores and body dissatisfaction, R = -.49, *n* = 120, *p* = <.001 (See Table 10 above). Results also revealed a significant positive correlation between the physical functioning scores, and functionality appreciation R = .43, *n* = 123, *p* = <.001 (See Table 10 above). This indicates that participants with lower physical functioning experience greater body dissatisfaction and lower functionality appreciation.

4.4.1.3 Examination of the relationship between Body Image and General Health

As per the hypothesis, there was a significant negative correlation between general health scores and body dissatisfaction, R = -.51, *n* = 120, *p* = <.001 (See Table 10 above). Results also revealed a significant positive correlation between general health scores and functionality appreciation, R = .44, *n* = 123, *p* = <.001 (See Table 10 above). This indicates that participants with lower general health perception experience greater body dissatisfaction and lower functionality appreciation.

4.4.1.4 Examination of the relationship between Body Image and Self-Compassion

As per the hypothesis, there was a significant negative correlation between self-compassion and body dissatisfaction, R = -.50, *n* = 120, *p* = <.001 (See Table 10 above). Results also revealed a significant positive correlation between the self-compassion scores, and functionality appreciation R = .40, *n* = 123, *p* = <.001 (See Table 10 above). This indicates that participants with lower self-compassion experience greater body dissatisfaction and lower functionality appreciation.

4.4.1.5 Examination of the relationship between Body Image and Control/Powerlessness

As per the hypothesis, there was a significant positive correlation between the control/powerlessness scores and body dissatisfaction, R = .58, *n* = 120, *p* = <.001 (See Table 10 above). Results also revealed a significant negative correlation between the control/powerlessness scores, and functionality appreciation R = -.33, *n* = 123, *p* = <.001 (See Table 10 above). This indicates that participants with lower control and greater feelings of powerlessness experience greater body dissatisfaction and lower functionality appreciation.

4.4.1.6 Examination of the relationship between Body Image and Self-Image

As per the hypothesis, there was a significant positive correlation between the self-image scores and body dissatisfaction, R = .73, *n* = 120, *p* = <.001 (See Table 10 above). Results also revealed a significant negative correlation between the self-image scores, and functionality appreciation R = -.28, *n* = 123, *p* = .002 (See Table 10 above). This indicates that participants with lower self-image experience greater body dissatisfaction and lower functionality appreciation.

4.4.1.7 Examination of the predictability of General Wellbeing on Body Image

A multiple regression was run to predict body dissatisfaction from the number of symptoms reported (a significant demographic related variable), emotional wellbeing, physical functioning, general health perception, self-compassion, control/powerlessness and self-image. These variables statistically significantly predicted body dissatisfaction, *F*(7, 112) = 40.602, *p* < .001, R^2 = .717. Self-Compassion (p = .002) and Self Image Perception (p <.001) were significant predictors of body dissatisfaction. Self-Compassion explained 2.6% of the variance in body dissatisfaction, whilst Self-Image Perception explained 16.4% of the variance in body dissatisfaction.

When running the same analysis to predict functionality appreciation from the number of symptoms reported (a significant demographic related variable), emotional wellbeing, physical functioning, general health perception, self-compassion, control/powerlessness and self-image, these variables also statistically significantly predicted functionality appreciation scores, $F(7, 115) = 8.880, p < .0001, R^2 = .351$. Physical functionality (p =.001) and Self-Compassion (p =.003) were significant predictors of functionality appreciation. Physical functionality explained 5.3% of the variance in functionality appreciation, whilst Self-Compassion explained 6.5% of the variance in functionality appreciation.

4.4.2 Qualitative Findings regarding the impact of endometriosis on body image and wellbeing

Qualitative findings showed the perception of oneself, physically and mentally, was impacted by endometriosis. Subthemes demonstrated that participants felt like a "*failure*", or as though their body had "*given up*" or was "*broken*", and therefore not functioning as it should. In addition to this, there was also a lack of perceived control and feelings of powerlessness, and "*fear for the future*" with a series of subsequent mental health difficulties mentioned. There was however also a sense of "*power*" and "*empowerment*" cited by some, demonstrating that through the process of their endometriosis journey, their general wellbeing was not always negatively impacted. This section includes themes of perception of self (codes - mental health difficulties, lack of connection to self, sense of power/empowerment) and social support (codes – self-care) (see Table 9).

The participants' inability to trust in their body's ability to function as they expected left them feeling like a failure, leading to "*shame*", "*embarrassment*" and "*resentment*":

> "*I mourn my old self a lot, my body has just disintegrated into an untrustworthy thing that continuously lets me down when I try and regain any semblance of normality*" (ID: Participant #90, age 31, UK, 5 years of symptoms prior to diagnosis)

Many described the combination of feeling like a failure, and feeling as though their body was broken resulted in a sense of conflict and hatred towards themselves:

> "*I think I would describe how I perceived my body as "conflicted". You know something's not right, but society presses that the symptoms are normal or we're being dramatic. So I ended up hating my body for being debilitated from the pain*" (ID: Participant #115, age 30, UK, 3 years of symptoms prior to diagnosis).

Their body's inability to function as expected left many less able to participate, both in their current activities:

> "*The pelvic, leg, and back pain have left me unable to work for months at a time. I am watching career opportunities pass me by because I'm in too much pain to physically do my job*" (ID: Participant #65, age 31, Canada, 7 years of symptoms prior to diagnosis)

and when making future plans:

> "*I'm in limbo as I do not know what my diagnosis means for my future plans. I would like to know my options and what is within my control*" (ID: Participant #49, age 30, UK, 17 years of symptoms prior to diagnosis).

This inability to participate resulted in a lack of connection with their body in a lot of participants:

> *"The symptoms make me feel like my body isn't my own and I have no control over it. It stops me doing things I want and I feel my body is always against me like we are separate thing.*" (ID: Participant #35, age 30, UK, 7 years of symptoms prior to diagnosis)

Some cited that they did not feel it was the body they were meant to have:

> "*I do not like my body. There are days when I hate my body and wallow in self-pity asking "why me". I feel disconnected from my body like it is not the one I feel I should have*" (ID: Participant #94, age 29, UK, 6 years of symptoms prior to diagnosis).

As a result, mental health difficulties were a common theme underpinning much of the quotes obtained, with frequent mention of "*anxiety*", "*stress*", "*mood swings*" and "*depression*", and holding fear towards themselves:

> "*I felt very disassociated from my body, and a bit frightened of it (because the pain was unpredictable*" (ID: Participant #27, age 32, UK, 9 years of symptoms prior to diagnosis).

However, there was some sense of power, empowerment and confidence that came through the journey of diagnosis and management of the condition. For a few participants, there was a shift in how they perceived themselves:

> "*It has changed my outlook of myself from being "dramatic" to "strong". I am proud of myself and what I have achieved since having three surgeries*" (ID: Participant #3, age 29, UK, 15 years of symptoms prior to diagnosis).

For others it gave them a sense of appreciation for what they can do, despite the condition:

> "*I now know that she is strong and doing so so much for me. I have learnt to appreciate my body and care much better for her*" (ID: Participant #58, age 34, Germany, 3 years of symptoms prior to diagnosis).

It also provided some with a sense of empowerment:

> "*I also feel empowered on some days, where I am able to do so much despite the condition*" (ID: Participant #1, age 29, UK, 9 years of symptoms prior to diagnosis).

Others also saw the symptoms and physical changes as a sign of what they have endured and perceived it with a sense of pride:

> "*In terms of scarring I am actually very proud of my scars as it shows how much I have been through*" (ID: Participant #103, age 29, UK, 15 years of symptoms prior to diagnosis).

The condition also provided a few with the opportunity to engage in self-care, and observe the positives of what their body is able to achieve, instead of just limitations and challenges:

> "*I've gradually become more in tune with my body and try to view myself and my body working together. I try to take pride in what it can do (growing my baby, swimming open water, walking my dog) rather than the limitations*" (ID: Participant #27, age 32, UK, 9 years of symptoms prior to diagnosis).

These results indicate that having endometriosis can have a significant influence on a person both physically and mentally, which can lead to reduced perceived control and a lack of connection to themselves. In some cases, individuals have been able to see the positives in their diagnosis. Therefore, interventions to address perception of control and connection to the self should be done so holistically, to target the multiple areas influenced by the condition.

4.5 Aim 3

To understand if individuals with endometriosis felt they would benefit from support to improve their body image; and if so, which areas they would like support in, and how they would like this delivered.

4.5.1 Quantitative Data

4.5.1.1 Methods of seeking support and information

Only 9.6% (*n* = 11) had received support for their body image, whilst 90.4% (*n* = 103) had not.

The ways in which individuals access information on endometriosis differed (see Table 11 below). Of the 128 participants, 125 participants responded to the question on how they access information on endometriosis, with the most common source being from others with the condition (*n* = 70, 56%). Social media and gynaecologists were also common ways in which information was accessed, and two additional 'other' examples included a participant's own pre-existing knowledge or 'trial and error'. Other NHS professionals were also cited as being supportive for accessing information, including pelvic physiotherapists, pain clinic practitioners, acupuncturists and gastroenterologists, highlighting the benefit of multi-disciplinary approaches to managing and treating endometriosis.

Method of seeking support and information	**Number of Participants**	**Percentage of Cases**
Other individuals with endometriosis	70	56%
Social Media	69	55.2%
Gynaecologist	62	49.6%
Personal Research Online	56	44.8%
Endometriosis UK	46	36.8%
GP	34	27.2%
Surgeon	28	22.4%
Nurse	10	8%
Other (2)	10	8%
Other NHS Professional	5	4%

Table 11 – Percentage of cases of methods to seek support and information, reported by participants

Social Media choices included Instagram, Facebook, TikTok and Reddit. Whilst social media was a common way to access information, 59.4% (*n* = 76) felt that social media had an influence on their body image, either positively or negatively. Personal research included the use of blogs, academic journals, resources from health boards in other countries, endometriosis specialist centres globally, and reading other people's experiences.

4.5.1.2 Body Image Area for Improvement

Although only 8.6% (*n* = 11) had received general support to improve their body image, 90.4% (*n* = 103) had not, and 85.9% (*n* = 110) quoted areas relating to their body that they would like to improve, suggesting support to improve body image may be beneficial in this cohort of participants.

The most common area participants wanted to improve was the feeling of control they had over their body and their endometriosis (*n* = 94, 83.2%; see Table 12 below). As per the hypothesis, wanting to improve their acceptance, thoughts and beliefs towards their body and their endometriosis was also very common amongst participants. There were also six additional 'other' areas participants reported wanting to improve, including wishing to gain weight, and improvements towards pain perception when over-exerting themselves.

Area they would like to improve	**Number of Participants**	**Percentage of Cases**
The feeling of control you have over your body and endometriosis	94	83.2%
The acceptance of your body and endometriosis	85	75.2%
The thoughts and beliefs you have about your body and endometriosis	84	74.3%
The way you see your body physically/how you look	78	69%
The way you treat or behave towards your body	66	58.4%
The way your body moves physically	56	49.6%
Other (6)	6	5.3%

Table 12 – Percentage of cases of areas participants would like to improve, reported by participants

4.5.1.3 Information Provision

Out of 110 participants who answered, the most common way in which participants would like support to improve their body image was through sessions from a psychologist or counsellor (*n* = 74, 67.3%; see Table 13 below). Hearing about others' experiences and guidance with physical fitness were also common ways in which participants would like support to improve their body image. There were eleven additional 'other' areas outlined by participants, including massage, group fitness support, dietary education and better public education of disabilities and 'real bodies'.

How Participant would like support to improve Body Image	**Number of Participants**	**Percentage of Cases**
Sessions with a Psychologist or Counsellor	74	67.3%
Hearing other's experiences	63	57.3%
Physical fitness support	59	53.6%
Support Groups	45	40.9%
Self-Led Physical Resource (e.g. workbook)	45	40.9%
Self-Led Online Resource (e.g. website)	42	38.2%
Other (11)	11	10%

Table 13 – Percentage of cases of methods in which participants reported wanting to receive support to improve their Body Image, reported by participants

4.5.2 Qualitative Findings regarding body image and support

Accessing support for endometriosis, and the challenges associated with this, was one of the most quoted areas for the participants, alongside quotes around loneliness or feeling less lonely, suggesting the influence of others to have had an impact. More specifically, participants wanted support to improve their body image, reporting a desire for input on improving feelings of control, thoughts and beliefs towards their body, and acceptance. Participants reported wanting this delivered through psychologists and counsellors, with input on physical support and self-led materials in some cases. This section includes themes of functionality (codes - gynaecological symptoms, less able to participate), appearance (codes - adapting clothing, inferior as a woman, body image changes) and social support (codes - breakdown of relationships, attitude towards clinician and care, feeling lonely/less lonely) (see Table 9).

Participants' experiences of accessing support for their endometriosis in general were varied, potentially due to the widely varied way in which their care was delivered and received. The experiences of interactions with healthcare professionals were predominantly negative, with the consensus that there was a lack of knowledge and understanding of the condition. When asked if they felt they would benefit from body image support, some described the lack of support received by their healthcare professionals to have had a negative impact on how they perceived their body:

> "*The first surgery was ablation and performed by a general gyno, I had no further support from them and felt more pain and isolated… I'm now dealing with body image issues due to scarring, weight gain and feeling overwhelmed by how bad it got before I was given support*" (ID: Participant #120, age 27, UK, 8 years of symptoms prior to diagnosis).

> "*I felt I couldn't trust my body, in part because I was repeatedly told by GPs that the pain must be in my head*" (ID: Participant #27, age 32, UK, 9 years of symptoms prior to diagnosis).

In some, the lack of support resulted in subsequent anger towards their body instead:

> "*I felt like I was being dramatic. So I generally felt the same anger towards my body… I felt unheard*" (ID: Participant #20, age 32, USA, 15 years if symptoms prior to diagnosis).

Others cited conflicting information being provided by their healthcare professionals and long waiting times for appointments, subsequently leading them to "*lose all trust in them*". There were also many comments about gaslighting from the medical community, leaving individuals without answers of what was happening to their bodies, with some being told it was just part of womanhood:

> *"The surgeries and medical treatments were very disempowering because I had to seek medical advice for those each time and my GP dismissed it as having a low pain threshold"* (ID: Participant #1, age 29, UK, 9 years of symptoms prior to diagnosis)
>
> *"My Dr told me I'm a girl so should expect painful periods"* (ID: Participant #37, age 38, UK, 10 years of symptoms prior to diagnosis).

Many cited that they had to seek answers for themselves from other sources, however, in some cases, this came with additional challenges of reliability of these sources and understanding what was based on fact or opinion:

> *"We crowd source most information ourselves. I have experienced a shocking and traumatic lack of information or access to a specialist to even discuss the condition, despite being under a specialist women's hospital."* (ID: Participant #59, age 34, UK, 15 years of symptoms prior to diagnosis).
>
> *"There's very little research on endometriosis and therefore it's difficult to decide what is factually correct"* (ID: Participant #83, age 41, UK, 20 years of symptoms prior to diagnosis).

Most participants sought information and support from other individuals with the condition, or from social media. However, whilst seeking information and support from family and friends was common, participants did not always get the support they wanted or needed because of the understanding surrounding the condition, and the subsequent impact on body image had mixed responses. Some felt that their family and friends did not see them any differently:

> “*They see me in the way they always have, no change*” (ID: Participant #86, age 39, Canada, 5 years of symptoms prior to diagnosis).

Others described feeling as though their families did not see them in the negative way they often saw themselves:

> “*I think they see me as healthy which is sometimes frustrating when I'm in pain etc”* (ID: Participant #41, age 38, UK, 20 years of symptoms prior to diagnosis).

> “*They all tell me and treat me as I’m beautiful, but I find it hard to believe them*” (ID: Participant #30, age 30, UK, 12 years of symptoms prior to diagnosis).

However, many quoted that they feel perceived very negatively by family and friends:

> “*Fat, lazy, flawed, broken, delicate, riddled with disease*” (ID: Participant #37, age 38, UK, 10 years of symptoms prior to diagnosis).

A number of participants quoted that they had been told they had “*gained weight*” or “*look fat*” from family and friends, particularly on days where they were experiencing a “*flare-up*” or “*endo belly*”:

> “*They have agreed I’ve gained weight*” (ID: Participant #72, age 35, UK, 16 years of symptoms prior to diagnosis).

> “*I feel judged all the time, especially by my in laws and friends because I’ve gained a lot of weight*” (ID: Participant #105, age 27, UK, 6 years of symptoms prior to diagnosis).

Social media use was a similar experience, with some seeing the positives it provided, whilst others found that it made them feel worse about themselves. There was a common theme of loneliness, or feeling less lonely, and how social media was supportive of this:

> "*Social media had made me feel more accepted with the advocates out there going through the same or similar*" (ID: Participant #12, age 40, UK, 28 years of symptoms prior to diagnosis).

However, "*inauthenticity*" was a common observation from those using social media, with a general consensus that until they had found other 'endometriosis' pages, they felt there was something wrong for not being the same as everyone else, or felt as though there was a lack of representation:

> "*Never really seen a body like mine*" (ID: Participant #45, age 33, UK, 22 years of symptoms prior to diagnosis).

> "*I think it's hard when you are shown (especially when I was younger) people with seemingly perfect healthy and perfect bodies. You are trained to think that is the norm and you're just wrong for not being just that*" (ID: Participant #2, age 27, UK, 10 years of symptoms prior to diagnosis).

There was also some mention of confusion from social media, around what they 'should' be or look like, and how this was contradictory between social media users:

> "*There is so much pressure to be thin or on the latest fad diet, or on the opposite side, be confident in your body no matter what you look like. It feels like you are criticised whether you like what you look like or not*" (ID: Participant #31, age 27, UK, 7 years of symptoms prior to diagnosis).

Some avoided it due to challenges around fertility and pregnancy, and finding it difficult seeing others going through this, or seeing what others were able to do that they were not able to:

> *"…showcasing their pregnancy which I found hard to see at times*" (ID: Participant #21, age 27, UK, 7 years of symptoms prior to diagnosis).

> “*I’m envious of others and bitter about the things I can’t do*” (ID: Participant #37, age 38, UK, 10 years of symptoms prior to diagnosis).

There were some that chose to avoid social media altogether, or did not feel that social media had influenced their body image in anyway:

> “*I don’t compare myself to others. I know what is real and what is done for show, social media doesn’t matter*” (ID: Participant #71, age 32, UK, 32 years of symptoms prior to diagnosis).

There were also several people who found that social media had helped them with seeing themselves in a more positive way, providing they were conscious in their choice of whose content they followed:

> “*I follow a lot of body positive accounts, and I have learnt over the past two years to love my appearance and not equate it to my worth. My next challenge is also loving my body including when my condition is making me feel powerless. I feel like social media will help me with this*” (ID: Participant #60, age 28, UK, 3 years of symptoms prior to diagnosis).

With many participants feeling their *basic* endometriosis treatment experience required further knowledge input and upskilling in their healthcare professionals, it is evident that seeking support for body image and appearance-related issues may not be perceived to be a priority. Those who had received support to improve their body image indicated that they did so because of *other* symptoms or side effects experienced:

> *“Because I lost a lot of weight from the disease”* (ID: Participant #93, age 20, The Netherlands, 10 years of symptoms prior to diagnosis).

In general, those that had not received support for their body image felt they would benefit from support with it, with some citing that they want to see the changes their body has been through as a positive:

> *"Yes. I'd love to look in the mirror and see my lumps and scars as a triumph"* (ID: Participant #19, age 37, UK, 18 years of symptoms prior to diagnosis).

Many cited that it would be beneficial in improving their "*self-esteem*" and being more "*accepting*" of the changes their body has experienced. However, despite the desire to receive support for this, several pieces of feedback indicated they did not know how to access support:

> *"I may have possibly benefitted from this [body image support] but unsure how to access this support."* (ID: Participant #38, age 25, UK, 7 years of symptoms prior to diagnosis).

When asked if there were any specific areas they would change about their body, other than the frequent wish that they could "*remove the endometriosis forever*" or "*find a cure*", "*bloating*", "*endo belly*", "*weight loss*" and "*no pain*" were regularly cited by participants. Quantitative data indicated that the top three areas that individuals would like support in improving were: the feelings of control over their endometriosis, the acceptance of their endometriosis and thoughts and beliefs of their body, something that if addressed with adequate support, may also help target acceptance of the specific areas mentioned.

Of these three areas that participants wished for additional support in, improving the feeling of control over their endometriosis was most common. There was frequent mention of being "*unable to make plans*", or not feeling able to control how they work *with* their body:

> "*I can feel at war with my body or that my body just will not cooperate*" (ID: Participant #128, age 43, UK, 20 years of symptoms prior to diagnosis).

Others felt trapped in their own body, with no control over their future because of it:

> “*I feel imprisoned by it. It's holding me back from doing all the things I want to do*” (ID: Participant #63, age 27, UK, 4 years of symptoms prior to diagnosis)

Some described a sense of autonomy being taken because of the condition:

> “*My body controls me instead of me controlling my body. I feel my body lets me down a lot*” (ID: Participant #35, age 30, UK, 7 years of symptoms prior to diagnosis).

Acceptance of the condition was also a highly requested area for support in the qualitative data, with many participants expressing their desire to accept that managing the condition will always be a part of their life and hoped to feel empowered, even on more challenging days:

> “*I need to accept endo as part of the rest of my life and try work on what I can control of it*” (ID: Participant #66, age 35, Ireland, 18 years of symptoms prior to diagnosis).

> *“…and feel empowered with my disease despite of the bad days I want to accept my chronic disease*” (ID: Participant #77, age 28, South America, 12 years of symptoms prior to diagnosis).

Some participants cited that they want to not only be able to accept the condition but move on too:

> “*My entire life has been engulfed by endometriosis and I want to be able accept it but also move on from it and be healthier*” (ID: Participant #57, age 27, UK, 9 years of symptoms prior to diagnosis).

Others were already in a position of having accepted their body, but wished to behave differently towards it:

> “*I have accepted my body as it is, but I still need to change my behaviour toward it better*” (ID: Participant #106, age 32, Australia, 17 years of symptoms prior to diagnosis).

The thoughts and beliefs participants had towards themselves was also another highly requested area for support from the quantitative data:

> "*Changing thoughts would enable me to look at things differently*" (ID: Participant #123, age 34, UK, 15 years of symptoms prior to diagnosis).

The qualitative findings provided context into what some of these thoughts and beliefs towards themselves were. The belief that they were "*weak*" was mentioned by a significant number of participants, often as a result of being told "*period pain was normal*" by medical professionals or observing the experiences of friends and family. They regularly compared themselves, believing they were "*not strong*" or just "*less able*" to manage their monthly cycle than others:

> "*I thought I was weaker than other women and lesser than them because they could do so much more than me on their cycle... I thought my body was normal and I just sucked at managing it*" (ID: Participant #15, age 22, Canada, 3 years of symptoms prior to diagnosis).

There was a common experience of participants not believing they were "*strong*" like others:

> *"…I was unable to handle pain, that was too sensitive to it, too weak, not strong and resilient like other girls*" (ID: Participant #17, age 44, UK, 15 years of symptoms prior to diagnosis).

This resulted in participants thinking of themselves in a negative way:

> "*So much of my thoughts are taken up by telling myself I'm worthless due to it*" (ID: Participant #60, age 28, UK, 3 years of symptoms prior to diagnosis).

Despite many negative experiences cited with several health care professionals, the preferred method for which participants would like to receive support to improve their body image was through sessions with a psychologist or counsellor. There were other mixed responses in how participants would like support to improve their body image, with some preferring to share experiences and hear from others, and others preferring to work through information at their own pace, and to have space to reflect. For those who preferred to receive facilitated support, the reasons for this were often put down to the level of experience they perceived those facilitating sessions to have, and having someone guide them through an intervention without extra mental load:

> "*Self-led stuff is too easy to disagree with and give up on. And people with endo have enough to deal with re extra work and emotional labour and admin of managing appointments and research and trying to find solutions ourselves to pain we are in while the NHS ignores us. An actual, informed human person would be the only effective intervention*" (ID: Participant #50, age 37, UK, 23 years of symptoms prior to diagnosis).

Seeing an "*informed human person*" still requires work and emotional labour, that they indicate they do not want to do, highlighting a potential desire for a simple fix, or lack of understanding of what is required to improve body image. However, there were several comments expressing a desire for these sessions to be delivered by someone with lived experience of the condition:

> *"I just want someone who understands not someone who doesn't suffer with it or deal with it on a daily basis"* (ID: Participant #80, age 22, UK, 5 years of symptoms prior to diagnosis).

The desire for physical fitness support was linked to increasing connectivity and perception of the strength of one's body:

> “*It is difficult to assess the physical capacities of a body that always betrayed you, it would be useful to be supported during while I build up a stronger and healthier body*” (ID: Participant #6, age 34, Germany, 20 years of symptoms prior to diagnosis).

The feeling towards group sessions was mixed, with some seeing them as a good opportunity to learn from others, and some felt it would be unhelpful to listen to “*negative experiences*”. For participant’s who preferred to conduct self-led support, using physical or online resources, some cited that this would be better for accessibility, both in being able to participate at their “*own pace*”, and so they could get support, regardless of the perceived or diagnosed severity of their condition:

> “*I genuinely feel like my endo isn't 'bad enough'. The stories online at the minute are of quite severe endo, which sometimes makes me feel like I wouldn't be taken seriously. Self-led approaches should therefore make me feel more included”* (ID: Participant #9, age 29, UK, 14 years of symptoms prior to diagnosis).

Others felt that self-led approaches would provide them with the tools they need to make progress and be able to manage their condition longer term:

> “*I think change comes from within me... And hearing other people's experiences as a form of support only perpetuates needing external approval... I want to console myself because I have the tools to do so*” (ID: Participant #89, age 27, UK, 7 years of symptoms prior to diagnosis).

In summary, the quantitative results showed that for Aim 1, there were less significant correlations between specific endometriosis related characteristics and body dissatisfaction and functionality appreciation than hypothesised. However, for Aim 2, general wellbeing significantly correlated with body dissatisfaction and functionality appreciation across all measures, with self-compassion in particular, significantly predicting both body dissatisfaction and functionality appreciation, suggesting that it could be a useful area to target when delivering interventions on body image. Aim 3 highlighted a desire for increased support on perceived control, thoughts and beliefs towards their body, and acceptance.

Qualitative findings supplemented this data, with many quotes indicating the significant physical and psychological toll the condition has had on how they perceive their body, how they connect with their body and how they feel their body functions.

Chapter 5: Discussion

The aim of this mixed methods study was to increase understanding of the influence of endometriosis on body dissatisfaction, functionality appreciation and general wellbeing outcomes, and how individuals can be supported to improve this. This was achieved through an online survey collecting both quantitative and qualitative data from a sample of 128 people who self-identified as having endometriosis. The results were primarily driven by the quantitative data, but the qualitative data complimented this and provided context.

This chapter will compare the findings from the present study against previous research. The wider implications for intervention delivery, clinician care and information seeking are then examined, and strengths and limitations of the present study considered. Future research and recommendations are then discussed in the context of research and practice. The chapter ends with a reflective section.

The main findings of the present study showed only a small number of significant results relating to diagnosis, symptom and treatment related factors, but a large number of significant results relating to general wellbeing. This included a significant association between body dissatisfaction and the number of symptoms, the geographical location of the participant, lower emotional wellbeing, physical functionality, general health perception, self-compassion, positive self-image and control and greater feelings of powerlessness. Furthermore, functionality appreciation was significantly associated with greater emotional wellbeing, physical functionality, general health perception, self-compassion, positive self-image, control and lower feelings of powerlessness. Following a multiple regression, self-compassion was a significant predictor of both body dissatisfaction and functionality appreciation.

5.1. Body Image and Diagnosis

There are currently significant delays in diagnosis, and necessity for upskilling in identifying the presence of endometriosis in some areas of the body, including those outside the pelvic region, meaning it is not always clear how extensive the endometriosis is (McKee et al., 2022). Therefore, it is hard to truly quantify how much the extent of the endometriosis impacts and influences body image. In line with the present study, many individuals endure symptoms for years *before* being diagnosed, and therefore, have suffered years of pain (Husby et al., 2003). As a result, they may have established methods of management during this time, that could render a diagnosis less relevant, and may potentially result in changes in their body dissatisfaction and functionality appreciation across this time. This may be why the number of body locations diagnosed with endometriosis did not have a significant correlation with body dissatisfaction and functionality appreciation in the present study and highlights the importance of addressing the subjective/individual experience of having endometriosis, instead of the ‘amount’ of endometriosis. In many cases, the diagnosis is only the starting point for those with the condition, often requiring additional specialist treatment that could subsequently influence body dissatisfaction and functionality appreciation (Van Der Zanden et al., 2020).

Many patients will require input from a specialist multi-disciplinary team before being able to diagnose endometriosis in some areas, so, it is possible that those who identified having it in just one area may have it in others too. Lamé et al. (2005) found patients from a multi-disciplinary pain management clinic, suffering specifically from migraine, back pain, fibromyalgia and neuropathic pain, all common in endometriosis (Berkley et al., 2005; Carlyle et al., 2020), had the lowest quality of life. Endometriosis is highly defined by pain, and ineffective pain-coping behaviours can negatively impact a person’s body image over time (Sündermann et al., 2020).

Participants being advised by healthcare professionals that the period pain is ‘normal’ for many years may influence the way in which the participants perceive their body, before receiving a diagnosis that confirms the pain is *not* normal. This may explain why there was no significant correlation between the years of symptoms experienced prior to diagnosis, and its subsequent relation to body dissatisfaction and functionality appreciation, as these participants may have found it to have an impact irrespective of how long they have been suffering before being diagnosed with it. The qualitative data also indicated that during the time prior to diagnosis, participants experienced "*confusion*", "*hatred*", "*fear*", a "*lack of trust*", and "*dissociation from their body*", and after receiving their diagnosis, whilst many felt "*less dramatic*" about the way in which they were managing and coping with their symptoms, they still felt helpless and fearful.

The view women have of themselves may be influenced by how they are perceived in society, thus making them potentially less likely to seek support for their symptoms until it is unbearable (Cox et al., 2003). Feeling "*less dramatic*" following diagnosis was cited frequently and demonstrates a perception that women may have of themselves where they deem themselves to be 'overreacting'. This could be due to medical gaslighting cited in the qualitative data, but could also be as a result of society's perception of women. It has been perceived that women would be less likely to receive support following a cardiac arrest because "people tend to not take women as seriously as they take men", and "people assume they are being dramatic and overreacting" (Perman et al., 2019), a sentiment echoed in a study on misogyny (Dickel & Evolvi, 2023). The commonplace of medical gaslighting towards women and minority groups could also leave those with endometriosis feeling like their health experience is less valid or 'real' (Sebring, 2021). It has been identified that healthcare providers also lack confidence and knowledge needed to have conversations around body image, whilst recognising its importance in patient care (Lamarche et al., 2020). This suggests that the relationship between healthcare professional and patient could be developed, by utilising the outcomes from the present study, as it outlines the reported needs of participants with endometriosis to improve their body image. It could therefore provide a steer that may improve confidence to have such conversations around body image with these patients.

5.1.1. Additional Conditions

It is thought that if health-related experiences affect the views of one's body (August et al., 2023), the more co-morbidities one has, the greater risk for implications on body image, as found by Geller et al. (2021) when examining women with endometriosis. However, the results in the present study did not indicate any significant correlation between those with additional conditions and body dissatisfaction or functionality appreciation. Those with multiple cancers were found to have greater body dissatisfaction, and other evidence suggests having more than one chronic condition may lead to a greater risk of poor body image (Clarke et al., 2008; DeFrank et al., 2007). Results may not have been significant in the present study due to there being no predefined lists of additional chronic illnesses being available for participants to select from when completing the survey, as was done in other studies (Geller et al., 2021). It may also be due to the average age of the sample being 31 years old, as despite the normative body image discontent of women of all ages, the loss of 'youth' and the onset of health problems later in life, often felt in older women (Clarke et al., 2008), is less experienced, suggesting that body image experiences may differ in the current sample because of their age. Changes to bodily functioning can negatively influence body image, suggesting that there is a necessity for further research in a variety of ages, to determine how interventions may be tailored to those with endometriosis of all ages, and additional conditions, to improve body image (Vinoski Thomas et al., 2019).

5.2. Body Image and Physical Symptoms

In line with the present study, findings in those with advanced cancers, including gastrointestinal and lung cancer, women with rectal cancer, and those going through menopause found a greater number of symptoms lead to greater body dissatisfaction (Benedict et al., 2016; Pearce et al., 2014; Rhondali et al., 2015). Greater body dissatisfaction may result from the greater impact that the symptoms have on day-to-day life, particularly as the condition is not visible externally. This affective disturbance is said to result from greater activation in emotional processing regions of the brain, associated with social processing, linked with social pressures. Social cognitive processing is said to contribute to development of body dissatisfaction, due to the way in which individuals think their body is perceived by others, and how this shapes their body image (Van Den Berg et al., 2002). As highlighted by Sullivan-Myers et al. (2023), it may also be because some of the symptoms include changes to bodily appearance and shape, e.g. bloating, and subsequently their perceived sexual attractiveness to a partner. Vinoski Thomas et al. (2019) found the symptoms of those with visible conditions influenced their day-to-day functionality, however, the present study did not observe the same. This may be due to the Functionality Appreciation Scale (FAS) not specifically referring to any symptoms in its questions, instead examining the body more holistically.

The present study's findings on the influence of physical functionality on body dissatisfaction and functionality appreciation is in line with other research in endometriosis, which found significantly poorer appearance satisfaction and functionality appreciation compared with a control group (Volker & Mills, 2022). Other research has shown that body functionality is a valuable component in positive body image and well-being, particularly if people are encouraged to appreciate what their body *can* do, and look at their body functionality holistically (Alleva & Tylka, 2021). Alleva et al (2018) found an intervention focusing on body functionality in those with rheumatoid arthritis was effective in improving body image and reducing depression. Similar interventions focusing on body functioning could be beneficial for an endometriosis population, where there is significantly higher functional pain disability interfering with daily activities, like sleep, relationships and work, compared with those without endometriosis (Evans et al., 2021).

The current research found participants perceived their body to have "*disintegrated*" and to be "*debilitated*" from pain, supported by Van Niekerk et al. (2022b) quantitative study, which found that endometriosis led to poorer general health perception, general body dissatisfaction, and a lack of familiarity with one's body. In line with the present study, Korn et al. (2013) quantitative study also found high correlations between health perceptions and positive self and body image, with physical exercise being a positive contributor to positive body image and health perceptions. This highlights the potential benefits that can be gained from physical exercise and rehabilitation interventions, something that was indicated in the present study as an area participants believed they would benefit from.

5.3. Body Image and Psychological Symptoms

The relationship identified between participants' emotional wellbeing and both body dissatisfaction and functionality appreciation is in line with cross-sectional research on UK adults, which found that emotional wellbeing significantly predicted body appreciation among 1148 male and female British citizens and greater body image concerns to predict depressive symptoms in those endometriosis (Geller et al., 2021; Pehlivan et al., 2022; Swami et al., 2018). Lamé et al. (2005) found lack of internal pain control to be associated with lower emotional role functioning, suggesting that feelings of control may influence emotion related outcomes. This was also found in the present study, with participants citing the lack of control they felt and significant mental health challenges experienced, including anxiety and depression, which Linardon et al. (2022) found could be improved through increasing body appreciation.

Lower positive self-image was associated with greater body dissatisfaction and lower functionality appreciation, complemented by the qualitative data which found many participants felt their appearance, clothing and confidence had been impacted by the condition. Those who find their body shape and size are impacted by medication may be less compliant in taking this regularly (Pearson et al., 2010), suggesting that those with lower positive self-image may also not be gaining the benefits from prescribed medications, resulting in potentially worsened physical symptoms too.

In line with the present study, lower self-compassion in those with endometriosis has been associated with higher sexual distress, and there is a positive impact of self-compassion on bodily satisfaction among women (Stern & Engeln, 2018; Sullivan-Myers et al., 2023). There have also been benefits identified to be gained from increasing acceptance towards having endometriosis (Mills et al., 2021a). Acceptance and Commitment Therapy and other self-compassion-based interventions could support in improving body image (Fogelkvist et al., 2016; Wetherell et al., 2011), suggesting that it could be a good intervention for the endometriosis population, as discussed below.

5.4. Body Image Treatment

With a scarce number of sources that clearly outline *all* treatment options, and a large regional variation in what is available and provided via the NHS, there is currently very little consistency in the treatment experience of those with the condition (Hudson, 2022). Whilst excision surgery is currently identified to be a more effective treatment than others, it does not necessarily always result in relief from symptoms for all individuals (Pundir et al., 2017).

As a result, body dissatisfaction and functionality appreciation may not always improve for all individuals following surgery. Garry et al. (2004) examined the impact of laparoscopic, abdominal or vaginal hysterectomies (surgical interventions often associated with endometriosis) and found laparoscopic hysterectomy to result in significantly better improvements to body image scores in the Body Image Scale (Hopwood et al., 2001). This suggests that there may be benefit in increasing understanding of the impact of different treatment approaches, like hysterectomy, on body image in endometriosis, so that future interventions can be developed and tailored with these different treatments in mind.

However, access to and desire for treatment options like hysterectomy may be mixed, particularly with participants averaging 31 years old in this sample. It is a drastic treatment option in a demographic of individuals where fertility may be of concern, as despite fertility challenges in many *because* of the condition, it could remove any *option* of carrying children themselves (Evans & Decherney, 2017). As the 'Objectification theory' outlines that women's bodies are there to serve for sexual pleasure (Fredrickson & Roberts, 1997), or valued based on their level of fertility (Bovet, 2018), removing an organ that may contribute to how a woman perceives their value as a 'heteronormative woman' could have implications on body image and subsequent intervention effectiveness (Mills et al., 2023). In the current study, 63.2% of participants either wanted children in the future, or were currently trying to conceive, and therefore they would be unlikely to even *consider* hysterectomy as an option. Others may be faced with choosing between their fertility and the promise of less pain after a hysterectomy. However, in some cases it does not stop the pain, potentially leaving individuals with no fertility and still in pain (Sandström et al., 2020). Bottomley et al. (2023) examined the fertility experience in women, primarily with endometriosis, following hysterectomy and found them to conceptualise their failure as a mother, as a failure as a woman, resulting in negative self-perception and poor body image. This highlights a necessity to implement measures to manage body image if undergoing treatments such as hysterectomy for endometriosis.

Leonardi et al. (2020) recently claimed that endometriosis should start to be treated 'as if it were cancer' to improve outcomes, due to the similarities of both conditions relating to their diagnostic and therapeutic challenges. Currently, for conditions like gynaecological cancer, treatment is based upon survival, as opposed to quality of life or fertility, like in endometriosis, which has resulted in more uniformity in treatment methods for gynaecological cancer (Leonardi et al., 2020). Yet gynaecological cancer survivors may still find themselves managing body image changes resulting from the loss of an organ, scars, or the use of stomas, which may make them more aware of their bodily dysfunction (Anderson & Lutgendorf, 1997). All of these factors may also impact those with deep endometriosis, which infiltrates into the peritoneal tissues of pelvic organs (Keckstein et al., 2020), and suggests that examination into the impact of *deep* endometriosis specifically, on body image could warrant further investigation. Furthermore, the qualitative data suggests that participants found some treatment methods made their symptoms worse, and that taking so much medication made them feel "*depressed*", "*useless*" and "*hopeless*", perceiving their body as "*damaged goods*" and "*flawed*", again highlighting that further investigation into the difference in treatment types and their influence on bodily perception could be beneficial.

5.5. Clinician Care and Information Seeking

5.5.1. Clinicians

Cox et al. (2003) found patient perceptions of health care provision in endometriosis was not always a positive experience. In line with findings from the present study, the input of a multidisciplinary team in gynaecological oncology was found to be beneficial, with patients perceiving the presence of a specialist nurse to be an advantage to their care (Cook et al., 2019). Other multidisciplinary team members found the presence of a specialist nurse improved contact, communication, support, advocacy, knowledge, education, and referral management. With benefits identified in improvement to body satisfaction and functionality appreciation resulting from psychoeducational interventions (Guest et al., 2019), it demonstrates there could be a benefit for promoting more specialist nurses in endometriosis care to improve patient perception of their healthcare provision, and body image.

Person-centered care that is 'compassionate, empathetic, responsive to values, where expressed preferences of patients are well known', can result in improved physical and social well-being and satisfaction with care (Kuipers et al., 2019; Rathert et al., 2013). Furthermore, client-centered therapy has resulted in body image improvements (Dworkin & Kerr, 1987). However, the current study indicates that a person-focused approach is not being felt by participants with endometriosis. The experience of having endometriosis cannot be treated through a 'one-size-fits-all' approach, and therefore, person-centered care should be considered throughout, whereby individual values and preferences are accounted for. This, combined with the lack of empathy felt by participants, suggests that this could be an important area of focus for healthcare professionals when supporting with treatment, or delivering interventions.

There can be challenges with clinical empathy, and there is a risk that empathy fatigue may lead to burnout (Anzaldua & Halpern, 2021). However, empathy can have a significant positive effect on those with chronic conditions (Hojat et al., 2011). Adams et al. (2017) found dehumanization from doctors in the medical context was particularly detrimental for women, with women more at risk than men of 'threats to identity' in a health care setting (Coyle & Williams, 2001). Many strongly prefer more 'person focused' doctors, due to the expectation that doctors should be 'empathetic', and are more likely to be compliant with treatment if treated by a more 'humanistic' doctor. It may be that participants perceive psychologists, counsellors and other 'talking therapy' professionals to be more likely to offer empathy and time to talk than GPs and other professionals trained in delivering support for physical ailments. Buszewicz et al. (2006) found when examining the impact of GPs in supporting psychological concerns, empathy was highly valued in supporting patient's efforts to make change, suggesting that it may not be the position of the healthcare professional in the patient's care, but instead, their ability to offer empathy to their situation that ultimately improves patient perception of their care. Kundu et al. (2015) found the main barrier to effective endometriosis management appears to be a lack of knowledge, empathy and communication skills, something that the qualitative data in the present study shows was felt by participants. Increasing time spent with patients may enable more opportunity to express empathy, which has been positively correlated with patient satisfaction in those with chronic pain and general therapeutic outcomes (Pearson et al., 2010; Too et al., 2021). Thus, it would be beneficial for healthcare providers to acknowledge and address where possible, barriers to empathy, including a lack of time, institutional culture and workload, which may all have an impact on empathic consultations (Jani et al., 2012). The joint working of a number of professionals may aid in overcoming issues such as these, with the use of individuals such as community pharmacists (Ilardo & Speciale, 2020).

Treating patients with respect, dignity and compassion are also said to be ways in which patient-centered care can be delivered, with a reduced likelihood of being impacted by the other barriers identified (Kwame & Petrucka, 2021). Training for patient-centered care has previously not had much focus in the realms of appearance dissatisfaction, highlighting another reason why clinician-patient interactions may have limited success when discussing topics surrounding body image (Chouliara, 2023). Clinicians are said to play an influential role in emphasizing self-love and acceptance towards one's body, and should therefore be aware of their own biases and the inclusivity of their language when supporting with body image to ensure it is patient-centered (Hartman-Munick et al., 2020). The use of patient-centered skills, such as trust building and good communication, improved body image in those with benign gynecological conditions, like endometriosis (Sayer-Jones & Sherman, 2021). Based on the Health Locus of Control, an area already identified as being beneficial in improving a number of factors outlined in this thesis, health care providers providing appropriate health plans may increase patient empowerment further (Wang et al., 2022). Increasing patient involvement in the decision-making process, and supporting individuals to feel more in control of their condition may also improve internal locus of control which may then subsequently improve outcomes (Wong & Anitescu, 2017).

Although some studies have identified areas in which interventions may be beneficial for those with endometriosis, there has not yet been any enquiry into the ways in which individuals would benefit from this information being delivered (Sherman et al., 2022; Volker & Mills, 2022). Sessions with a psychologist or counsellor, hearing others' experiences, and physical fitness support came out as being the most preferred ways in which participants would like support for improving their body image. In line with research on breast cancer survivors, who generally preferred face-to-face interventions over those delivered over the phone, website, or workbook, the present study found self-led resources, both physical (workbook) and online (website) were the least preferred option, building on the systematic review of psychological interventions for body image in gynecological conditions (Hall et al., 2022; Pehlivan et al., 2023). This contradicts findings on women with early-stage breast cancer, which found psychoeducation delivered via video tape or telephone decreased side effect distress and increased psychological wellbeing (Sherman et al., 2012). The qualitative results in the present study also indicate that whilst support from a psychologist or counsellor and hearing others experience was most highly preferred, there were still some who would prefer to have resources to work through and reflect on at their own pace. This reiterates that there is no single intervention approach that is appropriate for everyone, and highlights the needs to provide a range of easily accessible options for individuals to choose, simultaneously increasing autonomy.

5.5.2 Information Seeking

Social media was also a popular source for information in the present study. However, there were concerns and perceptions that it was not always accurate, or could be conflicting, and the benefits of using social media were sometimes outweighed with the challenges it creates in expectations of what a woman "should" look like or be able to do. Liu et a. (2020) found that videos with high engagement for chronic conditions on social media platforms were those that provided medical information in an 'accessible way'. In line with the chronic care model, to manage chronic conditions, a multifaceted approach using patient support groups and partnerships with patients and healthcare professionals can be beneficial (Coleman et al., 2009). Health services have often focused on providing information from provider to patient, which has not always engaged patients sufficiently (Dahl et al. 2019). However, Dahl et al. (2019) found individuals to be more mindful when seeking external health resources, so they suggest health services should be encouraging patients to seek information themselves, to *complement* the information provided by their healthcare professional to increase a shared decision-making environment and improve individual wellbeing (Storbacka et al., 2016). Shared decision making has been identified as a basic psychosomatic care need required in endometriosis, and is one that has potential to improve patient knowledge, lower anxiety and improve health outcomes in endometriosis (Bitzer, 2011; Metzemaekers et al., 2021). There are currently no studies examining the experiences of shared decision making in treatment for endometriosis, and its impact on body image in endometriosis. However, there are benefits identified in shared decision making and its influence of feelings of control and self-rated health, which do have an impact on body image, suggesting it warrants further investigation (Adams & Drake, 2006; Callow, 2005).

5.6 Study Strengths

One of the strengths of this study was that participants were sought from several sources, including social media, a number of online platforms and through word of mouth. The individuals were also not sought from just one group, targeted at endometriosis or body image. Whilst there were some groups who did fit this description, there were also several general lifestyle groups, women's groups and community pages in which the study was advertised, to try and reduce bias of the sample. As it was advertised through several means, the study did not just gather data from cis-gender participants. Although participants were not asked about their sexual orientation, the body image experience may differ in those in the LGBTQ+ community who may define their *gender* differently to the sex they were born, so it is important to begin to raise awareness of such individuals, as research on endometriosis in this demographic is still severely lacking. This is also observed in other women's health conditions, with effective care of LGBTQ+ patients still inconsistent and with large gaps (Bonvicini, 2017; Wingo et al., 2018). The number of participants identifying as transgender or gender variant/non-conforming were small, therefore, comparisons were not possible in the current study. However, further research on this group would develop knowledge, understanding, and intervention delivery in this much needed area.

Gathering data through an online survey was also an equitable, reliable method of enquiry, as all participants were asked the same questions, and were more able to participate from a variety of geographical areas, providing they had online access, and were not bound by their physical capacity to attend a specific location to participate. As there are several regional differences in the support offered to patients (Hudson, 2022), and geographical differences in body image and expectations (Wardle et al., 2006), gathering data from a variety of regions meant that results captured the experiences of a variety of patients and the reported experiences with their healthcare providers.

Lastly, being a mixed methods study, it built upon the qualitative studies that have currently been conducted in this area, whilst also combining this with the quantitative outcomes gathered on body image specifically. This provided an enriched data set, which provided context and explanation for some of the answers provided, meaning that the results go further than just identifying areas in which participants want support, and how they want this delivered, but also goes on to provide rationale for this. This built understanding further and meant that recommendations for both patient and healthcare provider could be considered. Nonetheless, it should be noted that there were some contradictions in findings, as is often the case in mixed methods research; with some demographic variables showing no significant results in relation to body dissatisfaction and functionality appreciation, yet qualitative findings suggesting that there is high frequency in the body disturbances recalled. However, through the use of mixed methods, both perspectives were able to be captured, something that would be less recognised in quantitative or qualitative research only. PPI groups were also used, which ensured that questions asked as part of this mixed methods study reflected different perspectives. It is acknowledged that the PPI input came from a UK-based sample, whilst the study gathered data internationally. Therefore, some perspectives or considerations may not have been captured, and future studies would benefit from gaining PPI input from participants in all locations from which the data is gathered.

5.7 Limitations

The generalisability of the results was limited by the predominantly British sample used. As the majority came from the UK, the treatment options, approaches, and cultural differences in Britain compared with other locations outside of the UK should be taken into account when considering the generalisability of the results. Individuals in the UK have access to free healthcare through the National Health Service (NHS), which means finances may be less of a consideration when accessing treatment (Coombes et al., 2023). This is not an option all other countries have, potentially resulting in years of symptoms without relief, either due to cost or lack of service provision (Singh & Suen, 2017). There has been unprecedented delays in surgical interventions, and thus diagnosis, following the Covid-19 pandemic (Piketty et al., 2022). Furthermore, due to the structure of healthcare delivery in the UK, surgical intervention may be more likely to be delayed in favour of other easier to administer treatment methods first, potentially resulting in unnecessary delays or additional symptoms that could be avoided, and thus increasing potential impact on body image (Ballard et al., 2006).

Due to lack of data on ethnicity, the results cannot confirm whether there were any differences observed between different ethnic groups. It has been suggested that Black women are less likely than white women to be diagnosed with endometriosis, and Asian women are more likely to be diagnosed with endometriosis compared with white women (Bougie et al., 2019). Differences in quality of life and body image have been observed between women with gynaecological cancers (e.g. cervical/ovarian) from South, South East and East Asian countries (Spagnoletti et al., 2022), suggesting the cultural differences that may occur between different ethnic groups are important to consider as this field of research on the impact of endometriosis on body image develops. Furthermore, the socioeconomic status (SES) of participants was not captured, therefore, differences between socioeconomic groups cannot be observed. The participant's knowledge base, journey to diagnosis, ability to articulate their experiences and needs, and subsequently their treatment options may differ between those of a different ethnicity, or SES (Ptacek et al., 2021). Therefore, it is acknowledged that future research would benefit from gathering this data, so any similarities or differences can be considered when developing interventions.

Lastly, there were also some challenges in data analysis, as due to the complexity and nature of chronic conditions like endometriosis, it was not possible to separate out variables like symptoms to make subsequent comparisons between them. There was a significant amount of crossover in this area, as well as treatments received, including lack of specification during the survey for participants to identify if keyhole/laparoscopic surgery was for excision/ablation or a hysterectomy, and whether hysterectomy was done through this method, or abdominally. Therefore, outcomes on specific symptoms or treatments received on body dissatisfaction and functionality appreciation could not be made.

5.8 Implications, Future Research and Recommendations

This research builds on existing research that has identified a need for the development of interventions and support specifically relating to body image for those with endometriosis (Mills et al., 2023; Pehlivan et al., 2023; Volker & Mills, 2022). It has extended understanding by gaining insight into whether individuals with endometriosis felt they would benefit from support to improve their body image; and if so, which areas they would like support in, and how they would like this delivered.

The results of this study have several implications that can promote a better informed, and potentially more effective intervention for patients. This section provides information that may inform theory, research and practice, to potentially achieve better outcomes in body image for those with endometriosis.

5.8.1 Theory

There is growing understanding that endometriosis may not be the 'menstrual' or 'gynaecological' condition that it was previously understood to be, with this description being challenged for not reflecting the true scope or manifestation of the disease (Taylor et al., 2021). Instead, it is now being considered a 'systemic disease', not just affecting the pelvic region. A better understanding of the condition, its presentation, and its impacts on the body may lead to better targeted treatment, which may have subsequent benefits on how patients perceive their body and its functionality. The Body Conceptualisation Theory (Franzoi, 1995) suggests women pay more attention to their body's appearance over its functionality, and the Objectification Theory (Fredrickson & Roberts, 1997) suggests a women's body is sexually objectified, evaluated and valued based on their physical appearance. However, for those with endometriosis, the feelings of shame identified when their body is 'not functioning' (Alleva & Tylka, 2021), and the participants in the present study describing their body as "*broken*", suggests that functionality could be equally as important to them as appearance. It highlights the role of body image theory in understanding and provision of care for those with endometriosis, as it supports the view that the focus on how women 'should' look or function, potentially worsens outcomes when experiencing a chronic condition that can impact both of these areas.

The results in the present study also suggest that the impact of endometriosis can be felt across a long period, and therefore, body image can be influenced at any stage. Placing more emphasis on positive body image as a distinct construct from negative body image, including 'body appreciation, body acceptance/love, broadly conceptualising beauty, adaptative investment in appearance and inner positivity' or promoting body 'neutrality' could result in better outcomes (Clark, 2022; Tylka & Wood-Barcalow, 2015, p. 127). The present study found self-compassion and self-image perception to significantly predict body image outcomes. This suggests that emphasising positive body image aspects like body acceptance, adaptive investment in appearance and inner positivity could be supportive for those with endometriosis to aid them in reframing their experience of having the condition towards what their body can do and achieve.

5.8.2 Research

Body image interventions for those with endometriosis would need to be developed and evaluated through research before being implemented, following feedback from PPI groups and following the Medical Research Council (MRC) framework for the development of complex interventions (Skivington et al., 2021). This outlines phases required for impactful intervention, which encourages consideration on whether the intervention interacts with its context, is underpinned by theory, includes diverse stakeholder perspectives, and with resources and outcome consequences considered.

Due to the preference for psychologist/counsellor led sessions or peer support groups, it would firstly be interesting to learn the outcomes of existing body image interventions in other patient groups (Lewis-Smith et al., 2018a), and adapting and testing these in those with endometriosis. This could then be complemented by additional research on how these same interventions, and their content, is developed and received by patients when delivered through self-led means. Some of the qualitative findings indicated that seeing an "*informed person*" like a psychologist or counsellor would be the "*only effective intervention*", as self-led interventions are "*too easy to disagree with*" and there is already enough "*work and emotional labour*" as an endometriosis patient. However, seeing a psychologist or counsellor would still require this work and emotional labour, indicating that there may be a desire for a simple fix, or reduced understanding of what is required to improve body image. It would also be recommended to further examine the influence of clinician training and awareness of endometriosis, and the impact this has on body image.

Furthermore, there may be benefit examining the differences between ages in participants with the condition. There may be differences in the perception of the body in adolescents just starting their period, and learning the ramifications of, and their experience of the condition for the first time, compared to those who have had the condition for many years. It would be interesting to learn as endometriosis interventions begin to develop, if the outcomes seen in some age demographics are the same in others. Rodgers et al., (2017) examined health, functional ability and life satisfaction in older people, and found that perceptions of health and function decreased with age, whilst perceptions of life satisfaction increased, suggesting bodily perception changes with age in a general population. Therefore, examining these differences in an endometriosis population across different ages may help shape future intervention development.

5.8.2.1 UK vs Outside UK

The statistically significant differences observed between participants based in the UK and those based outside of the UK highlights that there are geographical differences in these variables that could warrant further investigation, to learn whether interventions for improving body dissatisfaction and functionality appreciation could be tailored towards specific geographical regions. There were differences in group sizes, which means results should be treated with caution, however, examining different regions globally, due to the differences in treatment provision and body image perception in the present study, may support in understanding the different needs individuals in these regions have, aiding in the design and delivery of interventions on body image to those with endometriosis.

There have been several studies examining the differences in body satisfaction in different countries. McCabe et al. (2012) found adolescents in China perceived ‘higher status’ women to be slim. However, adolescents in Chile and Fiji, perceived ‘higher status’ women to be large, and these countries also had highest levels of body satisfaction, which could be due to a reduced pressure in those countries to strive for a slim ‘ideal’. Swami et al. (2010) found when comparing differences between 10 world regions that lower-economic status sites preferred 'heavier' bodies, and body dissatisfaction was greater in higher-economic status sites. Mulgrew & Hennes (2015) found women in Australia reported poorer outcomes in the perception of their fitness and size after viewing images emphasizing the aesthetic and functional qualities of the body, highlighting the differences that can be observed between regions.

5.8.2.2 Individual Differences

The results of the current study demonstrate the wide variety of experiences individuals with the condition have, with regards to the symptoms experienced, length of time with symptoms, time to diagnosis, the number of body locations where the condition is diagnosed, and treatments tried. After receiving their diagnosis, whilst many felt "*less dramatic*" about the way in which they were managing and coping with their symptoms, they still felt helpless and fearful. Therefore, examination into the impact of the length of time experiencing symptoms prior to diagnosis warrants further investigation in future studies, so that ineffective pain-coping behaviours that may develop across this time may be less likely to negatively influence body image (Sündermann et al., 2020). It also highlights that whilst improvements are needed in diagnosis and treatment protocols, and consistency across regions to reduce inequity, with everyone's experience and management of the condition being so varied, a 'one-size-fits-all' approach is not suitable, and a person-centred care approach should be adopted and considered during research. Further research is also needed to examine whether more representation of bodies like theirs is required, or desired, in those with endometriosis, and building understanding into how this could subsequently influence their perception of the aesthetic and functional quality of their bodies.

This examination into other individual differences could be developed by further examining the outcomes for individuals who are pregnant, transexual, or gender variant/non-conforming with endometriosis, due to the potential differences in body image perception and appraisal for these groups. There is an increase in awareness of the prevalence of endometriosis in transgender individuals, thanks in part to period campaigners, like Kenny Jones, who made history being the first trans man fronting a period campaign 'IM ON' (The Independent, 2018). Without understanding the challenges faced by these individuals, interventions cannot be tailored to the additional requirements they may face, such as the gender dysphoria experienced by having a health condition often worsened during a menstrual cycle (Denny, 2004). Furthermore, it may be beneficial for researchers to consider the use of language used to create an inclusive environment, to ensure that results and terminology used provide equal benefit to LGBTQ+ participants as well.

5.8.3 Practice

There is currently very little psychological support for those with Endometriosis, with no reference to it, or its potential benefits on the NHS website, only signposting to Endometriosis UK (NHS, 2017b). This also does not currently provide any information on psychological therapies, other than a brief mention of a GP referral for counselling (Endometriosis UK, 2023a). There is no guidance on what this involves, what it is for and what outcomes could be achieved by doing this. The only acknowledgement of the benefits of psychological therapies comes through blog articles, generally from those with lived experience, with no large organisations or charities, like Endometriosis UK or the Endometriosis Foundation making reference to it on their websites or social media sites (The Endometriosis Foundation, 2023). Therefore, systemic changes need to take place to make patients aware what could be available to them. Potential suggestions for practice are outlined below.

5.8.3.1 Health Psychology

Increasing an internal locus of control may be beneficial in the context of endometriosis, to build feelings of control over day-to-day tasks, despite feeling out of control of the condition. Over half of the participants wanted support in improving the control they had, and in a patient group where they are experiencing "*dissociation*" from their body, interventions to increase an internal locus of control would be beneficial.

Clinicians can also be supportive in improving perceived control, by increasing patient involvement in the decision-making process when it comes to their health management, expressing empathy and better information provision and promotion of autonomy (Pollak et al., 2011). Future research would benefit from examining how an improved patient-clinician relationship, and increased effectiveness of information provision could lead to positive outcomes for patients and their body dissatisfaction and functionality appreciation.

5.8.3.2 Interventions

The present study provided an increased insight into the under-researched element of body image, inclusive of body dissatisfaction and functionality appreciation, and how interventions can be developed to target these areas. Having tailored interventions to target body image may result in improved patient experience and outcomes achieved.

Interventions to improve body image found psychotherapy, psychoeducation and physical activity may improve body image in those with breast cancer, all of which may also benefit emotional wellbeing (Lewis-Smith et al., 2018b). This suggests the use of psychotherapy, psychoeducation and physical activity could be useful in the endometriosis population also, due to the similar way in which the conditions develop, and the potential increased risk of developing breast cancer with the presence of endometriosis (Swiersz, 2002).

Gollings & Paxton (2006) found group interventions for body dissatisfaction in those with disordered eating had significant improvements on *all* outcomes in both face to face and online groups, suggesting the benefits of group interventions were consistent regardless of mode of delivery. Pehlivan et al. (2023) also found group interventions to be beneficial for improving body image in gynaecological conditions. This suggests that a group-based body image intervention to an endometriosis population may see positive outcomes, and could be delivered with equal success, whether it is face to face or online; an important consideration where travel logistics and physical capacity to attend may be challenging.

Whilst self-led resources were less favoured by the participants in this study, it was still a preference by some, and both Acceptance and Commitment Therapy and Cognitive Behavioural Therapy have been found to have beneficial outcomes when completed through self-help resources with minimal or modest therapist contact (Cash & Lavallee, 1997; Johnston et al., 2010). For geographical areas with little clinical resource, or patients with a preference for self-help resources, it suggests the use of such modes of intervention delivery could see positive outcomes.

5.8.3.2.1. Functionality-Based Interventions

Just under half of participants wanted support in improving their body's physical functionality. Alleva et al. (2015) conducted a meta-analysis on 34 randomised control trials and found significant benefit of exercise on physical function in patients with cancer. Rooks (2007) found when introducing physical activity interventions in a patient population with fibromyalgia, there were additional benefits on top, including increased self-efficacy. This may subsequently reduce body dissatisfaction and improve functionality appreciation, as Alleva et al. (2015) found interventions on body functionality improved body image and led to reductions in self-objectification.

Many cited in the present study that there was little representation of "*bodies like theirs*". As outlined by the Tripartite Model of Influence, which proposes media to be a core source of influence (Hardit & Hannum, 2012), as social media is a source of information for many individuals with endometriosis, when users view 'idealised' functionality-based content, it can contribute to feelings of bodily dissatisfaction (Mulgrew & Tiggemann, 2018). Therefore, it is important for content creators to be mindful of the impact they may have when posting, and where possible promote content with a variety of body shapes and functional ability, which may aid positive bodily perception in those with endometriosis whilst seeking information on the condition. Similarly, for organisations like Endometriosis UK, this could involve the inclusion of a variety of body shapes in their social media posts and website, as currently all imagery used includes thin, able-bodied individuals. This is currently not representative of many with the condition, some of which may have been left wheelchair-bound from the condition (Nezhat et al., 2019).

5.8.3.2.2. Control-Based Interventions

A study with diabetics found that groups that provide knowledge and are co-delivered by people with lived experience *and* experts can result in improved feelings of control (Garrett et al., 2005). Moradi et al. (2020) found that for individuals with Polycystic Ovarian Syndrome (PCOS), interventions teaching them ways to manage feelings of hopelessness, regaining control, purpose and identifying values, led to positive outcomes with regards to body image and self-esteem. A study on ovarian cancer patients found that targeting patients' *external* locus of control was a successful way of improving feelings of control (Brown et al., 2015). Due to the increased risk of developing ovarian cancer in those with endometriosis (Heidemann et al., 2014), this may also be useful to target in the endometriosis population too, including those in the present study due to the low control and increased feelings of powerlessness reported, and its subsequent impact on body dissatisfaction and functionality appreciation.

Internal Locus of Control (ILC) can be increased through educational interventions (Tabak & Kadriye, 2006). Educational interventions to improve the understanding of endometriosis may be beneficial at improving internal locus of control, something that is currently identified as being low in those with endometriosis (Rees et al., 2022). The qualitative data in this study suggested that there was an increased sense of power and empowerment that came through understanding their condition better, and the current lack of knowledge provided by health care professionals meant that many individuals with the condition were trying to 'educate' themselves. This again highlights the importance of upskilling health care professionals to improve feelings of control for patients.

5.8.3.2.3 Acceptance and Commitment Therapy

Improving the acceptance, thoughts and beliefs participants had over their endometriosis was a frequently cited area that individuals wanted support in. Acceptance and Commitment Therapy (ACT) encourages acceptance of emotions and thoughts, instead of trying to 'change' them. ACT has been found to be beneficial in improving both body dissatisfaction, a functionality-focused mindset, body image flexibility and a series of positive body image constructs, including body appreciation, pride, adaptive appearance investment and a broad conceptualisation of beauty (Pearson et al., 2012; Piran & Tylka, 2019). Fooladvand & Zarei (2022) also found it to be beneficial in improving emotional regulation and body image in infertile women, an important consideration in a patient population like those with endometriosis where infertility can be present. McCracken et al. (2013) found group-based acceptance and commitment therapy to be effective in improving several outcomes for patients with chronic pain, including acceptance of pain.

ACT may also improve body compassion in those with endometriosis (Van Niekerk et al., 2023). Acknowledgement and acceptance of their body's 'deviation' from an 'ideal' may be better targeted through the reframing of thoughts, something that can often be achieved through use of ACT (Pehlivan et al., 2023). It would be beneficial to examine the influence of ACT in those with endometriosis, as it may be supportive of encouraging participants to be present, self-aware, observing thoughts without always believing them and participating in values-consistent activities (Leonardi et al., 2020), which Moradi et al. (2020) found linked with improving body image.

5.8.3.2.4 Compassion Focused Therapy

The current study found that self-compassion was a significant predictor for both body dissatisfaction and functionality appreciation, suggesting that it could be one of the most beneficial areas to target in an intervention. In line with Wasylkiw et al. (2012) study on self-compassion and body image in women, this demonstrates a potential benefit of compassion-based interventions, such as Compassion Focused Therapy (CFT). CFT encourages individuals to be more compassionate towards themselves and others and is grounded in appreciation exercises and mindfulness. Albertson et al. (2015) 3-week compassion-focused intervention for improving body image in women, found significant increases to body appreciation scores, and declines in body dissatisfaction and body shame. The low self-compassion and body compassion identified in the present study and other endometriosis studies suggests CFT could be a good intervention for the endometriosis population (Sullivan-Myers et al., 2023; Van Niekerk et al., 2023). Furthermore, with the associated pain and fatigue experienced in endometriosis also negatively predicting levels of self-compassion in other studies (Van Niekerk et al., 2022a), it indicates the potential benefits of therapies like CFT in targeting the physical pain related outcomes too. However, an online compassion focused feasibility and acceptability trial, evaluating an online self-compassion focused writing activity in those with endometriosis had a high drop-out rate (49%) (Lores et al. 2024). Whilst the study was considered feasible, several considerations must be taken for future compassion focused interventions. The high drop-out may be due to the high demand on participants to engage in long, emotionally-charged writing tasks. Furthermore, due to the inherently interpersonal and experiential nature of CFT, tasks like this may benefit from in-person delivery, instead of delivery through virtual settings, to create the strong therapeutic relationship, emotional safety and effective delivery of techniques surrounding body-focused exercises, to improve the overall experience.

5.8.3.2.5 Cognitive Behavioural Therapy

Cognitive behavioural therapy (CBT) is also well documented in its benefits for improving thoughts, feelings, and behaviours. Donatti et al. (2022) found CBT to be supportive in reducing pain, depression and stress, and improved quality of life, physical and social functioning, emotional wellbeing and control in those with endometriosis, which were also areas the participants in the present study cited needing support with. There has not yet been any studies examining the influence of CBT on body image in endometriosis specifically, but CBT has been successful in addressing body image concerns, increasing body appreciation and self-esteem in breast cancer survivors (Lewis-Smith et al., 2018a), suggesting it could be a beneficial way to improve body dissatisfaction and functionality appreciation in endometriosis. Endometriosis and breast cancer are both estrogen dependent conditions, characterized by cell invasion and unrestrained growth, with the presence of endometriosis potentially also increasing the risk of developing breast cancer (Swiersz, 2002), therefore understanding potential treatment methods that can cater to both are beneficial. Haraldseid et al. (2014) found group-based CBT to be beneficial for those experiencing feelings of loss as a result of chronic pain, including the loss of being able to engage in meaningful activities and the loss of self, both areas cited in this study as areas participants struggled with. The Haraldseid et al. (2014) study also identified the changes that can be achieved to support participants in moving towards a more meaningful life again, which draws upon the benefits acknowledged earlier, of value-based work in improving body image.

5.9 Reflexivity

Upon completing this thesis, it is still felt that the pragmatic, mixed methods approach was most appropriate for this study, and built upon the current lack of mixed methods research in body image and endometriosis. Having the combination of both quantitative and qualitative data was helpful, as it provided evidence that backed up anecdotal experiences of individuals from Endometriosis UK support groups, social media sites and forums. However, reading through so many negative experiences was challenging, particularly due to the researcher's lived experience with the condition, where there is no cure, and difficulty in defining its trajectory, it was hard at times reading the experiences of those who have been experiencing symptoms for longer periods of time, as the future of the researcher's own condition trajectory is unclear. However, it was hugely rewarding to feel as though this thesis may contribute a small part to this under-researched field, and it is hoped that this will contribute to intervention development, evaluation, and delivery.

5.10 What Comes Next

It is hoped now the thesis is complete, the findings will be disseminated through several means. Firstly, a meeting has taken place with the researcher and Endometriosis UK's Specialist Advisor to discuss ways in which psychological content can be created to improve the current lack of information provided by the charity. It has been agreed that the researcher will work with the Specialist Advisor and Endometriosis UK's Information Manager to create a series of resources, outlining the benefits of, and ways to access psychological therapies. The researcher has also been offered the opportunity to deliver a webinar to all Endometriosis UK members, to discuss the outcomes of the study in more detail, and provide further information on the various psychological interventions that could be accessed to support with the condition. The researcher is also preparing the thesis to submit for peer-review, in leading peer-reviewed journals that are expressly interested in endometriosis and Health Psychology.

6: Conclusions

The current study aimed to understand the impact of endometriosis on body dissatisfaction, functionality appreciation and general wellbeing outcomes. In addition to this, the study sought to understand whether individuals wanted support on improving this and if so, in what areas, and through what method of delivery. The study found that individuals' experiences with the condition was hugely varied, and the impact of this on other general wellbeing related variables have subsequently had an impact on body dissatisfaction and functionality appreciation. The current sample demonstrated that there is a desire for support in improving body dissatisfaction and functionality appreciation, with particular focus on improving feelings of control, acceptance and the thoughts and beliefs towards their body. The current sample wished for this to be delivered through health care professionals such as psychologists and counsellors, and hearing other peoples' experiences, with some preference for self-led resources. Future research would benefit from developing and evaluating interventions on body image based upon the Medical Research Council framework for development of complex interventions. These interventions could include Cognitive Behavioural Therapy, Acceptance and Commitment Therapy, and Compassion Focused Therapy, tailored to those with endometriosis.

7: References

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8: Appendices

Appendix 1 – Questionnaire Acceptability Feedback from Volunteers

Note: The feedback/suggestions that were incorporated are in green font, and the rationale for not incorporating any feedback provided is in red italics.

VOLUNTEER ONE – SI

Having read through the survey, I think it is brilliant. It really does highlight the reason of the survey. I have added my comments below for each question.

The survey is just the perfect length in my opinion. The questions are very inclusive, it targets all audiences. The questions target the main focal point of the survey and sufficiently focus on body image. The questions have a really good flow. Each question follows on perfectly from the last. Personally, I don't think there is anything missing. The survey is clear and concise and targets the aim of the survey.

For someone who suffers with endometriosis and has been conscious since having surgery and hormonal treatments because I have put on drastic weight, this survey will allow people like myself to express themselves freely. I've not been able to genuinely express how I feel since being diagnosed to health care professionals because I've been made to feel that this is part of having the disease.

I would like to say a huge thank you. This survey will open doors for people like myself to get the support they need whether it be emotional support or physical.

Thank you again for letting me be a part of this research group.

If there is anything else you need/want from me please feel free to contact me.

VOLUNTEER TWO – ZC

Hello,
I hope that you're as well as can be and having a good week.

I'm one of the volunteers through Endometriosis UK to give feedback on your body image questionnaire. I think the length is fine. I do appreciate when a survey tells me roughly how long it might take to complete at the beginning.

In terms of inclusion I do think it's widely inclusive. I am currently pregnant and have been a research participant for endometriosis during my pregnancy and think being able to state that is helpful. It gives me a different perspective on body image and my condition than I had pre-pregnancy. Fertility in general can have a big impact on the relationship between self and body image and may be worth considering or using to remove candidates.

Question 3 part b) 'how do these symptoms make you feel about your body' covers a wide variety as each symptom may create multiple different feelings. Phrasing I have seen previously which may work here is along the lines of: 'focusing on each symptom how does it make you feel about your body?'

Question 4 part b) again is quite general and covers a long period of time. For example my symptoms initially made me feel like my body was weak and feeble, but now understanding the cause I feel quite different. It might be useful to have this as a 'thinking back to before you were diagnosed, what impact did this have on how you perceive your body?' repeat this again after 'How many years have you had your endometriosis diagnosis now?' As the validation that comes alongside diagnosis can create drastically differing perceptions.

I would dig into how endometriosis impacts your clothing choice and how we present *(Included in the Body Image Questions already*). Is it practical eg. On flare days clothes don't fit, wearing dark clothes incase of leaks or is it choice to cover up because you feel dirty or self conscious about scars. Personally I find many endometriosis sufferers over compensate with their appearance for occasions as in this is the one time I can manage so I'm going to put a lot of pressure on myself to present as an ideal self - the opposite of my day to day when I struggle to shower and live in pyjamas.

Given the role that social media plays now in everyone's body image I think it might be prudent to dig into how that ties into our body image. As in do we withdraw because we feel less presentable, do we frame our online persona in a certain way or shy away because having people tell us we 'look well' is contradictory to how we feel.

I feel overall that asking how I feel about 'my body' doesn't necessarily reflect how I feel about my 'body image'. Given where I am (almost exactly 3 years post diagnosis, symptomatic for 20+ years and 6 months pregnant) I am not secure about how my body looks but I'm incredulous that I'm alive, can walk and grow a person. There's a superficial level but also a 'lucky to be alive with the bits that function functioning' bit. Possibly asking questions about what people might change (if anything) about themselves while provocative might reveal more truthful body image opinions.

Playing golf involves walking a considerable distance as well as physically hitting the ball and is not comparable with the effort involved in pushing a vacuum so this question is very confusing. (*This is a standardised question so will not be amended as it was not raised by other volunteers*)

It may simply be a design thing but the final 3 questions could illicit long answers so bigger boxes please!

Overall I would say dig deeper. I think this is an important issue and sufferers are likely to be happy to give the time needed for feedback.

I hope that this is helpful and wish you the best of luck.

Kind regards,

A brief follow up. Endometriosis does kill a lot of people's sex lives. The reasons vary from physical discomfort, the connection to fertility making sex a task rather than for pleasure to self-consciousness around scars/ stomas etc. From the experiences I've had as a friend of and web chat volunteer a healthy sex life or lack thereof can have a big impact on that body image relationship. Not sure how you include it but I do think it's often overlooked as tertiary outlier in terms of symptoms but feeds into self image. (*I completely agree with this feedback, but feel that opening this line of questioning may take the focus away from the specific links between diagnosis and body image/perception in the first instance, of which research is currently lacking*)

kind regards again,

VOLUNTEER THREE – JB

Hello

I hope you are well. Please see some feedback following your request on the survey.

Kind regards,

I think the length is good.

Yes- in my opinion the questions are framed well and are inclusive.

You may want to bring the body image questions out a bit more earlier to ensure the person completing knows that is your main topic (however, appreciate you may introduce this in a cover email or letter). *This will be covered in a brief that individuals will read when signing up to participate*.

See above

Maybe a bit more focus on the mental health implications of having endo.

VOLUNTEER FOUR – JV

How long the survey is - do you feel it needs to be shorter/longer?
I felt it was the right length

How the questions are framed - do you feel it is inclusive?

I did, but then again I am being a white, straight woman. I am not sure I am best placed to answer this!

Do the questions gather enough evidence to answer the research question - is it sufficiently focused on body image?
I do, but also wonder if another question could look at how you feel others e.g. partners, friends, feel about your body. Being someone who suffered fertility issues I often felt others thought my body wasn't 'good enough'! And sometimes that was worse than I how felt about myself.

Do the questions need to be ordered differently?
No

Is there any information or questions you feel are missing/could be added?
I do think there needs to be a little explanation of what she means by 'body image' (*This is explained in the information sheet given to participants before starting*.)

Any additional comments?
No

VOLUNTEER FIVE – LS

Hi,

The survey reads really well – just a few comments from me which other may have covered/suggested?

- The gender question could flow a little better – perhaps take out one word so it reads "To which gender do you most identify?" or you could ask "How do you define your gender?". (The latter is what the Consultation Institute recommend).
- In the symptoms question you have a typo which you have probably already spotted. Diarrhoea has an extra vowel.
- For the "How many years did you have symptoms before diagnosis" question You may want to reduce the amount of options but include more years? E.g.0-2, 3-5, 5-10, 10-20, 20+. Only because it personally took me 17 years and I know a lot of others in the same boat so you might want to highlight just how bad the situation is with more options for 10+.
- For the "Which part of your body have you been diagnosed with endometriosis?" just a little re-word would improve the flow of the question. "In which part/s of your body have you been diagnosed with endometriosis?".
- For the "Please provide more detail on why you chose to access information this way?" an alternative way of asking this question could be" Do you face/have you faced any barriers to accessing information?" Not sure if that would be of interest to your research worded that way? We tend to ask it a lot in our surveys - I work for local government – as we want to know why some channels are more popular that others

and we tend to get much more honest answers when asking about barriers to accessing information/services rather than just asking why they choose a specific way.
- Just an aside.... you might after asking how many surgeries has someone had, you might want to add “When was your last surgery?” I only mention this as later on when you as about things over the last 4 weeks you might get some answering ‘rarely’ or ‘never’ and that could be down to the fact they’ve had recent surgery to treat their symptoms. For example I would answer rarely, as I had a 6.5hr op at the end of last year – If you’d asked me the weeks leading up to the op the answers would be ‘often’ or ‘always’. It could give you some context to the answers you are getting?

Hope that helps? Feel free to ignore the above if it’s not relevant/helpful to your research.

Any questions, give me a shout.

VOLUNTEER SIX - CN

1. Will the questions be numbered?
2. Where you list possible endo locations, I don't think 'The' is necessary
3. 'Thinking back to before you were diagnosed...' should say 'perceived' not 'perceive'
4. 'What forms of treatment...' it would be helpful for understanding to have 'coil/Mirena' rather than just coil. Also the point on 'Surgery - multidisciplinary team' needs to be clearer. Some may not understand MDT.
5. The following questions are about how you have felt emotionally... not feel
6. In the 'moderate activities' list, golf seems a strange choice of sport! Perhaps switch to one which is generally more common.
7. In general there seem to be a lot of capital letters for words which don't really need them - it makes the text look very heavy. For example, the section on forms of treatment.

Appendix 2 – Research Advertisement List

List of places research was advertised

- Research Groups
  - Centre for Appearance Research Participant Pool – 900 people
- Websites
  - Endometriosis UK – sent via email to all volunteers and social media
- Instagram
  - Personal – 855 followers
  - Centre for Appearance Research (CAR) – 1.7k followers
  - Personal Instagram page – The Behaviour Change Mindset – 872 followers
  - The Fanny Diaries – 11.5k followers
  - Reality of Endo – 1.2k followers
  - In the deep Endo – 2.8k followers
  - Endometriosis Surgeon UK – 6.4k followers
  - Trans Endometriosis Influencer (preferred to remain anonymous for write up) – 2.1k followers
  - Menstrual Cycle Coach – 1.2k followers
  - In16yearsofendo – 8k followers
- Linkedin
  - Personal
  - Shared via multiple contacts from UWE, Workplace and Women's Health companies
- Facebook
  - Personal
  - Centre for Appearance Research (CAR) – 1.7k followers
  - Truly Twenties Group – 72k members
  - Truly Twenties London UK Group – 15k members
    Truly Thirties Group – 680 members
  - UK Women in Business Group – 3.6k members
  - Bristol Girl Group – 1.2k followers
  - UK Endometriosis Support and Awareness Group – 17k members
  - Endometriosis Support UK Group – 14k members
- Reddit
  - r/Endo, r/Endometriosis, r/Samplesize, r/womenshealth
- Twitter/X
  - Centre for Appearance Research (CAR) – 3.8k followers
  - Epidemiologist in female chronic pain at Oxford University
  - Senior Research Fellow in Endometriosis at Oxford University

Contacted but no response/not allowed

- Kenny Ethan jones (first trans man period campaign)
- London Mums Group on Facebook (not allowed)
- Women's running group (not allowed)

Appendix 3 – Questionnaire Questions

Please ensure that you have read and understood the information about this study, and contact the researcher, (anonymised for thesis submission), if you have any questions (email: anonymised for thesis submission). This survey has 34 questions and should take no longer than 15 minutes to complete. For further information please click for the Information Sheet and Research Privacy Notice.

By completing this survey, you are consenting to taking part in this study.

- I have read and understood the information provided about this study;
- I have had an opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time during data collection, and up to 4 weeks after the completion of the survey, without giving a reason, until the data has been anonymised;
- I agree to take part in the research

○ I agree (4)

○ I disagree (5)

Skip To: End of Survey If Please ensure that you have read and understood the information about this study, and contact the... = I disagree

Q1 Please create a unique participant identifier so that your personal details remain anonymous and we can still remove your data should you wish to withdraw. Please use the following format: Your initials, day of birth, first letter of your hometown (JB10Y)

____

Q2 How do you define your sex-assigned-at-birth?

○ Female (1)

○ Male (2)

○ Transgender Female (3)

○ Transgender Male (4)

○ Gender variant/Non conforming (5)

○ Prefer not to say (6)

○ Other (9) ____

Q3 How old are you?

____

Q4 Where do you live? (Country/County/State)

____

Q5 Are you currently pregnant?

○ Yes (1)

○ No - I have not got any children, but I am trying and wish to conceive soon (2)

○ No - I already have children, but I am trying and wish to conceive again soon (6)

○ No - I am not currently trying to conceive but would like children in future (4)

○ No - I already have children and do not wish for anymore (7)

○ No - I do not want children (5)

Q6 Have you been diagnosed with Endometriosis?

○ Yes (1)

○ No (2)

Skip To: End of Survey If Have you been diagnosed with Endometriosis? = No

Q7 In which part/s of your body have you been diagnosed with endometriosis? (Please select all that apply)

- ☐ Ovaries (1)
- ☐ Fallopian tubes (2)
- ☐ Ligaments that support the uterus (Uterosacral ligaments) (3)
- ☐ Posterior cul-de-sac, i.e., the space between the uterus and rectum (4)
- ☐ Anterior cul-de-sac, i.e., the space between the uterus and bladder (5)
- ☐ Intestines (6)
- ☐ Rectum (7)
- ☐ Bladder (8)
- ☐ Vagina (9)
- ☐ Cervix (10)
- ☐ Vulva (11)
- ☐ Abdominal surgical scars (12)
- ☐ Other (Please specify) (13)

____

Q8 How many years have you had your endometriosis diagnosis now?

____

Q9 What symptoms have you observed? (Please select all that apply)

- ☐ Menstrual cramps (1)
- ☐ Abnormal or heavy periods (2)
- ☐ Painful urination (3)
- ☐ Painful bowel movements (4)
- ☐ Constipation and/or diarrhoea (5)
- ☐ Nausea (6)
- ☐ Painful intercourse (7)
- ☐ Fatigue (8)
- ☐ Pelvic pain (9)
- ☐ Back pain (10)
- ☐ Leg pain (11)
- ☐ Infertility (12)
- ☐ Other (Please specify) (13)

____

Q10 Please describe the impact of each of your symptoms, individually and collectively, on how they have made you feel about your body.

____

____

____

____

____

Q11 For how many years did you have symptoms ***before getting diagnosed***?

____

Q12 Thinking back to ***before*** you were diagnosed, what impact did your symptoms have on how you perceived your body?

____

____

____

____

____

Q13 Now you ***have*** been diagnosed, has it ***changed*** how you perceive your body? If so, how?

____

____

____

____

____

Q14 Have you been diagnosed with any other health condition?

○ Yes (Please state) (1) ____

○ No (2)

Q15 What forms of treatment have you received or used for your endometriosis during this time? (Please select all that apply)

☐ Hormonal treatments - the pill (1)

☐ Hormonal treatments - the coil, e.g. Mirena (2)

☐ Hormonal treatments - injections (3)

☐ Surgery - keyhole/laparoscopy (4)

☐ Surgery - multidisciplinary team, e.g. colorectal surgeon, gynaecologist, urologist (5)

☐ Surgery - hysterectomy (6)

☐ Surgery - hysterectomy and oophorectomy (removal of the ovaries) (7)

☐ Complementary - heat (8)

☐ Complementary - acupuncture (9)

☐ Complementary - dietary changes (16)

☐ Complementary - pelvic physiotherapy (10)

☐ Complementary - other physiotherapy (15)

☐ Complementary - Transcutaneous Electrical Nerve Stimulator (TENS) machines (11)

☐ Painkillers (12)

☐ Other Medication (13) ____

☐ Other (Please specify) (14) ____

Display This Question:

If What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - keyhole/laparoscopy

Or What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - multidisciplinary team, e.g. colorectal surgeon, gynaecologist, urologist

Or What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - hysterectomy

Or What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - hysterectomy and oophorectomy (removal of the ovaries)

Q15A If you have been treated with surgery, how many have you had?

○ 1 (1)

○ 2 (2)

○ 3 (3)

○ 4 (4)

○ 5+ (5)

Display This Question:

If What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - keyhole/laparoscopy

Or What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - multidisciplinary team, e.g. colorectal surgeon, gynaecologist, urologist

Or What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - hysterectomy

Or What forms of treatment have you received or used for your endometriosis during this time? (Pleas... = Surgery - hysterectomy and oophorectomy (removal of the ovaries)

Q15B When was your last surgery?

- ○ Within the last year (1)
- ○ 1-2 years ago (2)
- ○ 3-5 years ago (3)
- ○ 6-9 years ago (4)
- ○ 10+ years ago (5)

Q16 How have these various treatments made you feel about your body?

____

____

____

____

____

You're half way Thankyou for your answers so far!

Q17 During the last 4 weeks, how often because of your endometriosis, have you...

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	**Always** (5)
Generally felt unwell? (1)	○	○	○	○	○
Felt frustrated because your symptoms were not getting better? (2)	○	○	○	○	○
Felt frustrated because you are not able to control your symptoms? (3)	○	○	○	○	○
Felt unable to forget your symptoms? (4)	○	○	○	○	○
Felt as though your symptoms are ruling your life? (5)	○	○	○	○	○
Felt your symptoms are taking away your life? (6)	○	○	○	○	○
Felt frustrated as you cannot always wear the clothes you would choose? (7)	○	○	○	○	○
Felt your appearance has been affected? (8)	○	○	○	○	○
Lacked confidence? (9)	○	○	○	○	○

Q18 The following questions are about how you have felt emotionally. During the last 4 weeks, how often because of your endometriosis, have you...

	All of the time (1)	Most of the time (2)	A good bit of the time (3)	Some of the time (4)	A little bit of the time (5)	**None of the time** (6)
Been a very nervous person? (1)	○	○	○	○	○	○
Felt so down in the dumps that nothing could cheer you up? (2)	○	○	○	○	○	○
Felt calm and peaceful? (3)	○	○	○	○	○	○
Felt downhearted and blue? (4)	○	○	○	○	○	○
Been a happy person? (5)	○	○	○	○	○	○

Q19 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	No, not limited at all (1)	Yes, limited a little (2)	**Yes, limited a lot** (3)
Vigorous activities, such as running, lifting, heavy objects, participating in strenuous sports (1)	○	○	○
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or yoga (2)	○	○	○
Lifting or carrying food shopping (3)	○	○	○
Climbing several flights of stairs (4)	○	○	○
Climbing one flight of stairs (5)	○	○	○
Bending, kneeling or stooping (6)	○	○	○
Walking more than a mile (7)	○	○	○
Walking several streets (8)	○	○	○
Walking one street (9)	○	○	○
Bathing or dressing yourself (10)	○	○	○

Page Break

Q20 How TRUE or FALSE are each of the following statements for you?

	Definitely false (1)	Mostly false (2)	Don't know (3)	Mostly true (4)	**Definitely true** (5)
I seem to get sick a little easier than other people (1)	○	○	○	○	○
I am as healthy as anybody I know (2)	○	○	○	○	○
I expect my health to get worse (3)	○	○	○	○	○
My health is excellent (4)	○	○	○	○	○

Q21 How do you access the majority of the information you require to manage your endometriosis? (Please select all that apply)

- ☐ GP (2)
- ☐ Surgeon (3)
- ☐ Gynaecologist (4)
- ☐ Nurse (5)
- ☐ Endometriosis UK (10)
- ☐ Other individuals with endometriosis (8)
- ☐ Social Media - please specify (7) ____
- ☐ Personal research online - please specify (1) ____
- ☐ Other NHS Professional - please specify (6) ____
- ☐ Other - please specify (9) ____

Q22 Do you face/have you faced any barriers to accessing information surrounding your endometriosis?

____

____

____

____

____

Q23 Please indicate the extent to which you agree with each of the following statements:

	Strongly disagree (1)	Disagree (2)	Neither agree or disagree (3)	Agree (4)	**Strongly agree** (5)
I appreciate my body for what it is capable of doing. (1)	○	○	○	○	○
I am grateful for the health of my body, even if it isn't always as healthy as I would like it to be. (8)	○	○	○	○	○
I appreciate that my body allows me to communicate and interact with others. (9)	○	○	○	○	○
I acknowledge and appreciate when my body feels good and/or relaxed. (10)	○	○	○	○	○
I am grateful that my body enables me to engage in activities that I enjoy or find important. (5)	○	○	○	○	○
I feel that my body does so much for me. (6)	○	○	○	○	○
I respect my body for the functions it performs. (7)	○	○	○	○	○

Q24 During the last week, have you...

	Not at all (1)	A little (2)	Quite a bit (3)	**Very much** (4)
Been feeling self-conscious about your appearance? (1)	○	○	○	○
Felt less physically attractive as a result of your disease or treatment? (2)	○	○	○	○
Been dissatisfied with your appearance when dressed? (3)	○	○	○	○
Been feeling less feminine as a result of your disease or treatment? (4)	○	○	○	○
Found it difficult to look at yourself naked? (5)	○	○	○	○
Been feeling less sexually attractive as a result of your disease or treatment? (6)	○	○	○	○
Avoided people because of the way you felt about your appearance? (7)	○	○	○	○
Been feeling the treatment has left your body less whole? (8)	○	○	○	○
Felt dissatisfied with your body? (9)	○	○	○	○
Been dissatisfied with the appearance of your scar? (10)	○	○	○	○

Q25 Please indicate how much you agree with the below statements.

	Almost never (1)	Seldom (3)	Occasionally (4)	Often (5)	**Almost always** (6)
When I fail at something important to me I become consumed by feelings of inadequacy. (1)	○	○	○	○	○
I try to be understanding and patient towards those aspects of my personality I don’t like. (2)	○	○	○	○	○
When something painful happens I try to take a balanced view of the situation. (3)	○	○	○	○	○
When I’m feeling down, I tend to feel like most other people are probably happier than I am. (4)	○	○	○	○	○
I try to see my failings as part of the human condition. (5)	○	○	○	○	○
When I’m going through a very hard time, I give myself the caring and tenderness I need. (6)	○	○	○	○	○

When something upsets me I try to keep my emotions in balance. (7)	○	○	○	○	○
When I fail at something that’s important to me, I tend to feel alone in my failure. (8)	○	○	○	○	○
When I’m feeling down I tend to obsess and fixate on everything that’s wrong. (9)	○	○	○	○	○
When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people. (10)	○	○	○	○	○
I’m disapproving and judgmental about my own flaws and inadequacies. (12)	○	○	○	○	○
I’m intolerant and impatient towards those aspects of my personality I don’t like. (14)	○	○	○	○	○

Q26 How do you feel others perceive your body? E.g. Partners, friends, family.

____

____

____

____

____

Q27 Would you change anything about your body if you could? If so, what and why?

____

____

____

____

____

Q28 Do you feel social media has had an influence on your body image?

○ Yes (1)

○ No (2)

Q29 Please explain your answer.

____

____

____

____

____

Q30 Have you received any support for your body image?

○ Yes - If Yes, why? (1) ____

○ No - If no, is this something you feel you would have benefited from support on? If so, why? (2) ____

Q31 Which of the following would you like to improve about your body image? (Tick all that apply)

☐ The way you see your body physically/how you look (1)

☐ The way you treat or behave towards your body (2)

☐ The thoughts and beliefs you have about your body and endometriosis (3)

☐ The acceptance of your body and endometriosis (5)

☐ The feeling of control you have over your body and endometriosis (6)

☐ The way your body moves physically (7)

☐ Other (Please specify) (4) ____

Q32 Please explain why.

____

____

____

____

____

Q33 Which of the following do you feel would support in improving your body image? (Tick all that apply)

☐ Support groups (1)

☐ Hearing others' experiences (7)

☐ Self-led online resource - E.g. Website, with tools and techniques (2)

☐ Self-led physical resource - E.g. Workbook to complete, with tools, techniques and journal prompts (5)

☐ Sessions with a psychologist, or counsellor (3)

☐ Physical fitness support (6)

☐ Other (Please specify) (4) ____

Q34 Please explain why you would like to receive support this way.

____

____

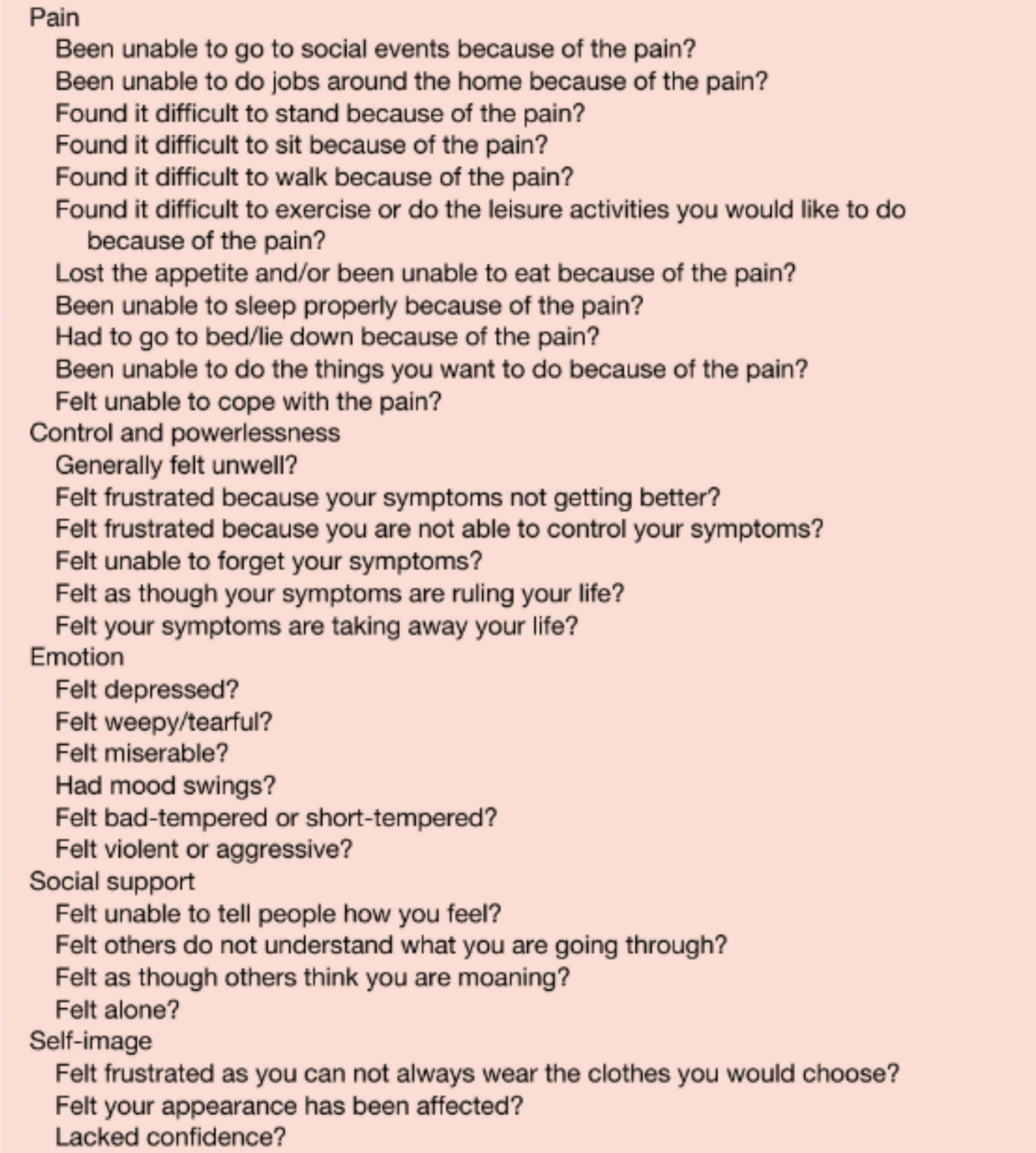
____

____

____

End of Block: Default Question Block

Appendix 4 – Endometriosis Health Profile – EHP-30



- Pain
  - Been unable to go to social events because of the pain?
  - Been unable to do jobs around the home because of the pain?
  - Found it difficult to stand because of the pain?
  - Found it difficult to sit because of the pain?
  - Found it difficult to walk because of the pain?
  - Found it difficult to exercise or do the leisure activities you would like to do because of the pain?
  - Lost the appetite and/or been unable to eat because of the pain?
  - Been unable to sleep properly because of the pain?
  - Had to go to bed/lie down because of the pain?
  - Been unable to do the things you want to do because of the pain?
  - Felt unable to cope with the pain?
- Control and powerlessness
  - Generally felt unwell?
  - Felt frustrated because your symptoms not getting better?
  - Felt frustrated because you are not able to control your symptoms?
  - Felt unable to forget your symptoms?
  - Felt as though your symptoms are ruling your life?
  - Felt your symptoms are taking away your life?
- Emotion
  - Felt depressed?
  - Felt weepy/tearful?
  - Felt miserable?
  - Had mood swings?
  - Felt bad-tempered or short-tempered?
  - Felt violent or aggressive?
- Social support
  - Felt unable to tell people how you feel?
  - Felt others do not understand what you are going through?
  - Felt as though others think you are moaning?
  - Felt alone?
- Self-image
  - Felt frustrated as you can not always wear the clothes you would choose?
  - Felt your appearance has been affected?
  - Lacked confidence?

Appendix 5 – The 36-Item Short Form Health Survey (SF-36)

Permissions information: All of the surveys from RAND Health Care are public documents, available without charge.

Choose one option for each questionnaire item.

1. In general, would you say your health is:

○ 1 - Excellent

○ 2 - Very good

○ 3 - Good

○ 4 - Fair

○ 5 - Poor

2. **Compared to one year ago**, how would you rate your health in general **now**?

○ 1 - Much better now than one year ago

○ 2 - Somewhat better now than one year ago

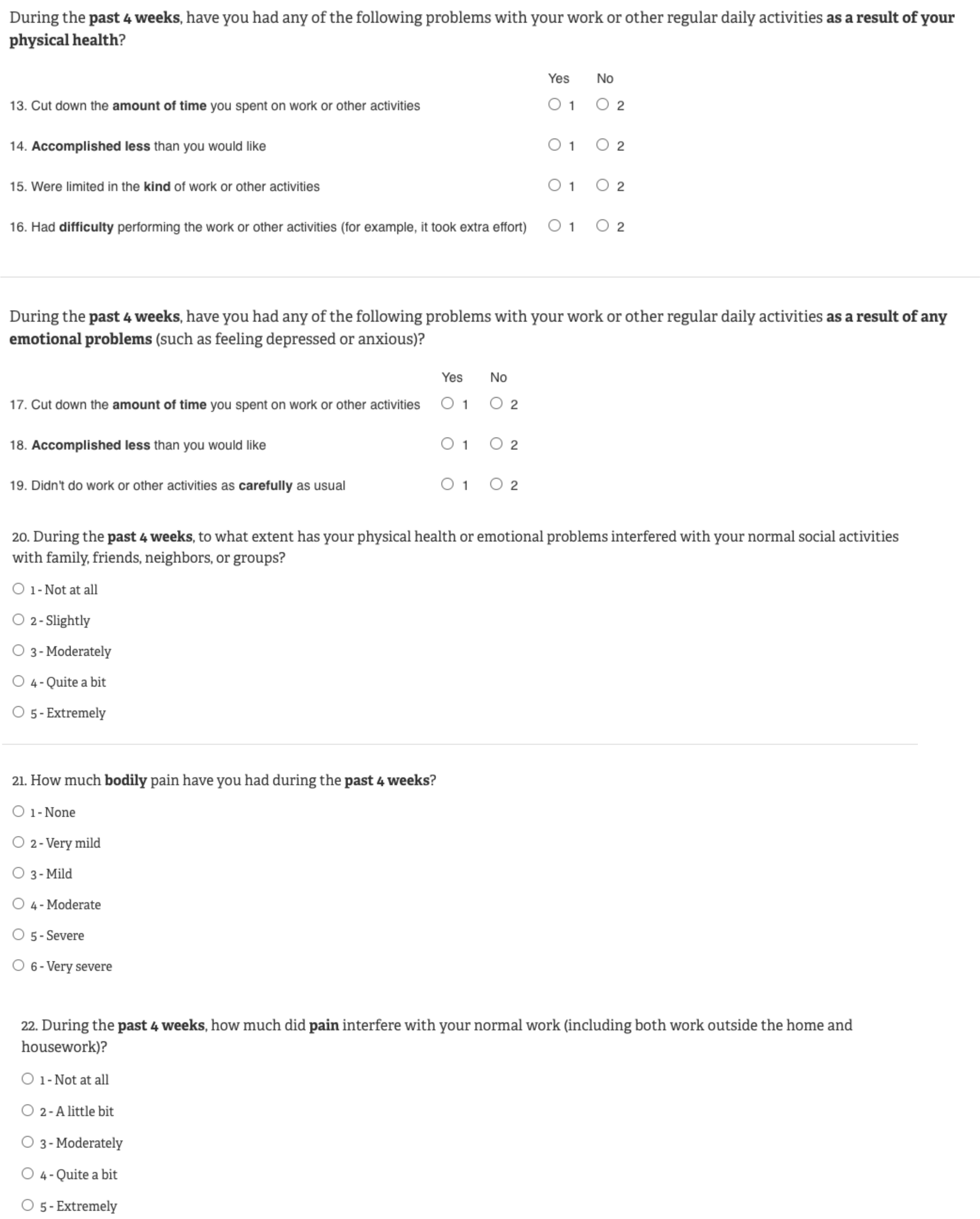
○ 3 - About the same

○ 4 - Somewhat worse now than one year ago

○ 5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	○ 1	○ 2	○ 3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○ 1	○ 2	○ 3
5. Lifting or carrying groceries	○ 1	○ 2	○ 3
6. Climbing **several** flights of stairs	○ 1	○ 2	○ 3
7. Climbing **one** flight of stairs	○ 1	○ 2	○ 3
8. Bending, kneeling, or stooping	○ 1	○ 2	○ 3
9. Walking **more than a mile**	○ 1	○ 2	○ 3
10. Walking **several blocks**	○ 1	○ 2	○ 3
11. Walking **one block**	○ 1	○ 2	○ 3
12. Bathing or dressing yourself	○ 1	○ 2	○ 3



During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	Yes	No
13. Cut down the **amount of time** you spent on work or other activities	○ 1	○ 2
14. **Accomplished less** than you would like	○ 1	○ 2
15. Were limited in the **kind** of work or other activities	○ 1	○ 2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	○ 1	○ 2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	○ 1	○ 2
18. **Accomplished less** than you would like	○ 1	○ 2
19. Didn't do work or other activities as **carefully** as usual	○ 1	○ 2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

○ 1 - Not at all

○ 2 - Slightly

○ 3 - Moderately

○ 4 - Quite a bit

○ 5 - Extremely

21. How much **bodily** pain have you had during the **past 4 weeks**?

○ 1 - None

○ 2 - Very mild

○ 3 - Mild

○ 4 - Moderate

○ 5 - Severe

○ 6 - Very severe

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

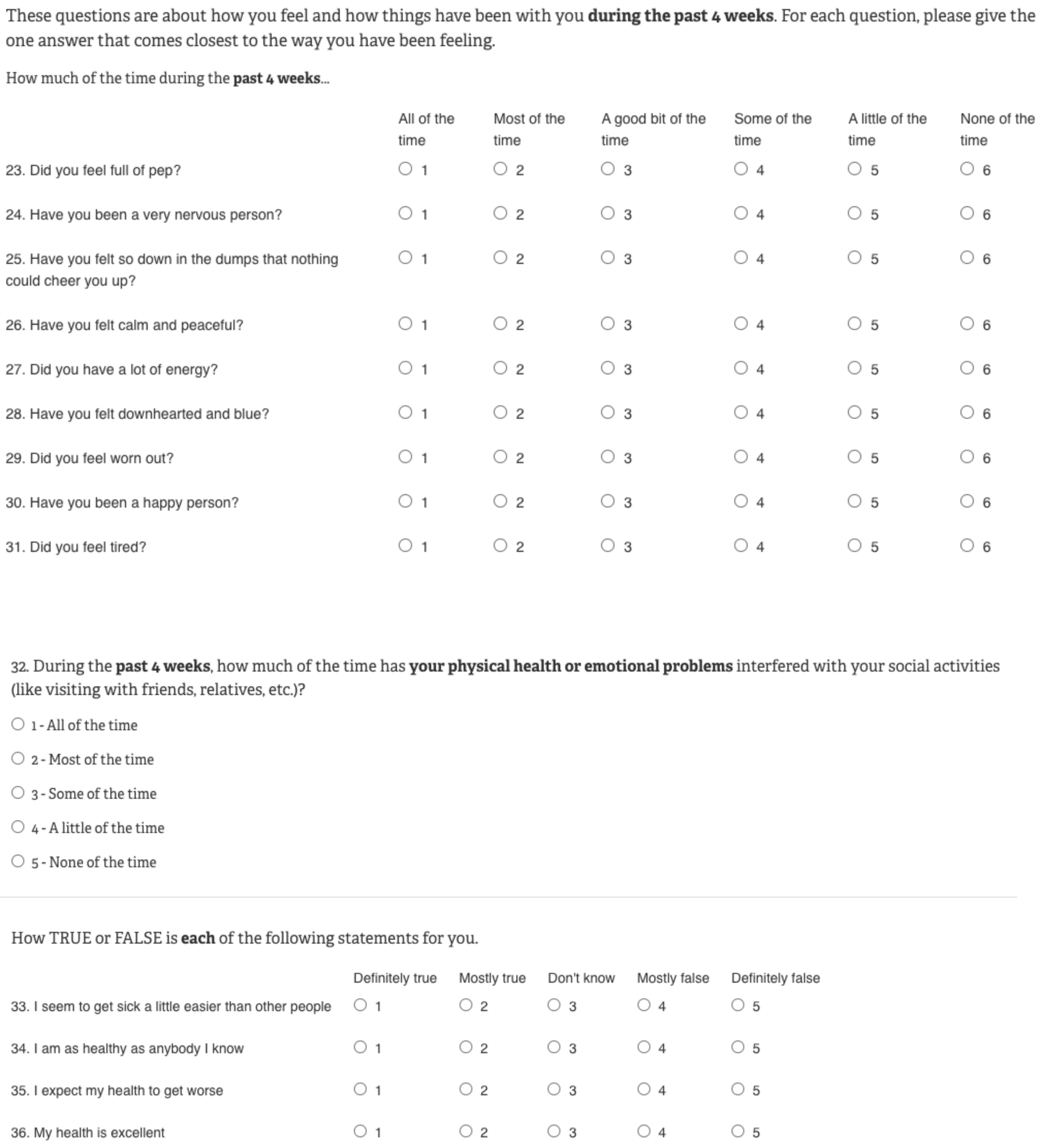
○ 1 - Not at all

○ 2 - A little bit

○ 3 - Moderately

○ 4 - Quite a bit

○ 5 - Extremely



These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23. Did you feel full of pep?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
24. Have you been a very nervous person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
25. Have you felt so down in the dumps that nothing could cheer you up?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
26. Have you felt calm and peaceful?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
27. Did you have a lot of energy?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
28. Have you felt downhearted and blue?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
29. Did you feel worn out?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
30. Have you been a happy person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
31. Did you feel tired?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6

32. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

○ 1 - All of the time

○ 2 - Most of the time

○ 3 - Some of the time

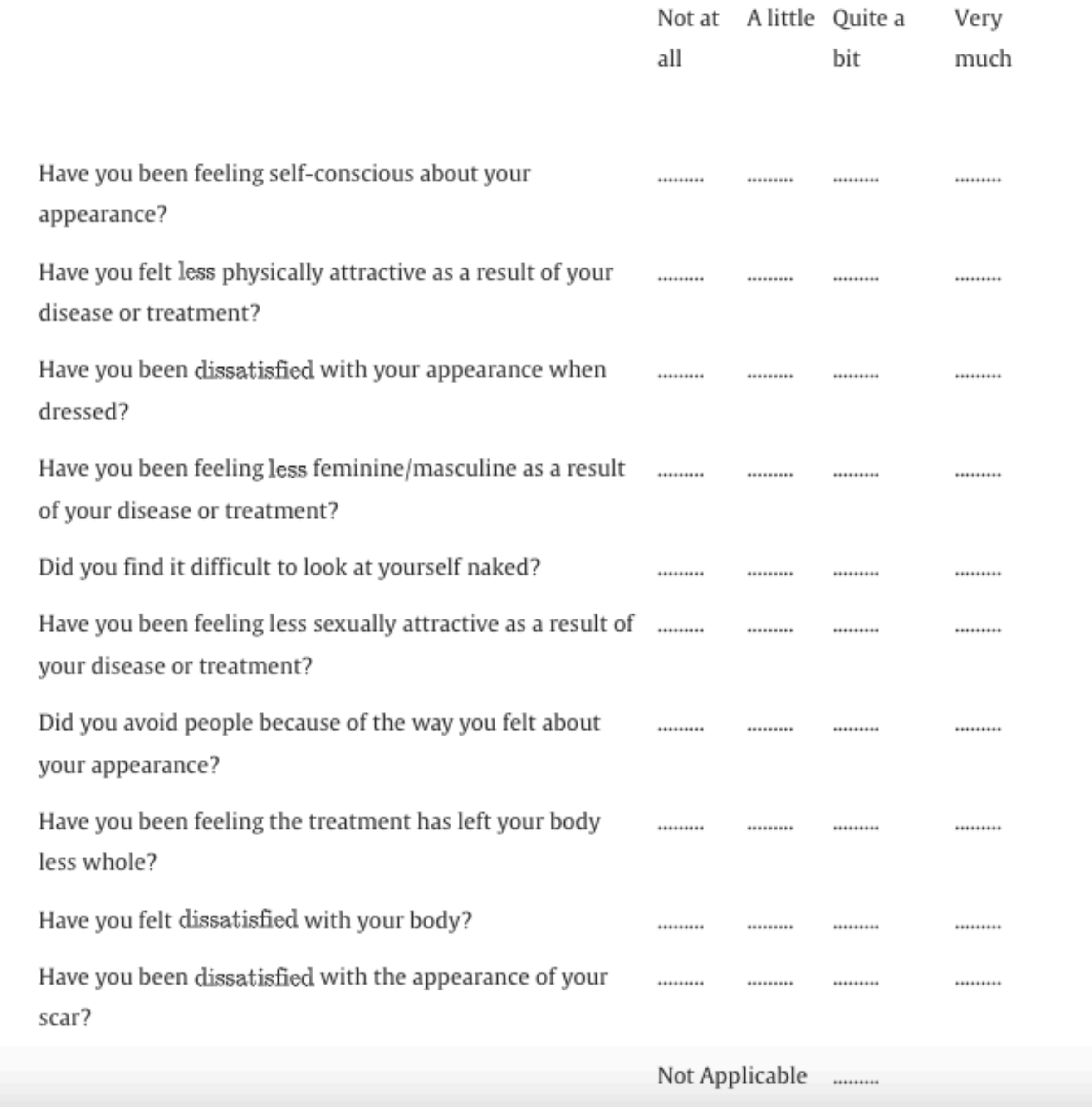
○ 4 - A little of the time

○ 5 - None of the time

How TRUE or FALSE is **each** of the following statements for you.

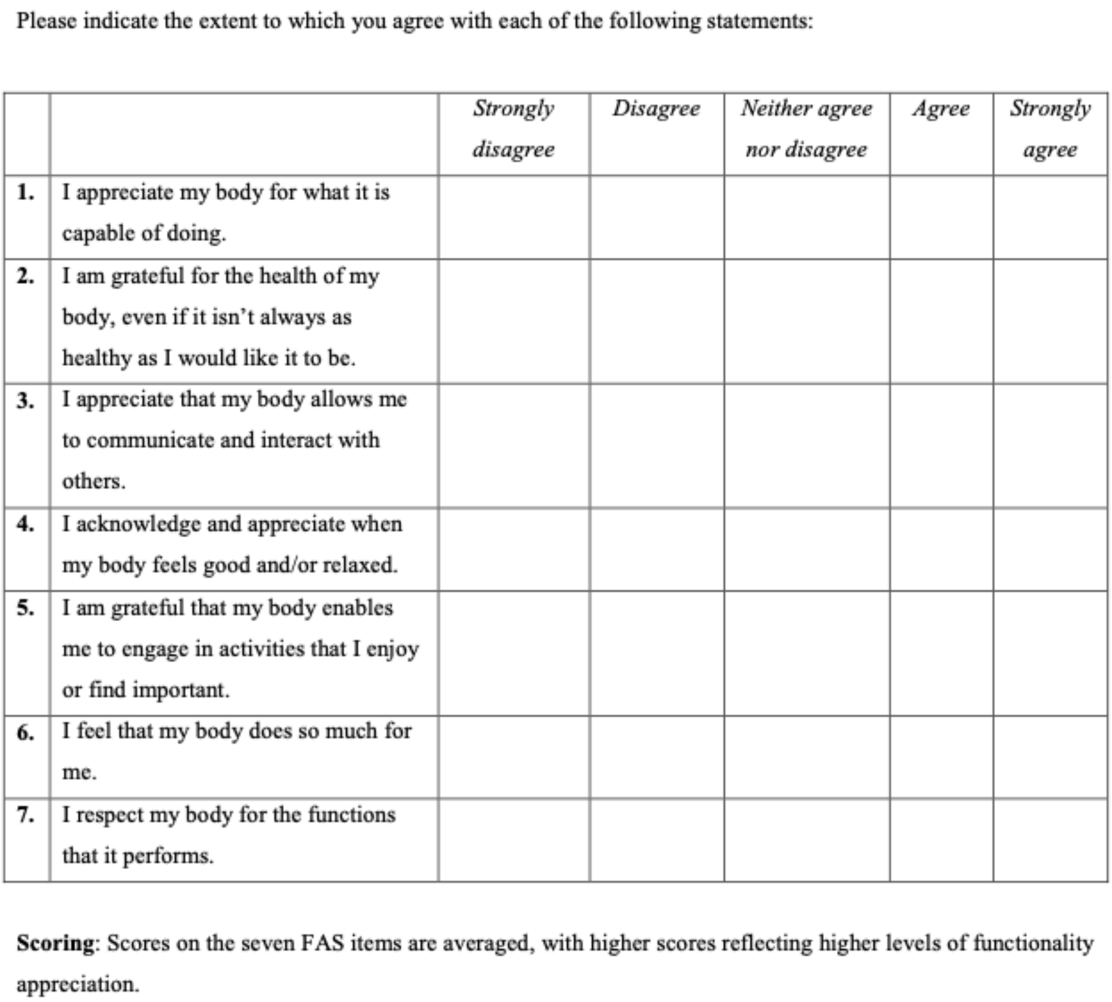
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33. I seem to get sick a little easier than other people	○ 1	○ 2	○ 3	○ 4	○ 5
34. I am as healthy as anybody I know	○ 1	○ 2	○ 3	○ 4	○ 5
35. I expect my health to get worse	○ 1	○ 2	○ 3	○ 4	○ 5
36. My health is excellent	○ 1	○ 2	○ 3	○ 4	○ 5

Appendix 6 – Body Image Scale (BIS)



	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	....	....	....	....
Have you felt less physically attractive as a result of your disease or treatment?	....	....	....	....
Have you been dissatisfied with your appearance when dressed?	....	....	....	....
Have you been feeling less feminine/masculine as a result of your disease or treatment?	....	....	....	....
Did you find it difficult to look at yourself naked?	....	....	....	....
Have you been feeling less sexually attractive as a result of your disease or treatment?	....	....	....	....
Did you avoid people because of the way you felt about your appearance?	....	....	....	....
Have you been feeling the treatment has left your body less whole?	....	....	....	....
Have you felt dissatisfied with your body?	....	....	....	....
Have you been dissatisfied with the appearance of your scar?	....	....	....	....
	Not Applicable		....	

Appendix 7 - Functionality Appreciation Scale (FAS)

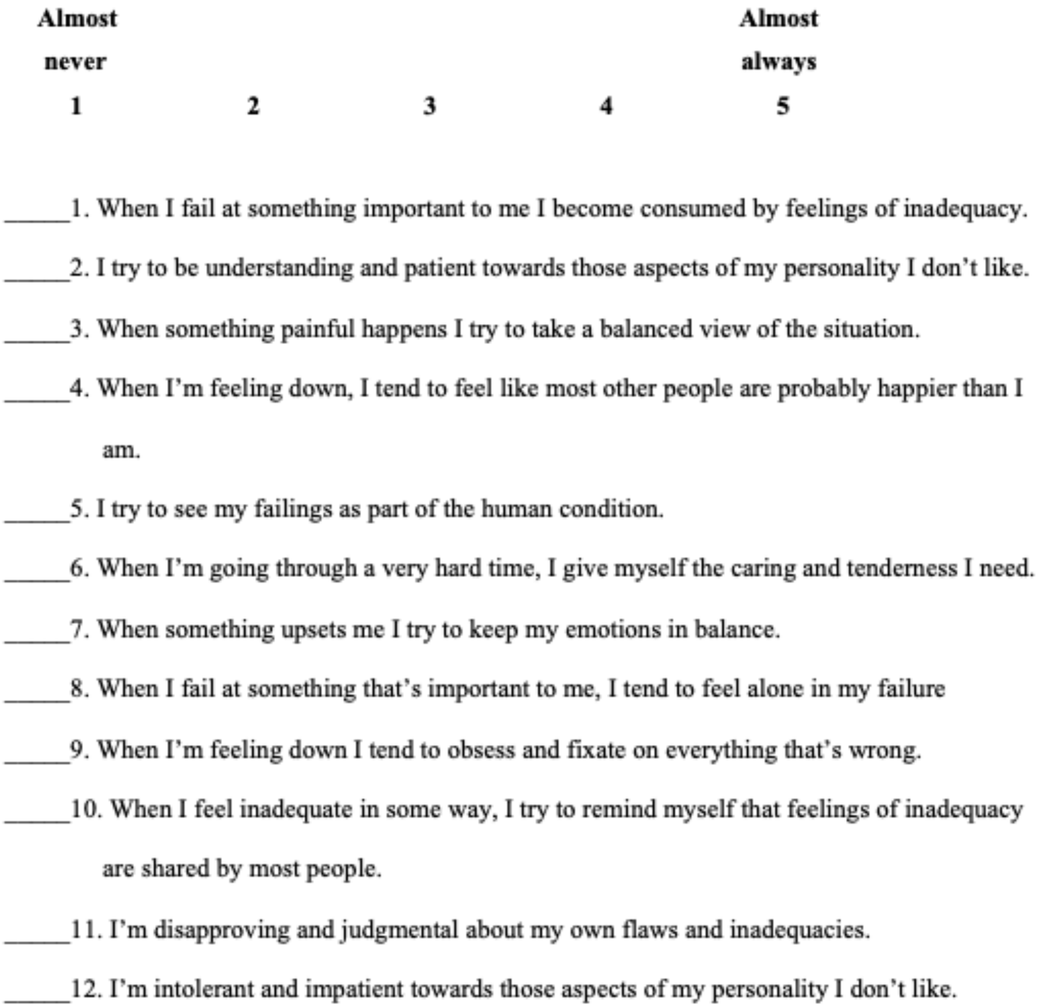


Please indicate the extent to which you agree with each of the following statements:

		Strongly disagree	*Disagree*	*Neither agree nor disagree*	*Agree*	*Strongly agree*
1.	I appreciate my body for what it is capable of doing.					
2.	I am grateful for the health of my body, even if it isn't always as healthy as I would like it to be.					
3.	I appreciate that my body allows me to communicate and interact with others.					
4.	I acknowledge and appreciate when my body feels good and/or relaxed.					
5.	I am grateful that my body enables me to engage in activities that I enjoy or find important.					
6.	I feel that my body does so much for me.					
7.	I respect my body for the functions that it performs.					

Scoring: Scores on the seven FAS items are averaged, with higher scores reflecting higher levels of functionality appreciation.

Appendix 8 – Self-Compassions Scale - Short Form (SCS-SF)



Almost never				**Almost always**
1	**2**	**3**	**4**	**5**

_____1. When I fail at something important to me I become consumed by feelings of inadequacy.

_____2. I try to be understanding and patient towards those aspects of my personality I don't like.

_____3. When something painful happens I try to take a balanced view of the situation.

_____4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.

_____5. I try to see my failings as part of the human condition.

_____6. When I'm going through a very hard time, I give myself the caring and tenderness I need.

_____7. When something upsets me I try to keep my emotions in balance.

_____8. When I fail at something that's important to me, I tend to feel alone in my failure

_____9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.

_____10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.

_____11. I'm disapproving and judgmental about my own flaws and inadequacies.

_____12. I'm intolerant and impatient towards those aspects of my personality I don't like.

Appendix 9 – Quantitative Questions

- Please create a unique participant identifier so that your personal details remain anonymous and we can still remove your data should you wish to withdraw. Please use the following format: Your initials, day of birth, first letter of your hometown (JB10Y)
- How do you define your sex-assigned-at-birth?
- How old are you?
- Where do you live? (Country/County/State)
- Are you currently pregnant?
- Have you been diagnosed with Endometriosis?
- In which part/s of your body have you been diagnosed with endometriosis? (Please select all that apply)
- How many years have you had your endometriosis diagnosis now?
- What symptoms have you observed? (Please select all the apply)
- For how many years did you have symptoms ***before getting diagnosed***?
- Have you been diagnosed with any other health condition?
- What forms of treatment have you received or used for your endometriosis during this time? (Please select all that apply)
- If you have been treated with surgery, how many have you had?
- When was your last surgery?
- In the last 4 weeks, how often because of your endo have you…? (EHP-30 Questions: 12, 13, 14, 15, 16, 17, 28, 29, 30)
- The following questions are about how you have feel emotionally. During the last 4 weeks, how often because of your endometriosis, have you... (SF-36 Questions: 24, 25, 26, 28, 30)
- The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (SF-36 Questions: 3, 4, 5, 6, 7, 8, 9, 10, 11, 12)
- How TRUE or FALSE are each of the following statements for you? (SF-36 Questions: 33, 34, 35, 36)
- How do you access the majority of the information you require to manage your endometriosis? (Please select all that apply)
- Please indicate the extent to which you agree with each of the following statements: (Functionality Appreciation Scale Questions: [all 1-7])
- During the last week, have you... (Body Image Scale Questions: [all 1-10])
- Please indicate how much you agree with the below statements. (Self Compassion Scale Questions: [all 1-12])
- Do you feel social media has had an influence on your body image?
- Have you received any support for your body image?
- Which of the following would you like to improve about your body image? (Tick all that apply)
- Which of the following do you feel would support in improving your body image? (Tick all that apply)

Appendix 10 – Qualitative Questions

- Please describe the impact of each of your symptoms, individually and collectively, on how they have made you feel about your body.
- Thinking back to ***before*** you were diagnosed, what impact did your symptoms have on how you perceive your body?
- Now you ***have*** been diagnosed, has it ***changed*** how you perceive your body? If so, how?
- How have these various treatments made you feel about your body?
- (RQ3) Do you face/have you faced any barriers to accessing information surrounding your endometriosis?
- (RQ3) How do you feel others perceive your body? E.g. Partners, friends, family.
- (RQ3) Would you change anything about your body if you could? If so, what and why?
- Do you feel social media has had an influence on body image
- (RQ3) Explain why you would like to improve the selected facets of your body image
- (RQ3) Explain why the selected method of support would improve your body image

Appendix 11 – Inductive Coding Initial Themes/Codes

Number of statements included under each code outlined in brackets

Themes	**Codes**
Functionality – Symptoms	• Bleeding • Bowel and Urinary Issues • Difficulties surrounding Sex • Digestive Issues • Exhaustion • Pain
Functionality – Practical	• Fertility • Less able to participate • Lack of control
Appearance	• Adapting clothing • Lack of confidence • Inferior as a woman • Body image changes
Sense of Self – Personal	• Fear for the future • Feel negative towards self • Feeling like a failure/body given up or broken • Feeling lonely/less lonely • Grieving previous self • Lack of connection to self • Mental health difficulties • Planning in advance
Sense of Self - Others	• Breakdown of relationships • Attitude towards clinicians and care
Empowerment	• Gratitude • Self-care • Sense of power/empowerment /strength/confidence

Appendix 12 – Copy of Published Paper

What is the evidence of effectiveness of non-pharmaceutical, non-surgical, biopsychosocial interventions for body image and pain management in individuals with endometriosis? A systematic review.

Abstract.
Aim: To identify and review the success of non-pharmaceutical, non-surgical biopsychosocial interventions in individuals with endometriosis, in managing pain and improving body image. ***Methods***: Cochrane, EBSCO, IBSS, NICE, Open Grey, OVID, Proquest, Scopus and Science Direct were searched in April 2021, using inclusion and exclusion criteria. ***Data collection and analysis***: Five randomised control trials, and one controlled clinical trial resulted from the search. Study quality was assessed using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool. Studies were synthesised by intervention type, into physical only, and physical and psychological. ***Results***: Across the six papers, 323 participants were recruited, through medical records or self-referral, and treatments largely administered by specialist practitioners. From the EPHPP quality assessment, two weak quality papers, and four moderate quality papers found improvements to pain, with large effect sizes in four papers. No studies used established body image measures to examine intervention effects on body image, and all lacked health psychology theoretical basis. There were common issues in selection bias, confounders and blinding. ***Conclusion***: Without gold-standard methodology, evidence of effectiveness cannot be concluded. However, there is promising rationale if these issues are addressed.

1. Introduction

Endometriosis is a chronic, painful condition affecting 10% of people born with female-assigned reproductive organs worldwide, and is the second most common gynaecological condition in the UK (1). Due to the subjectivity of pain, many face challenges articulating their pain severity with healthcare professionals, often leading to dismissal and prolonged diagnosis (2).

1.1. Treatment

Endometriosis is usually treated with pharmaceutical (hormonal/medicinal) and surgical treatments (3). However, cis-women report being dissatisfied with ‘conventional’ treatments received for their endometriosis, owing to persisting symptoms and lack of satisfaction with medical support (4). 61.5% of cis-women (n = 133) reported seeking naturopathic and/or complementary procedures instead (Grzanna N. et al., 2017). However, the evidence base for non-pharmaceutical, non-surgical treatments is still limited, highlighting a need for further research on their effectiveness in endometriosis. Providing options for self-management are important, given the value these provide in increasing autonomy and self-esteem (6), often damaged through dismissal or disbelief by health professionals (Cox H et al., 2003).

1.2. Current Challenges

The economic burden associated with endometriosis is estimated around £8.4 billion in the UK, with higher costs associated with increased pain presence (8), similar to diabetes (9), yet with no comparable financial or research investment. The lack of resource investment has meant despite 82% of physicians believing there is a need for those with endometriosis to receive psychosocial care, only 15% routinely refer patients for this, with 72% not feeling adequately trained to provide care for psychosocial aspects of endometriosis (10). Therefore, understanding the impact of endometriosis on people born with female-assigned reproductive organs, and increasing the evidence base of treatments is needed.

A narrative review on the effects of complementary therapies on managing the condition, and associated sexological concerns, highlighted the need for a multidisciplinary team, to support the multifaceted outcomes from endometriosis (11). There are important links between sexual functioning and body image, and greater body image perception has been found to have associated benefits related to sexual experience (12). Greater body esteem also correlated with improved psychological outcomes in those with endometriosis (13). However, interventions seeking to improve body image in endometriosis are scarce, suggesting a need to develop and understand intervention effects in this facet of the condition, for better psychological outcomes (14).

1.3. Body Image

Body image is defined as a person's perception, feelings and thoughts about their body, influenced by body size estimation, body attractiveness evaluation and associated emotions (15). Those with endometriosis may have negative body image distortions and general body dissatisfaction (16), due to scars following surgical interventions, or feeling overweight because of hormonal therapy (17). Many describe feeling 'less attractive', with their body 'not functioning as a woman's body should' (18). Dissatisfaction with one's body has been linked with disruptions to sense of wellbeing and self-compassion (19). Some see their relationship with their body as a constant struggle for control, with 34% (n=40) feeling their general appearance had been affected by the condition (20), negatively affecting self-esteem (21). Those with endometriosis also report feelings of shame and inadequacy alongside the body image concerns (22), creating a fractured sense of self in the body of the sufferer.

1.4. Pain

The relationship between the body and sense of self is further challenged in endometriosis (18), as many struggle making meaning of undiagnosed, unexplainable pain for years. Pain becoming a core part of a person's narrative identity (23), can result in further pain, suggesting the altered sense of self, can make pain experience worse in those with endometriosis (23). Pain associated with endometriosis significantly impacts psychological wellbeing (24), with reports of confusion and self-guilt from those with the condition, as though they are responsible (25). This negatively influences their beliefs that their health results from one's own doing (26). Those with endometriosis have reported their increased pain levels linked with an increased lack of familiarity with their body, possibly as a coping mechanism to distance themselves from the significant amount of pain their body faces (16). Perceiving a 'sick body' with endometriosis and its associated chronic pain can cause negative body image and general body dissatisfaction (16). Other research on chronic pain and body image suggests body appreciation can be more challenging when their body is a source of chronic pain (27), highlighting a need for interventions to target both facets, and echoing the suggestion that a one-dimensional focus may not be sufficient for advancing optimal treatment (28).

Interventions to improve both pain and body image are currently limited, but have shown promise in chronic pain patients, where multisensory feedback interventions, such as virtual reality, resulted in improvements to both body image and pain-related symptoms (29). Furthermore, increasing pain *acceptance* has been found to be effective at improving body image (27), suggesting treating one facet can influence the other. Therefore, interventions to manage pain and improve body image, need to take into account the many individual, personal challenges that come with endometriosis, reiterating the importance of treating the condition in an individualised, biopsychosocial way (22).

1.5 OBJECTIVES

There have been limited systematic reviews on the effects of complementary therapies on pain in endometriosis (30,31), and none also seeking to understand the effect of these therapeutic interventions on body image. The objectives of this review are to identify and review the methodological quality, and effectiveness of non-pharmaceutical, non-surgical biopsychosocial interventions in managing pain and improving body image in those with endometriosis.

2. MATERIALS AND METHODS

2.1. PROTOCOL AND REGISTRATION

This review was conducted in line with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) checklist and was registered with PROSPERO (ID: CRD42021245763). No information was amended after registration submission.

2.2. INFORMATION SOURCES AND SEARCH STRATEGY

Electronic databases were searched by the primary reviewer (LF), using the search criteria below. These included 9 databases, and grey literature, to counter publication bias; Cochrane, EBSCO, IBSS, NICE, Open Grey, OVID, Proquest, Scopus and Science Direct. Combinations of population ("endometriosis" and "wom?n" OR "female"), intervention ("diet*" OR "exercis*" OR "psychosocial" OR "complementary therap*") and outcome ("pain" OR "body image") were used with Boolean Operators.

2.3. ELIGIBILITY CRITERIA

To identify biopsychosocial interventions measuring pain and body image related outcomes in endometriosis, inclusion and exclusion criteria were created. Biopsychosocial is defined in this review as biological, physiological, psychological, social interventions influencing the outcome of interest, e.g. to alter physical or psychological functioning. Participants had to be females, aged over 18, with laparoscopically confirmed endometriosis, due to the high validity this has compared to medical records alone, and wide variety of symptoms presenting with the condition. Cisgender females were included due to the complex body image and identity related concerns potentially arising from the condition presenting in someone with female organs but identifying as male (32). Quantitative studies examining participants post intervention, against a comparator/control group were included. There were no date limitations. Theses, dissertations, articles, research reports and conference papers were included. Qualitative studies were excluded due to their difficulty in examining cause and effect. Studies not written in English were excluded, due to potential for misinterpretation with language translation. Studies using hormonal, medicinal, surgical interventions as the main treatment were excluded, to increase understanding of the effects of alternative treatments on symptoms and patient choice and autonomy. Studies without pain or body image as a primary outcome, e.g. endometriosis-related risk or fertility, were excluded. Studies that were not interventions were excluded, e.g. questionnaire-based studies of cis-women's experiences. Studies without pain, body image or endometriosis related scales/measures were excluded. Articles on chronic pelvic pain and primary dysmenorrhea in general were excluded due to the different way these conditions present.

2.4 STUDY SELECTION

Two independent reviewers (LF and EH) screened studies for eligibility. Zotero was used for title and abstract screening, followed by Covidence for full-text screening.

2.5. DATA EXTRACTION

The primary reviewer, LF developed and conducted a standardised data extraction protocol, reviewed by the secondary reviewer, EH. This included: reference; publication type/year; conflicts of interest; funding; study design; participant characteristics; intervention/recruitment methods; quality; outcomes/assessment tools; key findings. Missing data was obtained through request by LF, to the corresponding author of the relevant paper.

2.6. QUALITY ASSESSMENTS AND RISK OF BIAS

Eligible full-text articles were assessed for selection bias, study design, confounders, blinding, data collection methods, withdrawals and drop-outs, intervention integrity and analyses, using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (33). Quality assessment was carried out by LF, and reviewed by EH. Effectiveness was evaluated in strong quality studies. Findings from weak/moderate studies cannot signify effectiveness due to higher risk of bias, so methodology was evaluated.

2.7. DATA SYNTHESIS

Due to clinical and methodological heterogeneity, a meta-analysis was not appropriate, a common problem faced in social sciences research (34). Therefore, a narrative review was conducted, and table of characteristics (see table 1) created to display homogeneity and heterogeneity in results. Data was synthesised through grouping the studies into two groups: ‘physical only’ interventions, defined as tangible interventions delivered to the physical body, or ‘combined physical and psychological’ interventions. Interventions were considered effective if they were rated strong using the EPHPP, *and* found statistically significant improvements (*p value of <.05),* in pain or body image, against the control group. Where possible, effect sizes were calculated using Cohen’s d, using mean and standard deviation data. Effect sizes were interpreted as small d= 0.20, medium d = 0.50 and large d = 0.80 (35).

3. RESULTS

3.1. STUDY SELECTION

A total of six publications were identified from 9,101 records (five Randomised Control Trials, and one Controlled Clinical study, displayed in detail in Figure 1).

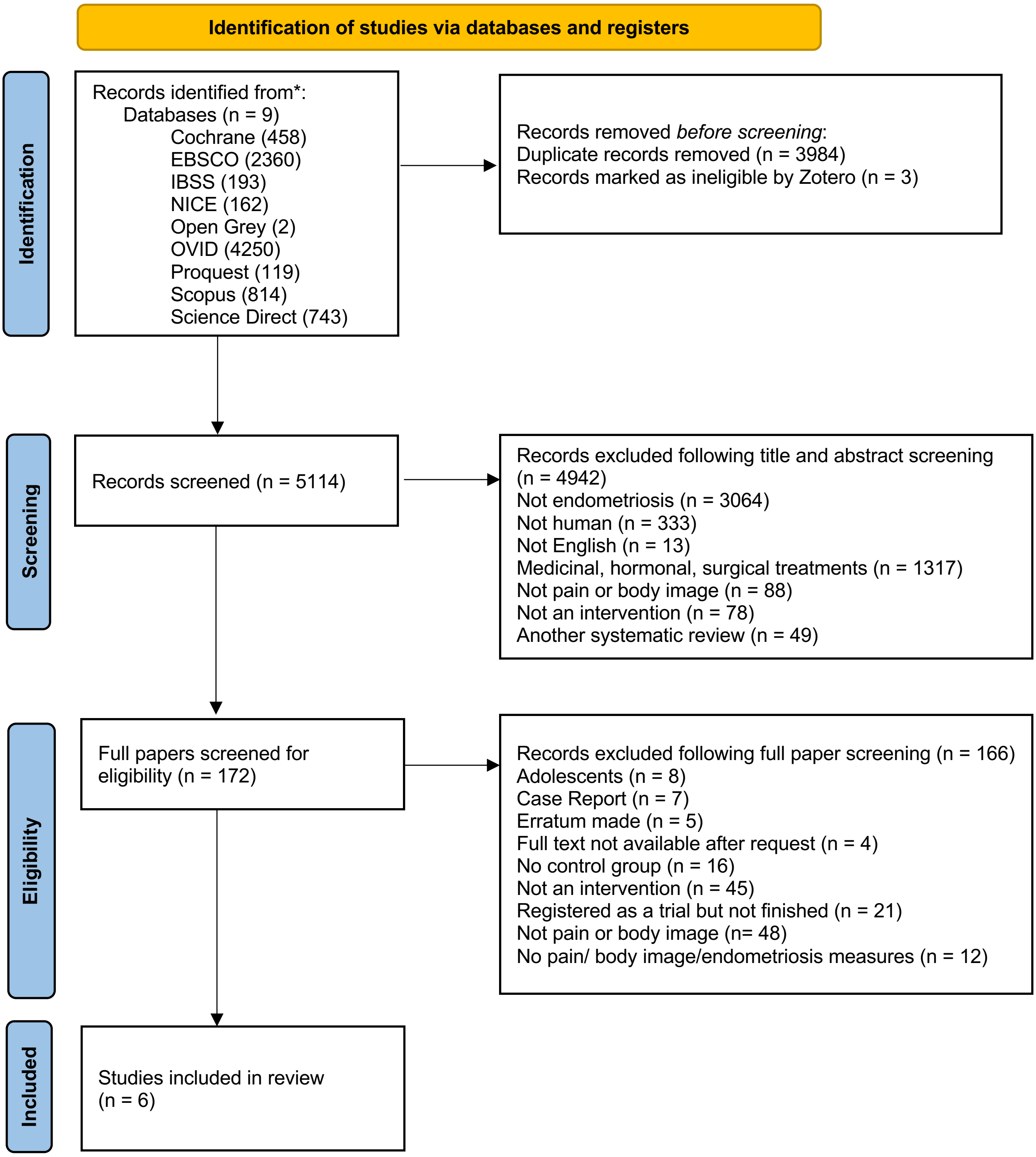


Fig 1. Flowchart of study screening – Adapted from (36)

3.2. STUDY CHARACTERISTICS

All studies included in this review were published between 2011 and 2021, and were conducted in Australia (37), Brazil (38,39), United Kingdom (40), Italy (41) and Germany (42). Details on author, publication year, location, participants, intervention type, duration, outcome measures, p-values, effect sizes (where calculated), and study quality (see below for details of assessment) are presented in table 1. All studies examined the results of the interventions on pain as a primary outcome, with none focusing specifically on body image. The only outcome measure recording variables *relating* to body image was the EHP-30, a valid, reliable disease specific endometriosis measure (43), consisting of 30 questions, with five core subscales: pain, control/powerlessness, emotional well-being, social support and self-image. No outcomes from established body image scales were reported.

3.3. SAMPLE CHARACTERISTICS

323 participants from the 6 studies included, had a mean age of 33.5 years. All were diagnosed with stage 1-4 endometriosis, and length of time since diagnosis varied from 4-12 years. Only two studies reported sociodemographic information (37,38), and in these two studies all the participants were white (n=45), apart from 4 who were of black ethnicity. Most had studied to higher level education, and were married or in a relationship. Participants were recruited via university (41), outpatient clinics (38,39) or self-referred (37,40). One study (42) did not state how participants were recruited.

3.4. QUALITY ASSESSMENT

The EPHPP tool identified two papers as weak (37,41) and four as moderate (38-40,42) (see table 1). Selection bias was the domain with the lowest ratings, with all papers rated weak (37,38,40) or moderate (39,41,42). Confounders were also an issue, with three weak (37,39,41) and one moderate rating (42). Blinding had one weak (42), and three moderate ratings (37,39,41). A strength across all papers was the use of valid, reliable tools to collect data.

3.5. OUTCOME MEASURES

Four studies (37-39,40) recorded EHP-30 results, An overall EHP-30 score was reported for papers without subscale scores. No standardised body image scales were used in any of these studies. This was instead measured with the self-image scale of the EHP-30. In addition to the EHP-30, Three studies (38-40) also recorded Visual Analogue Scale (VAS) results, an 11 point line measuring a continuum of symptom severity (44). One study used VAS (41) only. Another (42) used Numeric Pain Rating Scale (NRS) only, an 11 point numeric scale from ‘0’ (no pain) to ‘10’ (worst pain imaginable) (45). Both the VAS and NRS are widely used to measure pain and its related intensity, and best adapted for endometriosis pain measurement (46).

[insert Table 1 here]

3.6. INTERVENTION CHARACTERISTICS - SYNTHESIS OF RESULTS

The six studies included in this review were grouped by intervention focus; examining overall effects of physical interventions, and combined physical and psychological interventions. No effect sizes were reported, but were calculated where possible (37-40,42) (see table 1).

3.6.1.PHYSICAL ONLY

INTERVENTION

Four studies (total n=216), investigated the effects of physical interventions in endometriosis; acupuncture (37,38), Chinese Herbal Medicine (CHM) (40) and Dietary Supplementation (41). Two were feasibility studies (37,40), three were randomised control trials (37,38,40), and one was a controlled clinical trial (41). Interventions were conducted in hospital (38) and private clinic settings (37,40), delivered by specialist practitioners (e.g. physiotherapists (38), Chinese Medicine Practitioners (37,40), or the patient (40). Location and intervention delivery method were not stated in one study (41), and unattainable upon request. Interventions ranged from five (38) to sixteen (40) weeks, with treatment frequency ranging from five (38) to sixteen treatments (37). Session duration ranged from 25 (37) to 40 minutes (38). Supplements were provided for consumption twice a day (40,41). Control group participants were offered placebo treatments (38,40) or asked to continue their usual care (37,41). In one study (37), participants were permitted to use other therapies, e.g. physiotherapy/massage/nutrition, at the same time as receiving the intervention, potentially influencing results. One study conducted an intention to treat analysis (37).

OUTCOMES

None of the four physical intervention studies were assessed as strong quality, therefore the results, whilst promising, must be interpreted with caution. One study (41) did not report statistics, so there was not enough detail to report effect size. One weak study (37) found significant large effect sizes in pain outcomes (d=1.2, p=.01), with smaller effect sizes in self-image (d=0.29, p=.05). One moderate study (38) found significant large effect sizes in overall EHP-30 (d=2.3, p<.001) and VAS (d=1.81-2.14, p<.001) outcomes. Another moderate study found small effect sizes for EHP-30 (*d=0.03-0.16)*, but larger effect sizes for VAS outcomes (d=0.3-0.54) (40).

EHP-30

Three studies recorded EHP-30 results (37,38,40), with improvements in the intervention groups in all EHP-30 domains. Significant, yet weak evidence resulted from one acupuncture study for improvements in pain (p=.01*)* and self-image (p=.05*)* (37). Despite initial improvements in the control group, these were not maintained. The moderate quality studies resulted in significant evidence for overall EHP-30 improvements *(*p<.001*)* following acupuncture (38), and clinically important changes following CHM in all domains of the EHP-30 (> 0.5 point change) (40). There was moderate evidence of small improvements in both control groups provided with placebo treatments (38,40), however placebo treatments in CHM are often physically identical to non-placebo treatments (47).

VAS/NRS

Improvements to pain scores were reported in the intervention group of all studies. Significant, yet weak evidence showed improvements to pain (p<.001) in studies of acupuncture (37) and dietary supplementation (41). The control groups of these weak studies reported increased pain through placebo use (41), and usual pharmaceutical care, although results were not significant (p=.08) (37). Moderate evidence showed significant improvements to pain scores in another acupuncture study (p<.001) (38), and clinically relevant changes in period pain (31.5%), and pain on intercourse (55.2%) following CHM (40). The control groups of both moderate studies were provided placebo treatments (38,40) which showed initial improvements but were not maintained after two months (38).

SUMMARY OF PHYSICAL INTERVENTIONS

The weak quality of two studies (37,41) precludes their influence in the appraisal of effectiveness and reliability in wider application. Acupuncture (38) and CHM (40) provide moderate evidence of effectiveness of physical interventions offering improvements to pain management and body image. Weaknesses were identified in selection bias, lack of sociodemographic variability, and confounders in participants. One study conducted an ITT analysis (37) suggesting there is promise in the rationale of this, and the other studies in this review if the above methodological issues are addressed.

3.6.2. COMBINED PHYSICAL AND PSYCHOLOGICAL INTERVENTIONS

INTERVENTION

Two studies (total n=107) investigated mind-body interventions in endometriosis; yoga (39) and psychotherapy with somatosensory stimulation (acupuncture point stimulation) (42). They were both randomised control trials (39,42) conducted in outpatient settings, utilising a gynaecologic practice (42), and delivered by specialist practitioners, in traditional Chinese medicine (42), psychosomatic medical specialists (42), and qualified yoga instructors (39). The experimental group interventions ranged from eight (39) to twelve (42) weeks, with an average of eight (42) to sixteen sessions (39). Session duration ranged from 60 (42) to 120 minutes (39). The control groups received the same treatment as the intervention after a three month wait (42), or standard care and one physical therapy session each week (39). As found in the physical interventions, only one study conducted an intention to treat analysis (42).

OUTCOMES

Both studies were moderate quality, so the above methodological considerations should be accounted for before conclusions on their effectiveness can be made. In one study (39), significant large effects were found for pain (d=1.04, p=.0046) but small effects for self-image (d=.08, p=.0087). In the other study, significant large effect sizes for pain were found at 3 months (d=0.87-1.18, p<.001) (42). However, effect sizes reduced over the 3-24 month follow ups (d=0.36-33)(42).

EHP-30

In the yoga group, statistically significant improvements were found over time in most of the core EHP-30 domains, including pain (p=.0046*)* and self-image (p=.0087*)*. EHP-30 improvements were also observed in the control group, however they were offered physical therapy. The study also found that improving one domain may have affected other domains, e.g. having more control, potentially improving self-image, again highlighting the importance of targeting multiple facets of endometriosis (27).

VAS/NRS

Significant reductions in VAS pain scores were observed in the yoga group, compared with cis-women in the control group (p<.001), whose pain tended to increase (39). However, retrospective ratings were used which may lead to recall bias. The psychotherapy study observed NRS scores reduce to a clinically significant amount (p<.001)(42).

SUMMARY OF COMBINED PHYSICAL AND PSYCHOLOGICAL INTERVENTIONS

Yoga (39) and psychotherapy (42) provide moderate evidence of effectiveness, of combined interventions offering improvements to pain management and body image in endometriosis. Weaknesses were identified in selection bias, blinding, confounding and withdrawals. As both combined physical and psychological interventions were delivered face to face, adaptations may need to be considered in future, as this may have impacted dropout rates.

4. DISCUSSION

The aim of the current review was to describe and compare quality and effectiveness of non-pharmaceutical, non-surgical biopsychosocial interventions, in reducing pain and improving body image in those with endometriosis. All the studies examined pain management as a primary outcome, but despite the known impact of endometriosis on body image, no interventions measuring body image, using body image specific scales, were identified. The review considered a wide range of interventions, and six studies resulted from screening.

4.1. DISCUSSION OF STUDIES

4.1.1. SAMPLE CHARACTERISTICS

The samples participants were not representative of wider sociodemographic populations, reducing their external validity. Research on the impact of ethnicity on endometriosis treatment accessibility is scarce (48). Those from lower income or limited educational backgrounds (49) have less access to care for chronic pain, and those from lower socio-economic backgrounds feel health professionals are less likely to take their complaints seriously (50). This highlights a necessity for increased research on treatment choice, availability and accessibility in different sociodemographic variables.

It is not clear from the studies if observed effects would differ dependent on length of diagnosis, or disease severity. There is a risk of spectrum bias from the current studies, as all participants have diagnosed, symptomatic endometriosis. The impact of such interventions on those with symptoms, without an endometriosis diagnosis, needs consideration.

4.1.2. QUALITY

The interventions showed promising rationale for pain management, but their lower quality meant the evidence of effectiveness could not be affirmed. This corresponds with findings of another systematic review on complementary treatments in pain management in endometriosis, which also identified complementary treatments alleviated symptoms, but higher quality studies were required to confirm their effectiveness (49).

Using the EPHPP to examine quality, common weaknesses identified were selection bias, blinding and confounders. The moderate studies had weak ratings in one of these domains (38-40,42). Weak studies had low ratings in at least two of these domains (37,41). Participants were mainly recruited from clinics or self-referred. Issues surrounding selection bias and confounders is a common issue identified within the endometriosis population, due to the many sociodemographic and diagnostic differences surrounding the condition (51). People born with female-assigned reproductive organs self-referring, particularly from self-help groups, may present with more treatment-resistant disease than broader groups of people receiving conventional treatment (52), potentially due to their scepticism and mistrust of doctors, whose expertise on the condition they doubt (53). Furthermore, the complex process of diagnosis may impact recruitment of participants representative of the wider endometriosis population, as it does not account for those with symptoms but without diagnosis. Most studies reduced this bias by randomising participants to groups, but future studies would benefit from stratification, or minimisation, to equalise allocation proportions across groups. Blinding of care providers, outcome assessor and participants was also a weakness, risking detection and reporting bias. In future, where ethically and logistically possible, allocation concealment should be conducted. Lastly, confounding variables such as sociodemographic factors were not always reported, making it unclear whether groups were equally balanced at baseline, and unclear if there were differing outcomes for each demographic. Stratification or matching would benefit future studies to prevent issues around confounding. Dropout rates and subsequent disproportionate allocation of participants was an issue with two studies (37,40). One study was a feasibility study (37), so this did not affect planned analysis, but a fully powered study is required before conclusions about its effectiveness can be drawn. Participants could be stratified by disease severity to reduce issues surrounding confounding variables. Intention to treat analyses could also reduce this issue (40). Adding extra participants in the control group could reduce attrition bias, as it accounts for potential drop out due to lack of treatment.

4.1.3. INTERVENTION

Most of the interventions included were delivered face to face, something now more challenging due to the ongoing Covid-19 pandemic. There has since been increased acceptability towards telehealth, not only minimising geographic barriers, but also improving accessibility for those with limited ability to travel to healthcare settings due to their endometriosis pain (54). Therefore, adaptations may need to be made to current delivery methods, with increasing virtual delivery options where possible. This may reduce withdrawals and dropouts, an issue often faced in similar literature (55).

4.1.4. OUTCOMES

Effect sizes could not be calculated for one study (41). One weak study (37) reported small to large effect sizes (d=0.29–1.2), and the moderate studies (38,39,40,42) also reported small and large effect sizes (d=0.55–2.3). Larger effect sizes were reported for pain-related outcomes, compared with self-image outcomes, suggesting a stronger relationship between the interventions and their effects on pain than self-image. However, as two studies were of weak quality (37,41), and four of moderate quality (38-40,42), despite promising rationale, their effectiveness cannot be confirmed.

EHP-30

Four studies used the EHP-30 to gather outcomes (37-40). All showed statistically significant improvements. Acupuncture (38), CHM (40) and yoga (39) provided moderate evidence that these interventions offer promise in improving ‘pain management’ and ‘self-image’ in endometriosis. Acupuncture had a total EHP-30 score, not subscales, but showed significant overall improvement (p=<.001). Subscale scores for pain were significant in yoga (p=.0046) (39) and clinically important in CHM (> 0.5 point change) (40). Subscale scores for self-image were significant in yoga (p=.0087) (39) and clinically important in CHM (> 0.5 point change) (40).

VAS/NRS

All studies showed improvements to pain levels on VAS/NRS scales (37-42), indicating the positive effects of such interventions. Acupuncture (38), CHM (40), yoga (39) and psychotherapy (42) provided moderate evidence that these interventions offer promise in improving pain management in endometriosis. Clinically relevant reductions were reported for period (31.5%), and intercourse pain (55.2%) in the CHM study (40), global pain in the psychotherapy study ($p<.001$)(8), and reductions in pain in acupuncture ($p<.001$) (38), and yoga ($p<.001$)(39). However, the science and methodology behind these studies was not strong, therefore findings should be taken with caution.

Outcomes and their statistical significance were not all reported, with statistical analysis plans omitted in one study (41). No studies reported effect size, and not all provided enough detail for it to be calculated either. Many lacked confidence intervals, suggesting a lack of statistical rigour, a challenge frequently observed in social science research (52).

Furthermore, Intention To Treat approaches should be used to account for missing data in the studies, and all patients included for randomisation accounted for when reporting the results. This is more reflective of a practical clinical scenario, accounting for deviation from the protocol and non-compliance, providing less biased estimates of treatment effects. Without this, the effects found are conflated. In endometriosis research, this approach can be useful to negate frequent issues surrounding high drop-out (70). Future research would benefit from including data on those just assessed for eligibility, to increase generalisability of trials.

4.2. LIMITATIONS

There were limitations to the review processes. To examine effects against control groups, only quantitative research was included. However, exploratory research on thoughts and feelings of participants may add useful insight into the intervention, and outcomes. The yoga study (39) conducted a complementary qualitative study (56)**,** where themes were established on participant's expectations, physical/emotional state, pain management, and acquisition of self-knowledge. Participants did not refer to body image, focusing instead on pain management. However, it highlights a more comprehensive understanding that can be gained on the impact of interventions when a range of research methods are used.

The EPHPP Quality tool used in this review assessed internal and external validity of evidence. Overall intervention integrity, rating how many participants received the exposure of interest, and appropriateness of analysis, whilst documented, does not contribute towards the global rating of the papers. This risks the quality and effectiveness of assessed interventions being overstated.

4.3. IMPLICATIONS

4.3.1. PRACTICE AND POLICY

This systematic review built on the previous narrative review on complementary therapies and sexological concerns in endometriosis (11), examining effectiveness of interventions on additional endometriosis facets, pain and body image. There were more randomised control trials available, and this review included only human participants, making findings more transferrable, as the previous review included animals. The results of this review could be considered alongside reviews of the effectiveness of surgical/pharmaceutical treatments. However, there remains a need for more high-quality studies in this field of research. This echoes earlier findings that lack of investment in the health of people born with female-assigned reproductive organs, has resulted in less being known about conditions affecting only these individuals, and the impact of such conditions (20).

4.3.2. FUTURE RESEARCH

The searches showed no papers examining the influence of social interventions in pain and body image, highlighting an area currently lacking in research and would benefit from additional focus in future. There was also limited evidence available from the included interventions to conclude the effects on *body image*. The self-image domain of the EHP-30 included questions on body appearance, confidence and clothing. However, the interchangeable use of self-image and body image terminology in the literature presents an issue when interpreting results and drawing conclusions. There are over fourteen terms used to describe body image dimensions (57), so describing the body image dimension to be investigated and targeted by the intervention is key (58). This review defined body image as individual perceptions surrounding body size, attractiveness and associated emotions. Therefore, EHP-30 questions met the outcome of interest. However, future research with established, psychometrically strong body image scales, e.g. Body Image Scale (BIS) or Body Appreciation Scale (BAS) (59), is required to understand the body image dimensions in need of further investigation and intervention. More qualitative interventions are also required, to increase understanding of the impact and experiences of interventions on body image and pain, to increase patient choice.

Adapting interventions to be delivered remotely, particularly during the Covid-19 pandemic, is a priority, to increase patient choice, and offer solutions for accessibility (52). This would require acceptability and feasibility trials first, but could enable wider demographics of participants to be included in research, potentially targeting existing challenges surrounding selection bias and confounders, found in this review. Remote delivery may also reduce issues around blinding, as demonstrated in studies utilising online intervention software (60). To advance optimal treatment for endometriosis, research could benefit from examining intervention effects on multiple facets of endometriosis (12), as research that does so, is still lacking.

There is also an absence of health psychology theoretical basis in the current literature. The COM-B model (61) considers the knowledge, capability, barriers, facilitators and motivators to making change. Therefore, creating interventions based on established health psychology models and theories could increase the likelihood of addressing psychological, behavioural and cultural factors potentially influencing health-related outcomes and quality of life of those with endometriosis.

5. CONCLUSION

Of the six biopsychosocial interventions included in this review, there were no strong quality papers on interventions using Acupuncture, Chinese herbal medicine, dietary supplementation, yoga and psychotherapy with somatosensory stimulation. Therefore recommendations based on intervention effectiveness cannot be made. To draw stronger conclusions on intervention effects on body image, future studies could benefit from using psychometrically tested valid and reliable standardised body image measures. Stronger quality evaluations, large enough to be suitably powered, with participants from wider demographics, and more specific outcome measures are required. Increased emphasis on health psychology theory, is also necessary to determine the effectiveness of these treatments on both pain and body image.

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Appendix 13 – Ethics Application

Section 1: Applicant Details	
First Name	Anonymised for thesis submission
Last Name	Anonymised for thesis submission
Faculty	HAS
Department	Health Psychology
Co-researcher Names (internal and external) Please include names, institutions and roles. If there are no co-researchers, please state N/A.	Click or tap here to enter text. N/A
Is this application for a staff or a student?	Student

Section 1:1 UG and PGT Student Applications (only) See Section 1:2 for Doctoral Students	
Student Course details	Choose an item.
Name of Supervisor	Click or tap here to enter text.

1. For UG and PGT students, the supervisor **must justify** why this is a high-risk project. Failure to do so will result in the application being returned.

2. Students **should only be undertaking high-risk research in exceptional circumstances**.

The Supervisor should also consider:

Supervisors should ensure that all of the following are satisfied before the study begins:

- The topic merits further research;
- The student has the skills to carry out the research;
- The participant information sheet is appropriate; and procedures for recruitment of research participants and obtained informed consent are appropriate.

3. The FREC/RESC can only consider an application from an undergraduate or postgraduate taught student if it is **justified as high risk.**

The supervisor **must add comments** to justify high risk in the text box below

Click or tap here to enter text.

I confirm that I have assessed this project as high risk and requiring full ethical review	**Yes/No**

Section 1:2 Postgraduate Research - Doctoral students

All doctoral student research involving human participants and human tissue requires ethical review.

Evaluation studies with human subjects or research using identifiable personal data also require ethical review (even if they are exempt from review by an NHS Research Ethics Committee).

Director of Studies – Professor Diana Harcourt

Please insert your comments in support of this application.
You do not need to justify if it is high/low risk.

I fully support this application. (Anonymised for thesis submission) has discussed this in detail with her supervisory team and we are confident she has the necessary skills and connections with relevant support organisations needed to conduct a thorough and novel study with clear outcomes that could be of significant benefit to people affected by endometriosis.

Section 2: Project

Section 2:1 Project details

Full Project Title	
Examining the acceptability of a self-led psychoeducational resource in improving body image in individuals with endometriosis	
Project Dates These are the dates for the overall project, which may be different to the dates of the field work and/or empirical work involving human participants.	
Project Start Date	01/04/2022
Project End Date	01/09/2023
Dates for work requiring ethical approval You must allow **at least 6 weeks** for an initial decision, plus additional time for any changes to be made.	
Start date for work requiring ethical approval	01/06/2022
End date for work requiring ethical approval	01/03/2023
How is the project funded? (e.g. externally, internally, self-funded, not funded – including scholarly activity) Please provide details including the PIMS reference number where applicable.	
Self funded	
Is external ethics approval needed for this research?	No
If Yes please provide the following: For NHS Research please provide a copy of the letter from the HRA granting full approval for your project together with a copy of your IRAS form and supporting documentation, including reference numbers. Where review has taken place elsewhere (e.g. via another university or institution), please provide a copy of your ethics application, supporting documentation and evidence of approval by the appropriate ethics committee.	
Click or tap here to enter text.	

Section 2:2 Project summary

Please provide a concise summary of the project, including its aims, objectives and background. (maximum 400 words)

Please describe in non-technical language what your research is about. Your summary should provide the committee with sufficient detail to understand the nature of the project, its rationale and ethical context.

Endometriosis is a chronic condition affecting 10% of women worldwide, and is the second most common gynaecological condition in the UK (Endometriosis UK, 2022). Women with endometriosis have been found to have negative body image, and higher levels of self-criticism (Geller et al., 2021). However, interventions addressing this in endometriosis are scarce, suggesting a need to develop and understand the effects of multidisciplinary psychosocial interventions in this facet of the condition, for better psychological outcomes (Rush et al., 2019).

This research proposes the delivery of two parts. The first is an online survey for individuals with the condition, to gather information on what these individuals would benefit from additional support with, regarding their body image. The findings of this survey will inform the second part which will be the creation of a self-led psychoeducational resource, co-created with women with endometriosis, based on the feedback received from the questionnaire. The resource would then be delivered to individuals with endometriosis, as part of an acceptability study.

Full consent will be obtained from all participants before the study begins, obtained via Qualtrics, with the right to withdraw at any time. All data will be anonymous, unless opting into participation in the discussion, for feedback on the resource. In this case, protection and privacy of these participant's data will be prioritised, adhering to the Data Protection Act (1998). Participants will not be subjected to harm, and will be treated with dignity and respect throughout, as it is recognised that this could be a sensitive and emotive issue. Therefore, participants will also be signposted to the Endometriosis UK website as a potential further support for the condition. The research will also abide by all ethical frameworks and guidance for Endometriosis UK. All affiliations and conflicts of interest will be declared, and any conclusions drawn at the end will be presented in a non-biased way.

References

Endometriosis UK. (2022). *Endometriosis information hub | Endometriosis UK*. Www.endometriosis-Uk.org. https://www.endometriosis-uk.org/endometriosis-information-hub

Geller, S., Levy, S., Ashkeloni, S., Roeh, B., Sbiet, E., & Avitsur, R. (2021). Predictors of Psychological Distress in Women with Endometriosis: The Role of Multimorbidity, Body Image, and Self-Criticism. *International Journal of Environmental Research and Public Health*, *18*(7), 3453. https://doi.org/10.3390/ijerph18073453

Rush, G., Misajon, R., Hunter, J. A., Gardner, J., & O'Brien, K. S. (2019). The relationship between endometriosis-related pelvic pain and symptom frequency, and subjective wellbeing. *Health and Quality of Life Outcomes*, *17*(1). https://doi.org/10.1186/s12955-019-1185-y

What are the research questions the project aims to answer? (maximum 200 words)

The aims of this research are:

- To understand body image-related support needs and preferences for those with endometriosis
- To understand how those with endometriosis would like to receive body image-related support
- To ascertain the acceptability of a psychoeducational resource, with body image as a core focus, for individuals with endometriosis

To do this, the objectives of this research are to:

- Conduct a survey of body image amongst individuals with endometriosis. (This will involve gathering PI feedback on the questionnaire before disseminating it through routes including

- via Endometriosis UK)
- Using the results of the survey, co-create a psychoeducational resource on body image
- Gather feedback on the acceptability of the resource through PPI feedback

Please describe the research methodology for the project. (maximum 250 words)

Design: A mixed methods investigative study will be conducted. Eligible women will be asked to complete an online qualitative and quantitative survey, via Qualtrics. Using the data collected, the researcher and a small group of volunteers for Endometriosis UK will participate in the co-creation of a resource via Microsoft Teams, to target some of the challenges identified. Feedback on the acceptability of the subsequent resource created will then be gathered from those who agreed to participate in further research.

Survey and measures: Feedback will be gathered on a draft questionnaire, prior to dissemination, to ascertain it's acceptability from 5 women diagnosed with endometriosis, volunteering for Endometriosis UK. If necessary, the questionnaire will then be edited in response to their feedback. The study will be promoted via Endometriosis UK, the Centre for Appearance Research and social media, including a link to the online survey. The survey will gather quantitative data from established body image scales. Open questions will enable participants to provide qualitative feedback on their experiences of body image and endometriosis, and thoughts on what would be useful in a body image resource. Using the feedback from the survey, this resource will then be co-created with the researcher, and the 5 volunteers for Endometriosis UK, via Microsoft Teams. A short survey (~5-6 likert scale questions) will then be disseminated via Qualtrics to those who agreed to participate in further research, to gather feedback on the resource once created, to understand how helpful they found the resource to be, how easy it was to read, and an open box for further comments. By conducting all data collection online, it enables wider participation across geographical locations, particularly in a population suffering from chronic pain, where face to face contact may be more physically challenging.

Section 3: Human Participants

Does the project involve human participants or their tissue or data? *If not, please proceed to Section 5: Data Collection, Storage and Disposal, you do not need to complete sections 3-4.*	Yes

Section 3.1: Participant Selection

Who are your participants?

Individuals with endometriosis. To be eligible in the participant sample, they will need to be 18+.

Please explain how you will select your participant sample.

Participants will be recruited through advertisements for the opportunity to be involved in research, sent out via Endometriosis UK, the Centre for Appearance Research and social media, both from personal accounts and the social media pages of Endometriosis UK and CAR. They will then have the opportunity to sign up via a form created in Qualtrics.

Please explain how you will determine the sample size.

The research aims to get 250 participants to answer the questionnaire, and 5 for additional feedback, based on previous research by Jones et al., (2006), who disseminated the Endometriosis Health Profile questionnaire to participants at outpatient clinics and The National Endometriosis Society (NES). They found high data completeness in response to this questionnaire, therefore due to the number of members within Endometriosis UK and CAR, the number of participants proposed should be reasonable.

Please tell us if any of the participants in your sample are vulnerable, or are potentially vulnerable and explain why they need to be included in your sample.

NB: Please do not feel that including vulnerable, or potentially vulnerable participants will be a bar to gaining ethical approval. Although there may be some circumstances where it is inappropriate to include certain participants, there are many projects which need to include vulnerable or potentially vulnerable participants in order to gain valuable research information. This particularly applies to projects where the aim of the research is to improve quality of life for people in these groups.

Vulnerable or potentially vulnerable participants that you **must** tell us about:

- Children under 18
- Adults who are unable to give informed consent
- Anyone who is seriously ill or has a terminal illness
- Anyone in an emergency or critical situation
- Anyone with a serious mental health issue that might impair their ability to consent, or cause the research to distress them
- Young offenders and prisoners
- Anyone with a relationship with the researcher(s)
- Frail elderly

Click or tap here to enter text.

Section 3.2: Participant Recruitment and Inclusion

How will you contact potential participants? Please select all that apply.

☒ Advertisement
☒ Emails
☐ Face-to-face approach
☐ Post
☒ Social media
☐ Telephone calls
☐ Other
If Other, please specify: Click or tap here to enter text.

What recruitment information will you give potential participants?
Please ensure that you include a copy of the initial information for participants with your application.

Individuals interested in participating, will be able to access a summary of what the study is about, with a Qualtrics link to access the survey. The first page of the Qualtrics survey will provide the information sheet, with additional detail, providing context for the need for the research, the aims of the research itself, and how their participation will help develop this. The sheet will provide enough information so that participants are informed with what they are signing up to, including detail on data management and publication information. The lead researcher will also add their contact details (UWE Student email address) so if there are any additional questions prior to the study, these can be asked, so participants are as informed as possible before consenting.

How will you gain informed consent from the participants?
Please ensure that you include a copy of the participant information sheet and consent form with your application. Where written consent is not taken, please advise on how consent is obtained with a justification where appropriate.

An email will be put out by Endometriosis UK and the Centre for Appearance Research to their database of women who have consented to being sent information about studies. A social media post will also be put out by Endometriosis UK and the Centre for Appearance Research, as well as through the researcher's own social media channels. For the questionnaire, participants will have to read and confirm that they are giving their consent before continuing. This will be built into the

Qualtrics questionnaire produced. Once participants have completed the survey, there will be a question at the end asking if they would be interested in hearing about the next phase. This involves providing feedback on a co-created resource to help women with endometriosis, and if interested, they will be asked to provide their email address.
What arrangements are in place for participants to withdraw from the study?
Participants will be reminded at the start that their participation is voluntary, and they have the right to withdraw from the study at any time during data collection, and up to 4 weeks after the completion of the survey. By asking participants to set up their own participant identifier via Qualtrics, this enables easy subtraction of their data should they wish to withdraw. For the questionnaire, participants will not be able to continue with the survey until they have confirmed that they understand their right to withdraw, through the use of the Qualtrics software. All other questions will be voluntary, and participants will not have to answer anything they feel uncomfortable with. For the resource co-creation, participants will be asked to sign an emailed copy of the informed consent form prior to participation, which will also detail their right to withdraw.

Section 4: Human Tissue	
Does the project involve human tissue? For further information, see https://www1.uwe.ac.uk/research/researchgovernance/resourcesforresearchers/humantissue.aspx	***No***
If you answer 'No' to the above question, please go to Section 5	
I confirm that I have read the UWE Human Tissue Quality Management System	*Choose an item.*
Institution acting as Sponsor for the Project:	
Click or tap here to enter text.	
Please summarise the human tissue aspects of your proposed research here. This should include a summary of what tissue you will be using, how you will acquire it, why it is required, what you will do with it and how you will store it, ,what information you and the research team will have access to about the participants/donors, whether it will be rendered acellular and at what stage of the research and what will happen to any remaining tissue at the end of the project	
Click or tap here to enter text.	
Relevant Material	
Is the tissue considered to be 'Relevant Material' under the HT Act[1] for the purposes of this research project?	Choose an item.
Is the proposed use considered to be a 'Scheduled Purpose' under the HT Act[1] for the purposes of this research project? [2]	Choose an item.
Have you included with this application a copy of the project specific NHS REC Application Form and Approval Letter	Choose an item.
If the tissue is being provided by a Tissue Bank Application have you included the Form and Approval Letter with this application?	Choose an item.

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[1] Further details of the Human Tissue Act (2004) and the list of materials considered to be 'relevant materials' under the Act can be found at: https://www.hta.gov.uk/policies/list-materials-considered-be-%E2%80%98relevant-material%E2%80%99-under-human-tissue-act-2004.

[2] Please note: if you are using relevant material and it is for a 'scheduled purpose' you will need HRA approval.

Have you included the research protocol with this application?	Choose an item.
Is it necessary to have one or agreements relating to the transfer of human tissue for your project? This might for example include agreements relating to the sharing of tissue with collaborators, as well as with the supplier of the material to you.	Choose an item.
If any or all such agreements are in place, have you included them with this application?	Choose an item.
If not all necessary agreements relating the transfer of human tissue are currently in place, please explain what action you have taken.	
For projects involving 'Relevant Material' and / or the NHS please provide: the NHS REC Reference Number:	Click or tap here to enter text.
Non-relevant Material and/or use not for a scheduled purpose but which involves NHS Patients)	
Has a copy of the project specific NHS REC Application Form and Approval Letter been included with this application?	Choose an item.

Section 5: Data Collection, Storage and Disposal

Research undertaken at UWE by staff and students must be GDPR compliant. For further guidance see Research and GDPR compliance

☒Please confirm that you have included the UWE Privacy Notice with the Participant Information Sheet and Consent Form

☒ By ticking this box, I confirm that I have read the Data Protection Research Standard, understand my responsibilities as a researcher and that my project has been designed in accordance with the Standard.

Section 5.1 Data Collection and Analysis

Which of these data collection methods will you be using? Please select all that apply.

☒ Interviews
☒ Questionnaires/surveys
☐ Focus groups
☐ Observation
☐ Secondary sources
☐ Clinical measurement
☐ Digital media
☐ Sample collection
☐ Other

If Other, please specify: Click or tap here to enter text.

Please note that online surveys must only be administered via Qualtrics
Please ensure that you include a copy of the questionnaire/survey with your application.

What type of data will you be collecting?

☒ Quantitative data:

- Survey: Answers from standardised questionnaires
- Resource: Answers from the acceptability feedback

☒ Qualitative data: - Survey: Open questions within the survey - Content/thematic analysis from the discussions during co-creation of the resource and feedback on its acceptability after completion
How will you record your data and transfer it to secure storage?
To record the questionnaire data, Qualtrics will be used, as it is a UWE approved method for such practice. Once collected, data will then be downloaded onto excel, and will be stored on a password protected laptop on a restricted folder on UWE OneDrive. All participants who express an interest in being involved in the additional feedback for the resource, will be asked for their email address through the Qualtrics software, so that links to the teams meeting or resource feedback form can be sent, along with the consent forms and information sheet. All participants will be requested to set up their own participant identifier through Qualtrics. To record the resource feedback discussions, a recording device will be used to capture the conversations, and their participant identifier used to classify each participant. As above, these recordings will be stored on a password protected laptop on a restricted folder on UWE OneDrive.
Please describe the data analysis and data anonymisation methods.
All participants will be requested to set up their own participant identifier through Qualtrics. By doing this, the researcher will not know the participants identity, and only their email address will be required in addition to this for the resource feedback discussions. These email addresses will be stored securely separately from other data. Identifiable data will not be collected.
Section 5.2 Data Storage, Access and Security
Where will you store the data? Please select all that apply.
☐ H:\ drive on UWE network ☐ Restricted folder on S:\ drive ☒ Restricted folder on UWE OneDrive ☐ Other (including secure physical storage) If Other, please specify: Click or tap here to enter text.
Please explain who will have access to the data.
The lead researcher will have access to the data, and their supervisors Diana Harcourt and Pippa Tollow will also have access to provide feedback throughout.
Please describe how you will maintain the security of the data and, where applicable, how you will transfer data between co-researchers.
Qualtrics will be used for data collection, as it is a UWE approved method for such practice. The Teams Meeting collecting feedback for the co-creation of the resource will be recorded, and transcribed. All data collected in Qualtrics will be downloaded to an excel file, and along with resource feedback discussion recordings, will be stored securely on a restricted folder on UWE OneDrive, so if required, data can be shared securely. The computer used to conduct the research is password protected.
Section 5.3 Data Disposal
Please explain when and how you will destroy personal data.
In line with UWE's policies and standards for research, data will be held securely during the time of the research, and will be anonymised throughout, apart from participant

identifiers for the purposes of the resource feedback discussions. At the end of the data collection, the data will be collated, then archived or destroyed using the most appropriate method.

Section 6: Other Ethical Issues

What risks, if any, do the participants (or donors, if your project involves human tissue) face in taking part in the project and how will you address these risks?

Participants will be informed through the information sheet of the nature of the study. They will also be reminded at the start through the informed consent form that if they feel they require additional support, there is a selection of organisations and charities that they will be signposted to from the information sheet and at the end of the survey. There may be sensitive questions surrounding their appearance and treatment experiences which may cause discomfort in some, however, contact details for where to seek support will be provided.

Are there any potential risks to researchers and any other people as a consequence of undertaking this project that are greater than those encountered in normal day-to-day life?
For further information, see guidance on safety of social researchers.

No

How will the results of the project be reported and disseminated? Please select all that apply.

☒ Peer reviewed journal
☐ Conference presentation
☐ Internal report
☒ Dissertation/thesis
☐ Written feedback to participants
☐ Presentation to participants
☐ Report to funders
☐ Digital media
☐ Other
If Other, please specify: Click or tap here to enter text.

Does the project involve research that may be considered to be security sensitive? For further information, see RESC guidance for security sensitive research.	No

Please provide details of the research that may be considered to be security sensitive.

Click or tap here to enter text.

Does the project involve conducting research overseas?	No
Have you received approval from your Head of Department/Associate Dean (RKE) and is there sufficient insurance in place for your research overseas?	Choose an item.

Please provide details of any ethical issues which may arise from conducting research overseas and how you will address these.

Click or tap here to enter text.

Section 7: Supporting Documentation

Please ensure that you provide copies of all relevant documentation, otherwise the review of your application will be delayed. Relevant documentation should include a copy of:

- The research proposal or project design.
- The participant information sheet and consent form, including a UWE privacy notice (see links below).
- The questionnaire/survey.
- External ethics approval and any supporting documentation.

For further guidance concerning Participant Information Sheet, Consent form and Research Privacy Notice please visit Research Ethics policies, procedures and guidance

Please note, the Privacy Notice must be tailored to each specific research project. If the Privacy Notice is not provided alongside the PIS and consent form you may make this available to participants electronically by using a dedicated folder on OneDrive.

Please clearly label each document - ensure you include the applicant's name, document type and version/date (e.g. Joe Bloggs - Questionnaire v1.5 191018).

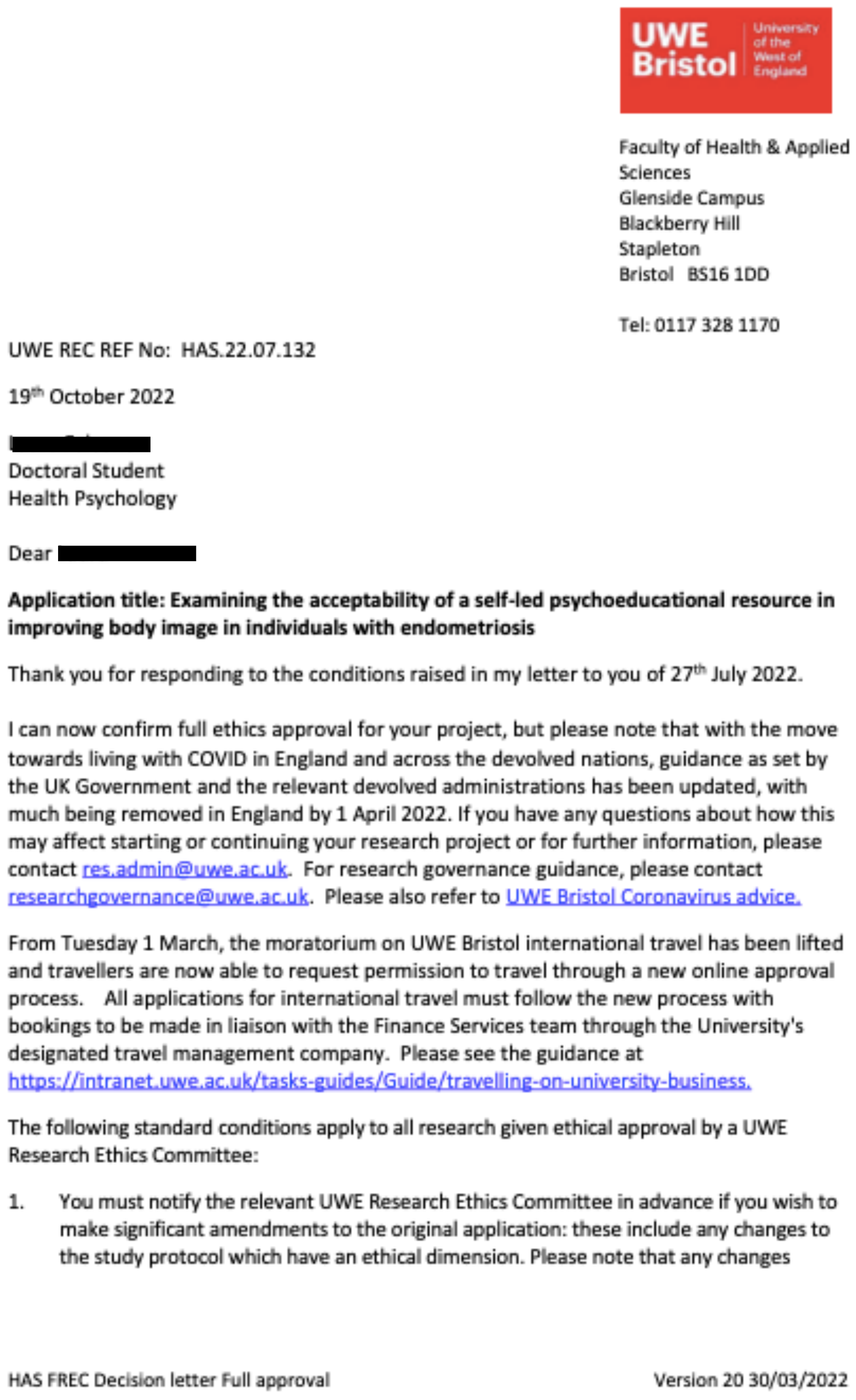
Section 8: Declaration

☒ By ticking this box, I confirm that the information contained in this application, including any accompanying information is, to the best of my knowledge, complete and correct. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the right of the participants.

Name: Anonymised for thesis submission
Date: 27/06/2022

This form should be submitted electronically to the Research Ethics Admin Team: researchethics@uwe.ac.uk and email copied to the Supervisor/Director of Studies where applicable, together with all supporting documentation (research proposal, participant information sheet, consent form etc). Please provide all the information requested and justify where appropriate.
For further guidance, please see http://www1.uwe.ac.uk/research/researchethics (applicants' information)

Appendix 14 – Ethics Application Approval Letter



UWE Bristol University of the West of England

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Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.22.07.132

19th October 2022

[redacted]
Doctoral Student
Health Psychology

Dear [redacted]

Application title: Examining the acceptability of a self-led psychoeducational resource in improving body image in individuals with endometriosis

Thank you for responding to the conditions raised in my letter to you of 27th July 2022.

I can now confirm full ethics approval for your project, but please note that with the move towards living with COVID in England and across the devolved nations, guidance as set by the UK Government and the relevant devolved administrations has been updated, with much being removed in England by 1 April 2022. If you have any questions about how this may affect starting or continuing your research project or for further information, please contact res.admin@uwe.ac.uk. For research governance guidance, please contact researchgovernance@uwe.ac.uk. Please also refer to UWE Bristol Coronavirus advice.

From Tuesday 1 March, the moratorium on UWE Bristol international travel has been lifted and travellers are now able to request permission to travel through a new online approval process. All applications for international travel must follow the new process with bookings to be made in liaison with the Finance Services team through the University's designated travel management company. Please see the guidance at https://intranet.uwe.ac.uk/tasks-guides/Guide/travelling-on-university-business.

The following standard conditions apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes

approved by an external research ethics committee must also be communicated to the relevant UWE committee.

2. You must notify the Faculty Research Ethics Committee if you terminate your research before completion.
3. You must notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please ensure that before proceeding with your research:

- you have sought contractual advice from the UWE Contracts Team Amy.Charles@uwe.ac.uk if your research involves external funding and/or contracts with partner organisations;
- You have sought advice from the UWE Data Protection Team (dataprotection@uwe.ac.uk) if, in relation to collecting and/or sharing personal data, a third party (i.e. any person or institution extraneous to UWE) is involved in the research project.

Please note: The Research Ethics Sub-Committee (RESC) is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the RESC and its committees.

We wish you well with your research.

Yours sincerely

[redacted]

Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c. Professor Diana Harcourt