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A mixed-methods investigation into the role of illness perceptions and coping in endometriosis-related quality of life

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This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

Signed:

Date:

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The title page of this thesis bears my name, but there are many individuals who have been instrumental in the completion of this work, and I would like to take this opportunity to thank these people for their contributions to this thesis.

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Conference presentations

Moore, C., Cogan, N., & Williams, L. (2022, June 28–29). *"It's like a constant black cloud": a qualitative investigation of quality of life and illness perceptions in endometriosis* [poster presentation]. British Psychological Society Division of Health Psychology Annual Conference 2022, Bristol, UK.

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Abbreviations

IPs:	Illness Perceptions
CSM-SR:	Common-Sense Model of Self-Regulation
QoL:	Quality of Life
HRQoL:	Health Related Quality of Life

APC:	Acting, Problem-oriented Coping
DP:	Depressive Processing
ISE:	Information Seeking and Exchange of experiences
ASI:	Active Search for social Integration
TMC:	Trust in Medical Care
FIS:	Finding Inner Stability
WAH:	Willingness to Accept Help
DSP:	Distance and Self-Promotion
TWD:	Trivialisation, Wishful thinking and Defence

PE:	Peritoneal Endometriosis
DIE:	Deep Infiltrating Endometriosis
IUD:	Intrauterine Device
GnRH:	Gonadotropin Releasing Hormone

EDs:	Eating disorders
IBS:	Irritable bowel syndrome
IBD:	Irritable bowel disease
CHD:	Coronary Heart Disease
COPD:	Chronic Obstructive Pulmonary Disease
CPP:	Chronic Pelvic Pain
MI:	Myocardial Infarction

IPQ:	Illness Perceptions Questionnaire
IPQ-R:	Revised Illness Perceptions Questionnaire
B-IPQ:	Brief Illness Perceptions Questionnaire
EHP-5:	Endometriosis Health Profile (5 item)
EHP-30:	Endometriosis Health Profile (30 item)
SF-36:	Short Form-36
WHOQOL-BREF:	The World Health Organization’s Quality of Life assessment
PHQ-4:	The Patient Health Questionnaire (4 item)
PSS-4:	The Perceived Stress Scale (4 item)
ECQ:	Essen Coping Questionnaire
CPG:	Chronic Pain Grade
SE-MCD-6:	Self-Efficacy for Managing Chronic Diseases scale (6 item)
B-PSSQ:	The Brief Perceived Social Support Questionnaire
CBT:	Cognitive Behavioural Therapy
ACT:	Acceptance and Commitment Therapy

ABSTRACT

Endometriosis is associated with reduced quality of life. The common-sense model of self-regulation (CSM-SR) theorises that illness perceptions (IPs) shape responses to a health threat, including coping strategies. However, the CSM-SR has not been comprehensively explored in endometriosis, despite evidence linking IPs to physical and mental health outcomes in several chronic health conditions.

The current mixed-methods research aimed to assess the CSM-SR in the context of endometriosis by evaluating the dynamic nature of endometriosis-related IPs and investigating coping as a mediator between IPs and wellbeing. Furthermore, the longitudinal psychosocial predictors of health-related quality of life (HRQoL) and mental wellbeing were investigated. A qualitative component aimed to uncover the IPs held by participants, and the impact of these IPs on HRQoL.

A longitudinal, two-wave survey spanning one year was distributed to individuals with a diagnosis of endometriosis. Four hundred and eight participants completed the baseline survey, with 283 completing the follow-up survey. Regression analyses revealed IPs, collectively, to be the strongest longitudinal predictors of HRQoL and mental wellbeing, over and above clinical and demographic factors. Perceptions surrounding the timeline and identity of endometriosis were amongst the strongest singular predictors of HRQoL. Mediation analyses indicated that coping influenced the relationships between IPs and outcomes.

Thirty in-depth interviews analysed using deductive and inductive reflexive thematic analysis enabled the construction of 5 themes, demonstrating the impact of endometriosis on the life trajectory and the ways in which participants navigated life with the condition. Each theme mapped onto the pre-defined IP dimensions, with fears surrounding the consequences and emotional impact of endometriosis prominent.

Integration of the quantitative and qualitative elements revealed points of convergence, complementarity, and divergence. Findings indicated a pervasive impact of IPs and coping styles on HRQoL and wellbeing outcomes, suggesting that interventions targeting these factors may support the wellbeing of affected individuals.

CHAPTER 1

Introduction to the thesis

1.1 Overview

The current chapter provides important background detail relating to endometriosis, including endometriosis symptomology, prevalence of the condition, theories of aetiology and pathology, available treatments, and diagnostic delays. It is important to consider these factors to make sense of the far-reaching impact of endometriosis on the lives of affected individuals. Furthermore, considering these aspects is essential to contextualise the current thesis, which draws upon factors such as the widespread misunderstanding of endometriosis, lengthy diagnostic delays, and debilitating symptomology throughout. First, a reflective account of the language and theories adopted within the current chapter is provided (1.2). It should be noted that a first-person writing style has been adopted for this section. Next, an overview of endometriosis is given (1.3). The psychological impact of endometriosis is then considered (1.4), along with an overview of the mental health support available to those experiencing the condition. Finally, the aims of the current thesis are provided (1.5) and the structure of the thesis is outlined (1.6).

1.2 Reflections on language and endometriosis

As stated above, this section of the current chapter will be written in first-person.

From the outset of my reading on endometriosis, I became acutely aware of the power of language. I rapidly realised the importance of selecting the language in which I described and discussed endometriosis carefully, keeping the implications of my choices in mind. As with all health conditions residing under the umbrella of 'women's health', there is ongoing debate surrounding the way in which we describe participants in endometriosis research (Moseson et al., 2020). Previous research in this area has overwhelmingly described participants as 'women', although a growing literature base now advocates for more inclusive terms such as 'people assigned female at birth' and 'individuals who menstruate' (Kosher et al., 2023; Women's Health Research Institute 2022). According to sociological theory, gender and language are highly intertwined, with some suggesting that our subjective experience in the material world is constructed and experienced through language (Butler, 1993; Kosher et al., 2023). Correspondingly, there is evidence that transgender and non-gender conforming individuals use language to shape their identity and form communities (e.g., Barrett, 2014). By the same mechanisms, language can also lead to significant discomfort, shame, and distress by triggering gender dysphoria in those that do not identify with the gender assigned to them at birth (Kosher et al., 2023; Schwartz et al., 2022). This is a particular concern in the sphere of women's health, where non-binary and transgender individuals may feel excluded from support and research due to non-inclusive language and practices.

I am conscious of the fact that women's health has a marred and complex history, with, in my opinion, the lack of research in this area demonstrative of entrenched systemic misogyny, where women's health concerns are perhaps seen as less worthy of research compared to men's issues and, traditionally, conditions affecting the female anatomy have been viewed as a taboo subject. As with many of these conditions, endometriosis does not constitute a threat to life, so it may not be considered important by many. Women’s health has been stigmatised throughout history, with menstruation and concerns around our sex organs confined to the private sphere, behind closed doors, not to be discussed in public (Johnston-Robledo & Chrisler, 2020). This has led to a lack of knowledge around the female reproductive system and how it operates, and as a result individuals living with related health conditions have had to fight harder for effective treatments, for more research and, at its core, to be believed.

Alongside these issues, non-binary and transgender individuals face additional, unique barriers to support, particularly in the realm of women’s health. There is currently a lack of research explicitly detailing the experiences of non-gender conforming individuals in the sphere of women’s health - however through my participation in support groups, interviews, and in reading around people’s experiences in preparation for writing the current thesis, it is clear that many individuals feel alienated and isolated due to non-inclusive research and gendered terminology, and this is reflected in recent research suggesting that traditionally gendered health conditions and gender dysphoria are linked (Schwartz et al., 2022). Attending a women’s health clinic, along with the experience of menstruation itself, something that is intrinsically associated with the experience of ‘womanhood’, can trigger feelings of deep shame and distress for people who do not identify with the gender they were assigned at birth (Kosher et al., 2023). This may lead many non-binary and transgender people to delay or reject support completely, which clearly has the potential to worsen health outcomes for many individuals. I recognise that there is a critical debate ongoing in this area, with concerns raised over the potential erasure of gendered language and the impact that may have on cis-gender individuals, and I feel it is important also to bear this in mind. However, in my opinion, it is important to reflect the views of all people affected by menstrual and gynaecological conditions, including non-binary and transgender individuals (Moseson et al., 2020), and it is therefore vital that no individual feels excluded from the conversation.

Therefore, following a period of reflection and in line with my views on the importance of inclusivity, I refer to “individuals with endometriosis” and “individuals assigned female at birth” throughout the current thesis. In coming to this decision, I have considered the positionality of relevant professional bodies along with my own perspectives on inclusivity. For example, The Royal College of Obstetricians and Gynaecologists (RCOG) often use the term ‘woman’ throughout their guidelines and publications, however they acknowledge that it is not only individuals who identify as women that require access to care (RCOG, 2022). Along with the Royal College of Midwives (RCM), the RCOG released an inclusivity statement, stating “The RCOG and RCM understand the importance of language in breaking down barriers for people accessing care and is committed to using inclusive language in its communications, publications and patient information to meet the needs of all individuals.” (RCOG & RCM, 2022). As the content of this thesis is intended to be viewed widely, and in-keeping with recent recommendations by professional bodies such as the RCOG, I felt that it was of pivotal importance that the terminology used throughout this thesis was as inclusive as possible. Ultimately, I hope that all affected individuals feel represented and included within the current research.

On a similar note, I have attempted to capture as many experiences of those living with endometriosis as possible within the current chapter, but due to the nature of endometriosis as an enigmatic and heterogeneous condition, I recognise that it may not be possible to reflect the experiences of all individuals with the condition. I may have included less information, for example, around individuals who experience relatively few symptoms of endometriosis.

Furthermore, it is likely that, with the advancing nature of endometriosis research, some of the points I raise within the current chapter may evolve and change over time. Throughout the time I have spent writing the current thesis, I have consistently revisited this introduction to give as accurate a picture as possible of the current field. Inevitably, there will be theories I have been unable to describe due to the constraints of the current project and my timescale for completion of the present thesis, but I have attempted to include the most relevant research. Similarly, multiple theories exist on the nature of endometriosis and its aetiology. The truth is that we do not have an infallible theory of the pathogenesis or cause of endometriosis. Inevitably this has led to the creation of a plethora of theories and models, which is a highly important step in the process of uncovering the mechanisms underlying the condition. The existence of multiple theories will certainly lead to split opinions amongst medical professionals and researchers who back one theory over the others. In short, this chapter should not be read as an exhaustive and infallible account of the theories and models associated with endometriosis, but as a broad overview of current scientific thinking at the time of writing.

1.3 Endometriosis

1.3.1 Symptoms, stages, and classifications

Endometriosis is a chronic, incurable condition in which tissue similar to the lining of the womb, the endometrium, binds to organs and tissue outside the uterus

(Zondervan et al., 2020). Endometrium-like cells commonly migrate to pelvic sites such as the ovaries, fallopian tubes, and uterine ligaments (Li et al., 2019; McGuinness et al., 2020; Xia et al., 2018), forming lesions on the tissue they infiltrate. Endometriosis-derived lesions have also been identified in several distant extra-pelvic locations, including on or around the lungs (Topbas Selcuki et al., 2022), the heart (Charpentier et al., 2019) and the brain (Meggyesy et al., 2020).

Recurrent pelvic pain is a significant symptom of endometriosis. Pelvic pain may be constant or cyclical, occurring most frequently around the time of menstruation and ovulation (Drabble et al., 2021). Alongside menorrhagia (painful, often heavy periods), pain-related symptoms commonly associated with endometriosis include dyspareunia (pain during sexual activity), bladder pain (often coupled with recurrent urinary tract infections), and dyschezia (painful defecation) (Montanari et al., 2019). Affected individuals have also described the presence of pain in their legs, back and joints (Drabble et al., 2021; Young et al., 2015). Alongside pain, symptoms typical of endometriosis include abdominal bloating, persistent fatigue, and low mood (World Health Organization, 2023). Additionally, fertility problems are common in those living with endometriosis. Although the link between endometriosis and infertility is well-studied (Bulletti et al., 2010; La Rosa et al., 2019), the prevalence of infertility in endometriosis patients is unclear, however it is estimated that up to 50% of individuals presenting with infertility have endometriosis (La Rosa et al., 2019). Those living with the condition may also be at a higher risk of some autoimmune and cardiovascular diseases, as well as ovarian cancer, melanoma, and asthma (Králíčková et al., 2020; Kvaskoff et al., 2015; Saraswat et al., 2018).

Whilst discussing symptomology, it is important to note that due to the heterogeneity associated with the location and presentation of endometriosis-derived lesions, there is significant disparity in the symptoms experienced by individuals living with the condition. For example, whilst many living with endometriosis experience several debilitating symptoms, others report more mild and manageable symptoms (Bulletti et al., 2010). Furthermore, individuals with rare and/or unusual clinical presentations of the condition may experience localised symptoms. For example, thoracic endometriosis, characterised by endometriosis-derived lesions on the lung(s), may induce breathing difficulties and chest pain (Azizad-Pinto & Clarke, 2014; Soares et al., 2021). Additionally, it must be stressed that endometriosis is a progressive disease and as such symptoms may develop or worsen over time. Symptom severity is not correlated with the classification, stage, or extent of endometriotic lesions (Andres et al., 2018).

For the consideration of treatment, three classifications of endometriosis have been derived:

i) Peritoneal or superficial endometriosis (PE), in which endometriosis-derived lesions are located on the peritoneum - the thin membrane that lines the abdominal cavity and most of the organs contained within the abdominal cavity (Ferrero et al., 2019). This is the most common form of endometriosis, accounting for approximately 80% of all diagnosed cases (Horne et al., 2019). PE frequently coexists alongside other types of endometriosis (Audebert et al., 2018; Somigliana et al., 2004) and there is considerable heterogeneity in the location and number of lesions between patients (Horne et al., 2019).

ii) Endometriomas (also known as chocolate cysts or cystic ovarian endometriosis), referring to nodules filled with dark endometrial fluid

(Chandra & Chaudhary, 2021). These cysts appear to be progressive (Ding et al., 2020) and are implicated in fertility complications (Berlanda et al., 2015). Endometriomas are estimated to affect between 17-44% of individuals living with endometriosis (Hoyle & Puckett, 2021). Although they are most frequently found on the ovaries, in rare cases endometriomas have been observed in distant abdominal locations, including on the liver (De Riggi et al., 2016; Tuech et al., 2003).

iii) Deep infiltrating endometriosis (DIE), defined as endometriotic tissue that has penetrated the peritoneal surface at a depth of at least 5 millimetres (Wild et al., 2019). Estimates of the prevalence of DIE vary, however it is thought that it accounts for 4-37% of all endometriosis cases (Koninckx et al., 2012). DIE is commonly located in extra-pelvic locations such as the bowel and the bladder, often disrupting the typical function of the organs and prompting debilitating symptoms and chronic pain (Busard et al., 2012; Halis et al., 2010; Parra et al., 2021). Such disruption can lead to delays in the diagnosis of DIE, as symptoms are mistaken for alternate conditions such as interstitial cystitis and irritable bowel syndrome. Surgical intervention targeting DIE is particularly complex due to the extent to which lesions are embedded into the organs, especially if scar tissue has bound organs together.

Additionally, the American Society for Reproductive Medicine (ASRM) classification (1997) categorises endometriosis into 4 stages:

i) Stage I: Minimal. Few endometriosis lesions have been identified.
ii) Stage II: Mild. Several endometriosis lesions identified, mainly superficial in nature.

iii) Stage III: Moderate. Many deep endometriosis implants identified, presence of cysts.

iv) Stage IV: Severe. Large adhesions (thick, fibrous scar tissue emanating as a feature of the body's natural healing process) present. Cysts and deep infiltrating endometriosis implants present.

According to this classification, 32% of affected individuals have moderate to severe endometriosis (Zhu et al., 2014). It must be noted that although the ASRM classification system is the most widely used method of categorising endometriosis, there are numerous classification systems in operation with no reported 'gold standard' tool at this time (Lee et al., 2021). As stated previously, the existing categorisation systems may not comprehensively capture the symptoms of those living with endometriosis (Vercellini et al., 2007; Anders et al., 2018; International Working Group of AAGL et al., 2021). For example, an individual with stage I 'minimal' endometriosis may present with chronic and severe pain, and an individual with stage IV 'severe' endometriosis may experience mild or no pain. Nonetheless, classification systems are useful tools for explaining the nature of endometriosis to patients and clinical teams.

1.3.2: Aetiology and Pathogenesis of endometriosis

At the time of writing, there is no widely accepted theory of the cause of endometriosis. The most prevalent hypothesis of endometriosis formation is that of 'retrograde menstruation', a process in which menstrual tissue and cells flow backwards through the fallopian tubes into the pelvic cavity instead of exiting the body through the cervix (Sampson, 1927). It is theorised that, during this process, some endometrial cells become attached to tissue within the pelvic cavity, forming endometriotic lesions (Lamceva et al., 2023). However, most people who menstruate experience retrograde menstruation, but only 6-10% go on to develop endometriosis (Halme et al., 1984). It is, therefore, unclear how this process leads to endometriosis in some individuals but not in others. Additionally, endometriosis growth and progression can persist in individuals who are no longer menstruating (e.g., following hysterectomy or menopause; Streuli et al., 2017), and there have been very rare cases of individuals assigned male at birth presenting with medically confirmed endometriosis (Rei et al., 2018). Finally, the theory of retrograde menstruation assumes that endometriosis is simply misplaced or ectopic endometrium cells, however, there are several disparities between endometrial and endometriosis cells. These differences are considered in further detail below (see section 1.3.2.2). Therefore, the theory of retrograde menstruation cannot fully explain the aetiology of endometriosis. Thus, researchers now generally consider retrograde menstruation as one of a multitude of factors contributing to the development and maintenance of endometriosis. A full review of each proposed mechanism is beyond the scope of the current thesis, however the most prevalent factors thought to contribute to the development and maintenance of endometriosis are outlined in table 1.1.

Table 1.1

Factors implicated in the aetiology and pathogenesis of endometriosis

Process	Description
Retrograde menstruation	A process in which menstrual blood flows backwards through the fallopian tubes and into the pelvic cavity, potentially allowing for endometriosis lesions to form (Sampson, 1927).
Metaplasia	Abnormal conversion of cells within the abdominal region into endometriosis cells. There is no widely accepted theory of the process by which metaplasia occurs (Sourial et al., 2014).
Hormonal	Individuals with endometriosis have higher levels of oestrogen. Oestrogen is thought to drive the proliferation of endometriosis lesions (Huang et al., 2020).
Oxidative stress, inflammation	An imbalance between reactive oxygen species and antioxidants (i.e., oxidative stress) may cause an inflammatory response in the peritoneal cavity, prompting the growth and maintenance of endometriosis lesions (Scutiero et al., 2017)
Immune dysfunction	Many individuals experiencing endometriosis present with autoimmune conditions (Shafrir et al., 2021). Immune dysfunction may prevent the elimination of menstrual debris, supporting the development of endometriosis (Sourial et al., 2014).
Apoptosis suppression	Endometriosis-derived cells have the capacity to evade apoptosis, a programmed cell death in which cells are eliminated without provoking an inflammatory response (Zheng et al., 2021). This may lead to inflammation and the development and maintenance of endometriosis cells.
Genetics	Several genetic variants have been identified that appear to increase the risk of endometriosis lesions and endometriosis-related pain (Rahmioglu et al., 2023). These variants may play a role in the aetiology and pathogenesis of endometriosis.
Stem cells	Stem cells can migrate outside the uterus by retrograde menstruation where they may form endometriosis lesions (Kong et al., 2021). Stem cells are displaced in the pelvic cavity through retrograde menstruation in a small number of cases (Gargett et al., 2016), which may explain why retrograde menstruation leads to endometriosis in only 6-10% of individuals (Halme et al., 1984).

Adapted from Sourial et al., 2014

Similarly, the pathogenesis of endometriosis is not fully understood. However, the presence of endometrial-like cells out with the womb is thought to invoke an inflammatory response, promoting and sustaining the growth of endometriosis lesions (Giacomini et al., 2021; Machairiotis et al., 2021; Wu et al., 2015). Lesions may be further exacerbated and maintained by hormones such as oestrogen (Chantalat et al., 2020; Mori & Kitawaki, 2022; Othman et al., 2021). One commonly cited theory is that endometriosis-derived lesions respond to hormones, particularly oestrogen, by haemorrhaging in a similar manner to the endometrium (Alimi et al., 2018; Burney & Lathi, 2009; Irving & Clement, 2011). However, due to their location, shed cells have no outlet and are subsequently trapped within the body (Donnez et al., 2016; Terzic et al., 2021). Inflammation arising from this process can trigger intense pain and is theorised to prompt the formation of adhesions or scar tissue (Guleken et al., 2022). In some cases, scar tissue can disrupt the typical function of organs by binding organs together, often causing debilitating pain and obstruction to the affected organs (Ezzat, 2017). This theory provides a clear and understandable explanation of the mechanisms underlying the pathogenesis and progression of endometriosis. However, this theory, and indeed all existing theoretical models on the pathogenesis of endometriosis at the time of writing, does not fully capture the nuances of the condition, particularly in relation to the heterogeneity of symptomology and symptom severity. For example, some people experience cyclical pain coinciding with the time of menstruation (Drabble et al., 2021), supporting the theory that endometriotic lesions respond to hormones in a manner similar to the endometrium. Meanwhile, in opposition to this theory, others report constant, chronic pain with no link to the time of menstruation (Drabble et al., 2021). Additionally, similarly to the aetiological theory of retrograde menstruation, this theory also assumes that endometriosis-derived cells behave in an identical manner to eutopic endometrial tissue, yet research has uncovered significant differences in the development and behaviour of these cells (see section 1.3.2.2). Ultimately, the aetiology and pathogenesis of endometriosis remain enigmatic, and resultantly there is ongoing debate surrounding the cause of endometriosis.

1.3.2.2 Endometriosis and the endometrium

Traditionally, endometriosis has been described as a condition of the endometrium, wherein endometrial tissue is simply displaced within the body. It is widely accepted that ectopic endometrial tissue does play a role in the pathogenesis of endometriosis (Laganà & Naem, 2022), however, there are marked differences in the activity and structure of endometriosis tissue and cells derived from the endometrium in healthy controls (Brosens et al., 2012; Maruyama, 2022; Pazhohan et al., 2018; Sharpe-Timms, 2002; Ulukus et al., 2006). Specifically, endometriosis-derived cells appear to overproduce oestrogen (Attar et al., 2009), proliferate and overwhelm tissue (Chen et al., 2018; Vinatier et al., 2000), and may have the capacity to evade apoptosis – a programmed cell death in which cells are eliminated without evoking an inflammatory response (Tanigushi et al., 2011; Zheng et al., 2021). Additionally, histological studies have challenged the claim that endometriotic tissue behaves similarly to the endometrium by haemorrhaging during menstruation (Colgrave et al., 2020). There appears to be no synchronicity between menstrual cycle phase and the shedding of endometriosis-derived cells, and evidence of shedding in endometriotic lesions has been identified in 75% of endometriosis patients regardless of menstrual cycle phase (Metzger et al., 1988). Therefore, some argue that the time and cause of endometriosis-related tissue haemorrhage is unknown (Colgrave et al., 2020). Furthermore, the association of endometriosis with the menstrual cycle implies that the condition is exclusive to individuals who menstruate, however, as stated previously, endometriosis growth and progression has been evidenced in non-menstruating individuals such as people assigned male at birth and individuals who have undergone surgery to remove the reproductive organs (Rei et al., 2018; Strueli et al., 2017). These factors strongly suggest that endometriosis and the endometrium are separate entities and should be researched as such. It should therefore not be assumed that endometriosis behaves in the same way as eutopic endometrium-derived cells until additional research on the heterogeneity of endometriosis lesions is conducted (Colgrave et al., 2020). Thus, throughout the current thesis, endometriosis and the endometrium are considered as separate entities.

1.3.3: Prevalence and diagnostic delay

One in ten women and individuals assigned female at birth are diagnosed with endometriosis, totalling 190 million individuals worldwide (World Health Organisation, 2023). The high prevalence of endometriosis translates into a considerable economic burden, costing the UK approximately £8.2 billion per year due to productivity loss and healthcare costs (Simoens et al., 2012). However, it is reported that around 6 out of 10 cases of endometriosis are undiagnosed (Morassutto et al., 2016) and it is therefore reasonable to suggest that the true burden of endometriosis is not fully captured by existing prevalence estimates. Furthermore, due to the stigma associated with menstruation, unreliable diagnostic techniques, and significant symptom disparity between individuals with the condition, it is possible that many individuals are unaware they have endometriosis, which may be reflected in current estimates. Only diagnosed cases of endometriosis are included in prevalence figures due to the overlap between the symptoms of endometriosis and alternate conditions affecting the pelvic area, such as adenomyosis and pelvic inflammatory disease (Bulun et al., 2023). It is therefore likely that current estimates underestimate the true prevalence of endometriosis.

Endometriosis clearly has a social, economic, and psychological impact, yet it remains an enigmatic condition. Medical professionals often feel unconfident in identifying cases of endometriosis due to the complexity of the condition and the overlap between endometriosis symptoms and the symptoms of other chronic conditions such as irritable bowel syndrome and adenomyosis (Bulun et al., 2023; Chiaffarino et al., 2021; Rowe et al., 2021). Furthermore, diagnostic tools are often unreliable in detecting endometriosis, contributing to a significant diagnostic delay in medical settings (Simko & Wright, 2022). At a societal level, 54% of the UK public do not know what endometriosis is (All Party Parliamentary Group on Endometriosis (APPGE), 2020), highlighting a general lack of understanding surrounding the condition. This lack of awareness and understanding of endometriosis in both medical and societal environments upholds a diagnostic delay of 7.5 years (Endometriosis UK, 2023) in the UK. This figure has remained unchanged in the last decade. Diagnostic delays are likely to be fuelled by: 1) help-seeking delays; and 2) dismissal within healthcare settings.

Individuals with symptoms of endometriosis delay seeking medical support for an average of 3.8 years (Cox et al., 2003). There are several reasons why an individual might delay help-seeking for endometriosis symptoms, although it is likely that insufficient awareness and education around endometriosis coupled with the pervasive and long-standing taboo associated with menstruation plays a significant role. ‘Menstrual etiquette’, a societal norm dictating that menstruation be kept private and hidden (Moffat & Pickering, 2019), creates a barrier to help-seeking amongst individuals experiencing menstruation-related symptoms due to anticipated and/or experienced stigma associated with disclosure of symptoms (Seear, 2009). Reluctance to disclose menstrual-related experiences may lead to difficulty in differentiating the symptoms of endometriosis from ‘regular’ menstruation-related symptoms, culminating in help-seeking delays. Those experiencing endometriosis also describe the minimisation and/or dismissal of their symptoms by friends, family, and work colleagues upon disclosing their experiences, even amongst acquaintances who have experienced menstruation-related and gynaecological issues themselves (Manderson et al., 2008; Young et al., 2015). This may lead to the internalisation of the notion that the severe, often debilitating symptoms associated with endometriosis are typical of menstruation rather than out of the ordinary, further fuelling help-seeking delays. It must be noted that there are no recent estimates of help-seeking delays, so future research should aim to address this.

Within healthcare settings, significant, long-standing diagnostic delays are likely to be fuelled by misunderstanding of the condition, the complexity of endometriosis symptomology, which often shares considerable overlap with several other conditions, and limited diagnostic tools. Correspondingly, prevalence figures may not account for those who may be trapped in the system awaiting a diagnosis, giving weight to the idea that current prevalence estimates may be an inaccurate reflection of the number of people living with endometriosis.

Those experiencing endometriosis have described feeling disbelieved and dismissed by medical professionals, with symptom management techniques such as painkillers and the contraceptive pill frequently prescribed in lieu of further investigation and diagnosis (Brown et al., 2018). In qualitative studies, participants living with endometriosis regularly describe the normalisation and dismissal of their symptoms as typical of menstruation by medical professionals (Grundström et al., 2018; Rowe et al., 2021; Young et al., 2015), particularly in the initial stages of help-seeking. Those living with endometriosis generally make several trips to their GP before referral for further investigation and, ultimately, diagnosis. Indeed, according to the UK-wide 2020 All Party Parliamentary Group report on endometriosis, 58% of those seeking support for endometriosis symptoms in the UK attended 10 or more GP appointments related to their symptoms prior to their diagnosis (APPGE, 2020). When a referral for further investigation is made, often the focus is on non-menstrual symptoms, such as gastro-intestinal symptoms or painful urination, and consequently many are referred to departments out with gynaecology, such as gastroenterology or urology. Resultantly, those living with endometriosis are regularly misdiagnosed with conditions such as irritable bowel syndrome, fibromyalgia, and interstitial cystitis (Bontempo & Mikesell, 2020; Yazdanian et al., 2014) or discharged completely following negative test results. Presentation to a GP with fertility problems is often the primary catalyst for further investigation and referral to appropriate medical streams (Dmowski et al., 1997; Evans et al., 2017; Young et al., 2015), and consequently delays may be further prolonged for those for whom fertility is not a priority or an issue.

There are further barriers to diagnosis even when appropriate referral is made to gynaecological departments. Diagnostic options for endometriosis are few and often limited in their effectiveness. Non-surgical investigative tests such as transvaginal ultrasound and magnetic resonance imaging are often utilised prior to surgical examination. These tests can rule out alternate causes of pelvic pain and menstruation-related symptomology, and in some cases can show endometriomas on the ovaries and DIE (Guerriero et al., 2016). However, they are largely ineffective in detecting other forms of endometriosis (Chen-Dixon et al., 2022; Hsu et al., 2010; Tirlapur et al., 2015), to the extent that official diagnosis of peritoneal endometriosis can be made only through surgical laparoscopic investigation. Nonetheless, to combat the lengthy diagnostic delays associated with endometriosis, some medical experts have suggested moving away from a surgical diagnosis to a 'clinical' diagnostic model, in which a medical professional makes a diagnosis based on the symptoms presented and physical examinations (Agarwal et al., 2019). However, there are several potential issues associated with this approach, for example, individuals may be misdiagnosed with endometriosis and subsequently provided with the wrong treatment, or, on the other hand, their endometriosis may be missed, particularly due to the heterogeneous nature of the condition. Further, several health bodies in the UK and internationally suggest that, although DIE can often be picked up by MRI and transvaginal ultrasound (Goncalves et al., 2021), endometriosis can only be definitively diagnosed through surgery (John Hopkins Medicine, n.d.; NHS, 2022). Waiting times for endometriosis surgery within the NHS can be lengthy, particularly following the outbreak of COVID-19, following which there has been a significant increase in waiting times for 'non-urgent' surgery and a decrease in the number of surgeries conducted (Carr et al., 2021). Further contributing to delayed surgical investigation for endometriosis in the UK, and thus delayed diagnosis, are the current guidelines presented by the National Institute for Health and Care Excellence (NICE, 2017), which promote the management of suspected endometriosis symptoms prior to laparoscopy, through means such as analgesics and hormonal treatment. As surgery carries an inherent risk it is unsurprising that symptom management techniques are first explored, however this significantly delays definitive diagnosis, potentially resulting in unreflective prevalence figures. Furthermore, the effectiveness of symptom management treatments varies significantly between patients (see section 1.3.4), with many prescribed ineffective treatments for lengthy periods without further investigation (Ferries-Rowe et al., 2020).

Laparoscopic surgery is the gold standard tool for detecting endometriosis. This keyhole surgery allows medical professionals to view the organs in the pelvis and the abdomen and is generally sensitive to identifying endometriosis lesions (Mak et al., 2022). However, laparoscopies frequently fail to detect cases of endometriosis due to unusual sites of presentation (Mettler et al., 2003; Singh & Suen, 2017; Wykes, Clark & Khan, 2004) and heterogeneity in the appearance of lesions (Albee et al., 2008; Simko & Wright, 2022). Therefore, a negative laparoscopic result does not necessarily indicate the absence of endometriosis. At the time of writing, research to identify biomarkers of endometriosis is ongoing (Shamsa et al., 2023; Sun et al., 2023; Tomkins et al., 2022) with the expectation that this may streamline the diagnostic process by providing an efficient, non-invasive means of testing for endometriosis and monitoring treatment response. As diagnostic delay has been linked to mental wellbeing (Nnoaham et al., 2011; Van Niekerk et al., 2022), the identification of a biomarker which serves to reduce diagnostic delays might have far-reaching, positive effects on the quality of life of individuals diagnosed with endometriosis. Furthermore, if a simple test for endometriosis is developed, a more accurate estimate of endometriosis prevalence may emerge.

1.3.4: Treatment of endometriosis

There is no known cure for endometriosis. Whilst treatment may provide some relief for endometriosis symptoms, treatment effectiveness varies between patients (Becker et al., 2017), and medical professionals are therefore encouraged to recognise the nuanced nature of the condition within treatment plans. A full review of all available treatment methods is beyond the scope of this thesis; however, the current section will outline some of the main treatments utilised for endometriosis within the UK. Current NICE guidelines promote progestins and the oral contraceptive pill as first line treatments for endometriosis (NICE, 2017). These treatments are thought to address the imbalance of hormones that can exacerbate endometriosis symptoms, by encouraging the production of progesterone and reducing oestrogen secretion. Evidence suggests that the combined oral contraceptive pill may reduce dysmenorrhea and is more effective than placebo for reducing endometriosis pain and symptom severity, even at low doses (Donnez & Dolmans, 2021; Harada et al., 2008). The combined oral contraceptive pill may also support increases in quality of life for patients with DIE (Alcalde et al., 2021). However, general conclusions regarding the effectiveness of the combined oral contraceptive pill cannot yet be drawn due to low quality research, which is often at a high risk of bias (Brown et al., 2018). Authors who have attempted to review the link between the oral contraceptive pill and endometriosis symptom reduction have been unable to do so due to the poor quality of existing research, which is marred by low sample sizes, non-randomisation, and insufficient data (Brown et al., 2018). Similarly, there is a lack of research on the effectiveness of alternate progestins such as the intrauterine device (IUD) in alleviating the symptoms of endometriosis. At the time of writing, no comprehensive review of the effect of the IUD on endometriosis symptomology exists. There is some evidence that the IUD may alleviate endometriosis symptoms following surgery to remove endometriosis (Abbou-Setta et al., 2013), however there is currently a lack of high-quality evidence to support this practice (Gibbons et al., 2021).

Gonadotropin releasing hormone (GnRH) is a commonly used second-line hormonal treatment, employed when first line treatments have been ineffective. This treatment temporarily mimics the menopause by ceasing the production of oestrogen and, with it, menstruation (Manchester University NHS Foundation Trust, 2019). There is more promising evidence of the effectiveness of this treatment in stemming the symptoms of endometriosis, with one meta-analysis reporting that GnRH was the most effective pharmacological therapy for reducing dyspareunia (Samy et al., 2021). However, GnRH can only be used for short periods of time due to the potential for serious and debilitating side effects such as osteoporosis (NHS, 2021). Therefore, this is not a long-term treatment option for individuals experiencing endometriosis.

Surgery is used to treat endometriosis if all other treatment routes have been ineffective. Most commonly, endometriosis is excised or ablated through laparoscopic keyhole surgery (Burks et al., 2021). Ablation surgery destroys the lining of the uterus using heat or electromagnetic energy, whilst excision surgery allows the surgeon to cut out endometriosis-related lesions and cysts. Excision allows for biopsies to be conducted to test the cells for endometriosis. There is a debate as to whether excision or ablation of endometriosis is more effective at removing endometriosis, however it is largely accepted that excision surgery is more precise and methodical, allowing surgeons to remove more patches of endometriosis that may have migrated beyond the uterus (Bignardi et al., 2019; Burks et al., 2021;

Pundir et al., 2017). Surgery cannot cure endometriosis, and, as it is a progressive condition, endometriosis-related cells will likely grow back. However, many do experience lessened pain after surgery, which can be long-lasting and life changing (Comptour et al., 2020). Nonetheless, recurrence of endometriosis symptoms and lesions following surgery is estimated at between 40-50% 5 years after surgery (Horne & Saunders, 2019). It is suspected by some researchers that for some types of endometriosis, specifically stage I and II, surgical intervention may actually exacerbate symptoms by causing additional scar tissue and lesions to form (Osbourne-Crowley, 2021). Work is ongoing to test this theory (University of Edinburgh, 2022).

A hysterectomy is often considered a last resort treatment for individuals with endometriosis. Patients can be referred for either a partial hysterectomy, where the cervix and/or ovaries may be left intact, or a full hysterectomy which removes the womb, cervix and ovaries. A hysterectomy is an effective treatment for many, often alleviating pain in cases where endometriosis-derived cells have not migrated beyond the pelvic area (Sandström et al., 2020). However, endometriosis-related pain can persevere even following hysterectomy, particularly when the hysterectomy is incomplete (e.g., ovarian conservation) or where surgery has not eradicated all endometriosis (Rizk et al., 2014). Rizk et al., (2014) identified a 62% risk of endometriosis recurrence after hysterectomy in advanced cases where the ovaries were left intact. A hysterectomy itself also comes with inherent risks. For example, long-term chronic pain has been reported in 10-50% of hysterectomy cases (Brandsborg & Nikolajsen, 2018). Additionally, sexual dysfunction, vaginal cuff dehiscence, and urinary incontinence have been reported following hysterectomy, all of which can have a long-lasting and detrimental impact on quality of life (Ramdhan et al., 2017).

It is likely that ineffective and, often, risky treatment options are a source of poor mental wellbeing for many experiencing endometriosis. Coupled with painful, often debilitating symptoms, a general lack of understanding relating to endometriosis, and significant hurdles within medical environments, the condition has a marked impact on the mental health and quality of life (QoL) of affected individuals.

1.4 Endometriosis and mental wellbeing

Considering the wide-reaching impact of endometriosis on the lives of those diagnosed with the condition, it is perhaps unsurprising that endometriosis is associated with adverse mental wellbeing outcomes (Gao et al., 2020; Pope et al., 2015; Wang et al., 2021). Furthermore, there is a well-established link between endometriosis and adverse QoL (Della Corte et al., 2020; Wang et al., 2021). The mechanisms underlying the relationship between endometriosis and QoL are considered within chapter 2 of the current thesis. The current chapter will outline the evidence of a link between mental wellbeing and endometriosis specifically.

Living with endometriosis increases the risk of common mental health problems exponentially, with approximately 56.4% of endometriosis patients meeting the clinical parameters for psychiatric diagnosis (Pope et al., 2015). Symptoms of depression and anxiety are particularly prevalent for individuals experiencing endometriosis (Laganà et al., 2015; Vannuccini et al., 2018).

1.4.1 Depression and anxiety

Depression and anxiety are the most common psychological conditions associated with endometriosis (Pope et al., 2015). Estimates of the prevalence of depression and anxiety for those experiencing endometriosis are as high as 86.5% and 87.5% respectively (Sepulcri & Amaral, 2009), although it must be noted that there is significant variation in prevalence estimates between studies. Depression estimates, for example, lie between 39.5% (Greenbaum et al., 2019) and 86.5% (Sepulcri & Amaral, 2009) across the literature. Some of the most recent figures place the prevalence of depression at 63% amongst those living with chronic pelvic pain (CPP; Siqueira-Campos et al., 2019), although those living with endometriosis may experience additional risk factors for depression compared to those with CPP alone, such as negative body image (Van Niekerk, 2022) and fertility concerns (Bonavina & Taylor, 2022). Therefore, prevalence figures for depression in CPP may not be comparable with the prevalence of depression in endometriosis. Furthermore, experiencing a co-morbid condition, such as fibromyalgia, significantly increases the risk of depression and anxiety in individuals diagnosed with endometriosis (e.g., Greenbaum et al., 2019) so it is important that researchers account for this when calculating depression and anxiety prevalence in endometriosis. Nonetheless, there is a strong consensus within the literature that endometriosis is associated with a heightened risk of both depression and anxiety (Barneveld et al., 2022; Casalechi et al., 2021; Cavaggioni et al., 2014; Chen et al., 2016; Gambadauro et al., 2019; Laganà et al., 2015; Laganà et al., 2017; Wang et al., 2021). For individuals experiencing endometriosis, anxiety and depression often co-occur (Nasyrova et al., 2011). This link is perhaps not surprising considering the strong association between depression and anxiety within the general population (Kaiser et al., 2021; Melton et al., 2016 Wu & Fang, 2014).

A meta-analysis of 44 articles from 13 countries identified significant differences in depression and anxiety risk between individuals with endometriosis symptoms and symptom-free controls (Wang et al., 2021). Individuals with endometriosis were consistently more likely to present with anxiety and depression than control groups, regardless of the country of origin of the research or the methods used to assess depression and anxiety symptoms. However, depression and anxiety risk tended to be strongest in research utilising self-report measures. Heightened risk of anxiety and/or depression in the context of self-report may be expected because many individuals experience symptoms of depression and anxiety without a medical diagnosis, particularly if depression symptoms are mild and/or manageable. It must also be noted that self-report tools screen for symptoms of depression and/or anxiety at a single point in time and are not diagnostic tools. Therefore, although an individual may express symptoms of depression and/or anxiety at the time of completing a self-report measure, it is not possible to ascertain whether this is a transitory or enduring state, or if this person meets the criteria for clinical diagnosis. Wang et al. (2021) also reported that studies incorporating smaller sample sizes tended to report higher prevalence of depression and anxiety for endometriosis patients. Studies with smaller sample sizes can lack statistical power, and generally research using a larger pool of participants is more representative of the wider population (Baker et al., 2021). Nonetheless, anxiety and depression were consistently and universally related to the presence of endometriosis symptoms in the studies reviewed by Wang et al. (2021).

Similarly, Chen et al. (2016) conducted a large-scale longitudinal study of 20,878 individuals, half of whom were diagnosed with endometriosis. Living with endometriosis significantly increased both depression and anxiety risk over the course of 2-13 years. Specifically, those with endometriosis were at increased risk of developing major depression, depressive disorder and anxiety disorder compared to the general population. However, individuals diagnosed by techniques such as ultrasound were included in the study as having endometriosis, yet, as previously mentioned, international guidelines state that an individual can only be diagnosed through laparoscopy and histologic analysis (NICE, 2017). Thus, concerns have been elicited around the validity of the diagnoses used within Chen et al.’s study (Laganà et al., 2017). Additionally, the study assesses depression and anxiety through medical notes and the opinions of psychiatrists. However, using validated self-report measures to assess the symptoms of depression and anxiety may produce more reflective results because, as previously stated, it is likely that many individuals who experience depression and anxiety symptoms do not have an official diagnosis. On the other hand, demonstrating symptoms of depression and anxiety through a self-report questionnaire does not necessarily indicate the presence of clinical depression and/or anxiety. Furthermore, using medical notes may allow for more detail regarding the nature of diagnosed psychiatric conditions to be given. Additionally, issuing self-report questionnaires to all 20,878 participants would most likely reduce the quantity of responses received, and the overall power of the study.

Laganà et al. (2015) echoed Chen et al.’s (2016) findings. They compared individuals with an endometriosis diagnosis to people experiencing other unspecified benign conditions affecting the female reproductive organs. Both groups were recruited from hospital clinics where they had recently undergone laparoscopic surgery. Individuals with endometriosis demonstrated higher rates of depression, phobic anxiety, and emotional sensitivity than the control group. It is perhaps unsurprising given the context in which recruitment occurred that those with endometriosis demonstrated higher phobic anxiety and depression. Some of the individuals participating in this study are likely to have had multiple surgeries for endometriosis due to the incurable and progressive nature of the condition (Zanelotti & DeCherney, 2017), which may fuel feelings of hopelessness and anxiety relating to the impact of surgery. Indeed, Cheong et al. (2008) report that around 51% of individuals require repeated surgery for endometriosis. Additionally, as the medical conditions that individuals in the control group presented with were not disclosed in this study, it is also unclear how comparable the two groups are. For many in the control group, surgery may represent a cure or effective treatment, potentially lessening the risk of depression and anxiety that is prevalent in chronic pain conditions (Li et al., 2019; Mousavvi et al., 2007). Furthermore, the authors did not ascertain the duration that individuals had experienced their conditions. It is possible that the longer an individual has experienced ill health, the higher the risk of poor mental health. Nonetheless, this research adds to an abundance of literature demonstrating the negative impact of endometriosis on the mental health of affected individuals.

Depression and anxiety are risk factors for suicidal ideation and behaviours (Bachman, 2018; Brådvik, 2018; Hawton et al., 2013). It follows that individuals experiencing endometriosis may be at an increased risk of attempted suicide and self-harm, although at the time of writing there is limited research on this topic. Emerging literature suggests that endometriosis is indeed associated with an elevated risk of self-directed violence, including self-harm, suicidal thoughts, and suicidal ideation. Estes et al. (2020) assessed anxiety, depression and self-directed violence in individuals diagnosed with endometriosis (n = 72,677) against a control group of individuals never diagnosed (n = 147,251). People living with endometriosis were twice as likely as those without endometriosis to experience clinically recognised self-directed violence. Endometriosis-specific symptoms such as fatigue and pain were linked to the incidence of self-directed violence. Conversely, a study on the mortality of individuals living with endometriosis in Finland found no difference in mortality due to suicide or self-harm between individuals with and without endometriosis (Saavalainen et al., 2019). Taken together, this suggests that attempted suicides and self-harm may be more prevalent amongst individuals experiencing endometriosis compared to the general population, whereas no such disparity exists in completed suicides. However, additional cross-cultural research is necessary to aid understanding of the potential link between self-harm, suicide and endometriosis, as well as theoretically informed longitudinal work.

1.4.2 Endometriosis and other psychiatric conditions

Beyond depression and anxiety, endometriosis has been linked with various mental health conditions including bipolar disorder (Chen et al., 2020), eating disorders (Koller et al., 2023) and attention deficit hyperactivity disorder (Gao et al., 2020). However, the evidence linking endometriosis with these conditions is far less robust than the literature linking anxiety and depression to endometriosis. There is a lack of consensus between authors on the presence of a relationship between psychiatric conditions and endometriosis, and a lack of research makes it difficult to assess the strength of any potential link.

Nonetheless, a small but significant body of literature indicates a link between endometriosis and bipolar disorder. The risk for bipolar in people experiencing endometriosis is thought to be higher than the risk for individuals experiencing CPP alone (Kumar et al., 2011). Pooled prevalence of bipolar disorder in endometriosis patients has been calculated at 16.7%, compared to 2.7% of those with CPP (Pope et al., 2015). In a large-scale longitudinal study of 17,382 endometriosis patients and 17,382 age-matched controls, endometriosis was associated with a significant increase in developing bipolar disorder over the course of 13 years (Chen et al., 2020). Conversely, Walker et al., (1989) identified no difference in the prevalence of mood disorders between individuals with and without endometriosis. However, this study only included 14 participants, half of which were asymptomatic. Additionally, Kumar et al. (2011) reported that the experience of endometriosis accompanied by pelvic pain was the most significant risk factor for bipolar disorder, and therefore comparisons drawn between symptomatic and asymptomatic individuals may be problematic. Moreover, when contemplating Walker et al.'s (1989) research, the context in which this study was conducted cannot be detached from the acquired results. For example, endometriosis classification, diagnosis, treatment, and overall understanding has evolved between the time of this publication and today. To exemplify, endometriosis prevalence in the late 1980s was underestimated, with the condition thought to affect 1-7% of women and individuals assigned female at birth (Barbieri, 1990). This figure is now placed at 10% (World Health Organization, 2023). Therefore, it is possible that individuals with undiagnosed endometriosis were included in the control condition of Walker et al.'s (1989) research which, coupled with a small sample size, may have influenced the results. Further research on the prevalence of bipolar in the context of endometriosis is required, as well as deeper understanding of the mechanisms underlying this potential link.

A limited but growing evidence base has suggested a link between endometriosis and disordered eating. In a large-scale study of 8,187 endometriosis cases, Koller et al. (2023) reported a strong association between endometriosis and eating disorders (EDs). The strength of this relationship was over and above the strength of the association between endometriosis and depression. Furthermore, Aupetit et al. (2022) also identified a link between endometriosis and EDs which appears to be influenced by the presence of symptoms associated with irritable bowel syndrome (IBS), a common complaint in individuals experiencing endometriosis (Chiaffarino et al., 2020). However, this study included only 54 individuals and larger-scale research is required to determine any potential link between endometriosis, EDs and IBS symptoms. It is likely however that if a link between endometriosis and EDs does exist, it is mediated by low body satisfaction which has been observed in individuals with endometriosis (Geller et al., 2021; Van Niekerk et al., 2022). Decreased body satisfaction is thought to be fuelled by endometriosis-specific symptoms such as bloating and gastrointestinal problems, corresponding with the findings of Aupetit et al. (2022) as described above. Gao et al. (2020) also identified a cyclical relationship between endometriosis and EDs. Endometriosis was not only a potential cause of EDs, but EDs themselves predicted endometriosis in later life. Further evidence is required to shed light on the mechanisms by which endometriosis and EDs are linked, and to reveal the prevalence of EDs in endometriosis.

Despite some gaps in the literature, it is clear that endometriosis is associated with an increased risk of adverse mental health outcomes. Consequently, there is an obvious need for psychological intervention to support individuals experiencing endometriosis, particularly due to the progressive and incurable nature of the condition.

1.4.3 Current psychological support for endometriosis

A wide-reaching report on the impact of endometriosis commissioned by the UK Parliament (APPGE, 2020) found that 90% of individuals surveyed felt they would benefit from some form of psychological support specifically to address the adverse mental health impact of endometriosis, but only 10% had been offered any such support. This highlights a reliance within healthcare settings on a medical model of endometriosis and the treatment of specific physiological symptoms, rather than the adoption of individualised and multifaceted treatment plans. Accordingly, there has traditionally been a lack of research into the effectiveness of psychological support for endometriosis. However, as awareness of endometriosis has grown, so too has the number of interventions trialled with those experiencing endometriosis. There have been promising results for the use of psychotherapy in conjunction with medical treatment to support pain reduction and the QoL of individuals experiencing endometriosis (Farshi et al., 2020; Meissner et al., 2016).

One systematic review on the effectiveness of psychological and mind-body interventions with endometriosis patients highlighted largely positive contributions of these interventions on the QoL of those experiencing endometriosis (Evans et al., 2019). All but one study reviewed observed a reduction in pain and an increase in QoL following interventions such as cognitive behavioural therapy (CBT), mindfulness-based counselling, Chinese medicine, and yoga. In some cases, these interventions were paired with physical treatment for endometriosis, and the outcomes of individuals in the therapy group were compared against the outcomes of others who had undergone the physical treatment only. However, of the 12 studies reviewed, only 3 were randomised control trials, limiting the conclusions that can be drawn regarding the effectiveness of each intervention. Additionally, many studies included small sample sizes and there was a lack of longitudinal follow-up to ascertain whether the observed effects were short-term or enduring. The authors highlight a need for additional interventions to be designed and reviewed, a sentiment echoed by others who have reviewed the existing literature on psychological interventions for endometriosis (Van Niekerk et al., 2019). In their review of psychological interventions for endometriosis, Van Niekerk et al. (2019) identified a high risk of bias and several ‘weak’ quality papers according to the Cochrane quality assessment tool. Studies considered to be of weak quality were often at high risk of performance, detection, attrition, and reporting bias. The authors concluded that the effectiveness of psychological interventions for improving the mental wellbeing and pain intensity experienced by endometriosis patients cannot be determined by the current literature base. Nonetheless, of the interventions reviewed, CBT and mindfulness-based approaches appear to be the most promising interventions for supporting the mental wellbeing of those experiencing endometriosis (Donatti et al., 2022). It must be noted that psychological interventions are not intended to replace medical treatment for endometriosis, rather they are to be used alongside physical treatments for endometriosis to improve the QoL of individuals diagnosed with the condition.

In the UK, pain clinics may offer some psychological support for individuals experiencing endometriosis, however a referral is required to these clinics, and support is often group-based rather than individualised. There is currently a dearth of research on the effectiveness of group therapy specific to endometriosis, but at a general level, group therapy appears to promote mental health improvements in several chronic conditions including type 2 diabetes, cancer, and fibromyalgia (Breitbart et al., 2010; Sallinen et al., 2011; van Son et al., 2013). However, it may not be appropriate to generalise these effects to endometriosis, as the condition affects individuals in often vastly different ways. Therefore, individualised support may be more appropriate. Correspondingly, much of the psychological support available to people experiencing endometriosis is generalised and not tailored to the condition itself. Research has consistently stated that support (including physical and psychological support) should be tailored to endometriosis due to the complexity of the condition (e.g. Hogg & Vyas, 2018; Young et al., 2017). Many existing CBT-based approaches for the treatment of chronic pain are not condition specific, and, therefore, not informed by patient needs. The longitudinal impact of these approaches may be improved by tailoring interventions to the specific condition they aim to address. CBT approaches tailored to a range of mental health conditions, including EDs, post-traumatic stress disorder, and anxiety, have shown promising results compared to more generic CBT approaches (Atwood & Friedman, 2020; Vancappel et al., 2022), so further research into developing endometriosis specific CBT approaches has the clear benefit to support those experiencing the condition.

Overall, the effectiveness of psychological interventions in improving the QoL and pain-related outcomes of individuals experiencing endometriosis cannot be determined from the existing literature. It is clear, however, that there is a need for more widespread and tailored psychological support, and further research which seeks to identify the most appropriate support to meet the needs of patients experiencing endometriosis would be beneficial.

1.5 Aims of the thesis

There is a clear need for increased psychological support for individuals experiencing endometriosis. However, to devise such interventions, it is important that the factors underlying QoL and mental wellbeing are understood. The current research therefore aims to assess a series of psychosocial factors and their relation to QoL and wellbeing outcomes in the context of endometriosis. A key focus of the current thesis is illness perceptions (IPs).

Qualitative research suggests that the way in which individuals perceive their endometriosis, for example, perceived control surrounding the progression and impact of the condition and the anticipated consequences of experiencing endometriosis, is linked to QoL (Jones et al., 2004). A useful framework for examining IPs is Leventhal's (1997) common sense model of self-regulation (CSM-SR). In this model, IPs are conceptualised as a person's beliefs and expectations relating to a health condition. The CSM-SR theorises that IPs are dynamic and changeable, and work together with the emotional response to a health threat to drive behavioural and coping responses (Leventhal et al., 2016). IPs contribute to QoL and wellbeing outcomes in several chronic conditions including fibromyalgia (van Wilgen et al., 2008), irritable bowel disease (Rochelle & Fidler, 2013) and arthritis (Hyphantis et al., 2013), and interventions directly targeting condition-specific IPs have yielded promising results in improving the health-related quality of life (HRQoL) of individuals experiencing several chronic conditions. Chapter 3 provides a more detailed description of IPs and the CSM-SR, as well as an overview of the literature on IPs and wellbeing.

IPs have not yet been directly studied in relation to endometriosis. Previous qualitative literature, however, suggests that beliefs surrounding control and the consequences of endometriosis are related to QoL (Moradi et al., 2014; Young et al., 2015), with more negative perceptions increasing QoL detriments. Therefore, interventions focussed on reframing the IPs of individuals experiencing endometriosis may support HRQoL in the absence of reliable and effective treatment for endometriosis.

To address this gap in the literature, there is first a need to ensure that the pre-existing IP framework, as outlined by the CSM-SR, is applicable to endometriosis. Additionally, if IPs do predict QoL/and/or wellbeing, it is important to ascertain whether this impact is enduring over time. Therefore, 5 aims were constructed for the present thesis:

i) Investigate the longitudinal predictors of HRQoL and wellbeing outcomes in endometriosis;
ii) Determine if IPs predict HRQoL and wellbeing outcomes over and above demographic and clinical factors;
iii) Investigate coping as a potential mechanism explaining the link between IPs and outcomes, as theorised by the CSM-SR;
iv) Determine the stability of IPs in the context of endometriosis;
v) Gain an in-depth understanding of the IPs held by individuals experiencing endometriosis

Establishing the role of IPs in endometriosis-related health and wellbeing outcomes has the clear potential to inform endometriosis-specific interventions to support the mental wellbeing and HRQoL of individuals living with the condition.

1.6 Structure of thesis

Chapters 2 and 3 provide an overview of relevant literature. Specifically, chapter 2 gives an overview of current knowledge with regards to endometriosis and HRQoL, whilst chapter 3 summarises the literature on IPs and their relation to QoL and wellbeing outcomes in alternate chronic conditions. Chapter 4 describes the methods used within the current project, including details of the philosophical stance of the researcher, the recruitment process, and data analysis. Chapter 5 outlines the results of the quantitative, longitudinal study conducted as part of this investigation, whilst chapter 6 provides a full overview of the qualitative study conducted for the current thesis. Finally, chapter 7 offers an account of the integration of the qualitative and quantitative components of the current research, before concluding the thesis with a discussion that contextualises the findings of the current project. Here, the implications of the research findings and possible avenues for future research are explored.

CHAPTER 2

An overview of the factors associated with health-related quality of life in endometriosis

2.1 Introduction

To contextualise the current thesis, this chapter considers the factors theorised to influence HRQoL in individuals experiencing endometriosis. Primarily, as a widely used but often poorly conceptualised term, ‘quality of life’ is defined, discussed, and compared to a more specific term, ‘health related quality of life’, which has been adopted for the present thesis (2.2). Next, the approach adopted by the current overview is outlined (2.3). The central component of the current chapter, an overview of the factors contributing to decreased HRQoL in individuals with endometriosis, is subsequently presented (2.4). Primarily, demographic variables are considered (2.4.1), followed by a critical exploration of the evidence linking medical factors such as pain (2.4.2), functioning (2.4.3), healthcare experiences (2.4.4), and infertility (2.4.5) to aspects of HRQoL. Next, the evidence relating psychosocial factors such as body image (2.4.6), self-efficacy (2.4.7), coping (2.4.8) and IPs (2.4.9) to HRQoL are explored, before the literature is summarised (2.4.10). After each of these factors are critically considered, methodological considerations relating to the literature in this field are presented (2.5) before suggestions for future research directions are given (2.6) and the chapter is summarised (2.7).

2.2 Quality of life and health-related quality of life

There is no universally accepted definition of QoL. However, The World Health Organization (WHO, 2012) describe QoL as “an individual’s perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. Measuring QoL in people experiencing chronic illness provides insight into the individual’s daily experience and the impact of their condition and treatment on prominent aspects of their life and health (Haraldstad et al., 2019). Utilising QoL measures in clinical practice ensures that the focus remains on the person rather than just the disease or condition they experience (Hall, 2020; Higginson & Carr, 2001). As such, it is widely recommended that QoL is measured in clinical settings alongside alternate means of assessing change in patients, such as physical examination (Haslam et al., 2020). Despite the significance placed upon measuring QoL in health research, there are diverse understandings and definitions associated with the term and as such the concept is open to interpretation (Kaplan & Hays, 2022). Correspondingly, several existing measures of QoL lack any underlying theoretical conceptualisation (Carr & Higginson, 2001; Kaplan & Hays, 2022) and as such the extent to which different measures evaluate the same underlying concept is unclear.

To circumvent the aforementioned issues associated with measuring QoL, some chronic illness researchers instead measure HRQoL, a narrower term used to describe the physical, psychological and social aspects of experiencing and managing an illness (Jia et al., 2006; Jones et al., 2004; Rush & Misajon, 2018; Van Niekerk et al., 2022).

By focussing on health aspects specifically, measures of HRQoL collect more detailed and specific information on the impact of an individual’s health status on their daily life, wellbeing, and expectations than broader QoL evaluations. However, HRQoL measures are often affected by the same conceptual ambiguity as QoL questionnaires. Whilst it aims to capture the multidimensional impact of health on various aspects of life, the boundaries of what constitutes “health-related” factors can be subjective, varying across individuals and contexts (Karami & Brazier, 2016). Additionally, generic measures of both QoL and HRQoL are designed to capture information across a broad spectrum of diseases and as such may not effectively capture information on wellbeing and functioning relevant to individuals with various chronic conditions. The neglect of illness-specific factors important to people experiencing chronic conditions has implications for HRQoL scores, which may be unusually inflated given the functional and health problems they experience (Carr & Higginson, 2001). For example, in one study, more than 50% of patients with moderate to severe disabilities reported good or excellent HRQoL despite experiencing social isolation and severe daily functioning limitations (Albrecht & Devlieger, 1999). It has therefore been argued that the QoL and HRQoL measures used in clinical and health research settings should be disease-specific and informed by patient accounts of the factors important to them (Bourdel et al., 2019; Page et al., 2017).

In the context of endometriosis, aspects such as dyspareunia, fatigue, and endometriosis-specific symptoms that have the potential to impact upon quality of life for people experiencing endometriosis are often missed in generic measures of HRQoL, such as the SF-36 (Bourdel et al., 2019). The EHP-30 (Jones et al., 2001) and its shortened version, the EHP-5 (Jones et al., 2004), were built based on the accounts of individuals experiencing endometriosis to ensure specificity and relevance to endometriosis. A meta-analysis of HRQoL measures used in endometriosis research recommends that endometriosis-specific measures of QoL such as the EHP-30 are utilised due to the omission of several important endometriosis-related factors in non-specific measures (Bourdel et al., 2019).

It should be noted that the literature discussed within the current chapter incorporates a variety of non-specific and condition-specific QoL and HRQoL measures, with some authors using the terms interchangeably, and this should be considered when reading the following overview.

2.3 Approach of the current overview

The chapter is intended to give a broad overview of the factors associated with HRQoL in the context of endometriosis. It aims to provide a summary of the landscape of the available published research on endometriosis and HRQoL to situate the current project and provide a clear rationale for the current study’s aims. By taking this approach, this overview aims to provide a wide-ranging synopsis of a broad and rapidly evolving field. Additionally, the current overview of the literature outlines gaps in the existing literature base, giving the reader background into the processes which led to the formulation of the aims of the current thesis. This review should therefore not be read as systematic or comprehensive, but as an overview of major trends in the available research at the time of writing. It should be noted that systematic reviews have already been published on this topic, from authors such as Kalfas et al. (2022) and O’Hara et al. (2021).

Broadly, the approach taken to this overview was as follows:

i) Identification of topic of interest (i.e., factors associated with HRQoL in endometriosis)
ii) Broad searches conducted on several databases (including Google Scholar, Web of Science, APA PsycInfo, and the University of Strathclyde’s SuPrimo database)
iii) Search terms narrowed as key factors emerged
iv) Paper structured according to prevalent themes
v) Critical overview of identified factors
vi) Formulation and revision of key research questions
vii) Formulation of second literature overview topic

The key question underpinning the process was: What factors are associated with detrimental HRQoL in the context of endometriosis?

As is evident, the process adopted for the current overview differs from that of many other types of review, including systematic reviews and scoping reviews. A systematic review is a comprehensive, structured review in which methods are collected and analysed through rigorous methods, with a focus on ensuring transparency and reproducibility (Pollock & Berge, 2018). By its nature, this is an in-depth and lengthy process which aims to provide commentary on the robustness of the currently available data. Meanwhile, a scoping review takes a broader approach, aiming to map the existing literature on a broad topic. Whilst the search strategy tends to be systematic in this type of review, there is less of a focus on research quality within scoping reviews, with a quality assessment not traditionally involved in this process (Peters et al., 2017).

In choosing to provide a general overview of the literature in lieu of a more systematic or scoping approach, some potential limitations of the current chapter should be borne in mind before considering the evidence presented. Firstly, reproducibility and transparency of the current review may be limited as no defined protocol for searching, selecting, and analysing studies has been outlined. Correspondingly, there is the potential for bias without adopting a systematic approach. Additionally, some important studies in relation to the topic may have been missed due to the non-exhaustive nature of a general overview. Formal assessments of the quality and risk of bias within the studies outlined are not provided within the current overview, so the robustness of the incorporated evidence cannot be easily gauged.

However, it should be noted that the current chapter, along with the subsequent chapter 3, are intended to serve as introductory chapters, designed to provide context to the reader and clearly outline the processes which led to the formulation of the research questions. By taking a more general approach, as opposed to a systematic approach, general trends in the data are outlined clearly and logically. This approach can be particularly advantageous when the area of investigation is dynamic and still developing, as is the case with the topic under consideration within this overview. Finally, the approach allowed for flexibility in the structure of the current chapter, to support a more narrative flow. With this in mind, as well as the availability of previously conducted systematic reviews and the capacity of the researcher in this time limited project, the decision was made to provide a broad overview of the factors underpinning HRQoL in the context of endometriosis, rather than adopting a more systematic approach.

2.4 Factors contributing to decreased HRQoL in endometriosis

Endometriosis is associated with decreased HRQoL (Gao et al., 2006; Gete et al., 2023; Jia et al., 2012; Kalfas et al., 2022; La Rosa et al., 2019; Marinho et al., 2018; Vitale et al., 2017). Poor HRQoL is a risk factor for mortality (Phyo et al., 2022), cardiac events (Conradie et al., 2020), and additional comorbidities (Butterly et al., 2023). Therefore, it is widely recommended that HRQoL be measured in clinical settings as a treatment outcome in chronic conditions including endometriosis (Bourdel et al, 2019). Despite the importance ascribed to measuring HRQoL in healthcare settings, the mechanisms by which endometriosis leads to decreased HRQoL are not fully understood. However, several factors are thought to contribute to this association including demographics, pain, physical functioning, medical experiences, infertility, body image, self-efficacy, and coping strategies. This section of the current chapter will provide a critical overview of each of these factors, specifically focussing on their relationship with HRQoL in endometriosis.

2.4.1 Demographic variables

At the time of writing, there is a lack of research pertaining to the impact of specific demographic variables on HRQoL in endometriosis. However, advancing age has been associated with reduced wellbeing in this population (Facchin et al., 2015). Table 2.1 provides an overview of the age ranges, mean ages, and findings of the literature included in this section of the current literature overview.

In a Brazilian survey-based study of 104 participants diagnosed with endometriosis, Sepulcri & do Amaral (2009) identified a positive correlation between age and depression. Depression might increase with age due to the progressive and incurable nature of endometriosis, which often requires multiple surgeries. In the same vein, feelings of powerlessness against the condition may increase as treatments fail and the condition continues to persevere, even beyond menopause or following hysterectomy (Streuli et al., 2017). However, importantly, age was not associated with participants' HRQoL scores. This implies that age-related declines in mental wellbeing may be attributed to factors out-with the health status of participants. Indeed, research has uncovered a link between the peri-menopause and increased symptoms of depression (Vivian-Taylor & Hickey, 2014), which may underlie heightened depression scores in older participants. Additionally, the modest sample size of 104 participants may have amplified these effects. Moreover, alternate research has demonstrated the reverse effect – that younger age is correlated with more symptoms of depression in individuals with endometriosis (Lövkvist et al., 2016; Soliman et al., 2017). For example, a Swedish questionnaire-based study including 500 participants conducted by Lövkvist et al. (2016) observed that individuals aged under 30 years experienced more symptoms of endometriosis compared to older participants, including pelvic pain, dysmenorrhea, and dyspareunia. Resultantly, younger participants also experienced lower HRQoL. In a large-scale cross-sectional US-based study including 1269 participants, Soliman et al. (2017) echoed these findings, reporting that pain scores were significantly higher for individuals with endometriosis aged between 18 and 29 compared to older participants. Social support and emotional well-being was rated significantly lower by those aged under 30 years compared to alternate age groups. Correspondingly, younger individuals may be more recently diagnosed with endometriosis, and therefore may be less likely to have established effective coping strategies, including sourcing social support. This may explain, in part, why younger individuals with endometriosis seem to be at greater risk of detriments to HRQoL elements such as mental wellbeing and bodily pain. Additionally, participants who have experienced endometriosis for a longer period are more likely to have identified effective treatments to lessen their symptoms, and are more likely to be at a point of acceptance in their condition which may lower pain perception (Hughes et al., 2017). These findings are substantiated by Rush & Misajon's (2018) mixed methods study of 500 Australian individuals, which found that individuals under 25 reported poorer wellbeing and HRQoL outcomes compared to older individuals living with endometriosis. The qualitative component of their study elucidated these findings, highlighting a lack of control and the perceived unpredictability of the condition as more prominent in younger participants compared to older individuals with endometriosis.

It is important to note that the majority of the literature included within this section of the current review only includes individuals over the age of 18 (see table 2.1). Adolescents experiencing endometriosis have previously reported reduced quality of life (Gallagher et al., 2018), however it is as yet unclear whether reported figures are comparable to the quality of life detriments experienced by older adults with endometriosis, and further research into the impact of age on endometriosis-related quality of life is therefore required. Nonetheless, the literature heavily implies that younger individuals with endometriosis are at the greatest risk of detrimental HRQoL and mental wellbeing outcomes.

Table 2.1

Age and findings of the incorporated literature

Literature details	*N*	*Age range*	*Mean age*	*Key findings*
Sepulcri & Do Amaral, 2009 *Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis*	104	19-48	34.6	Statistically significant positive correlation between age and depression, but no correlation between age and QoL
Lövkvist et al., 2016 *Age-related differences in quality of life in Swedish women with endometriosis*	400	16-67	36.7	Individuals under 30 experienced lower QoL compared to older participants
Soliman et al., 2017 *The burden of endometriosis symptoms on health-related quality of life in women in the United States: a cross-sectional study*	1269	18-54	34.3	HRQoL scores were significantly worse for individuals aged 18-29 than those aged over 40.
Rush & Misajon, 2018 *Examining subjective wellbeing and health-related quality of life in women with endometriosis*	500	18-63	30.5	Significant age differences identified in HRQoL score, with younger participants consistently reporting poorer HRQoL

2.4.2 Pain

Pain is frequently linked to HRQoL in the context of endometriosis (Centini et al., 2013; Jia et al., 2012; Márki et al., 2017; McPeak et al., 2018; Van Niekerk et al., 2022). Individuals presenting with high levels of endometriosis-related pain are likely to report significant impairments to their HRQoL (Centini et al., 2013), as well as depression (Lorençatto et al., 2004), anxiety (Sepulcri & do Amaral, 2009), and sexual dysfunction (Melis et al., 2015). Importantly, there is considerable disparity in the way in which endometriosis-related pain manifests. For example, individuals experiencing endometriosis report pain of varying intensity in several different areas of the body, including the pelvic area, bowel, bladder, lungs, kidneys, nerves, and lower body (Drabble et al., 2020). Therefore, there is substantial heterogeneity in how endometriosis pain is experienced (Drabble et al., 2020), and consequently it is likely that the impact of pain on HRQoL varies considerably between individuals living with the condition. As discussed in chapter 1, dysmenorrhea, dyspareunia, dyschezia, and non-menstrual pelvic pain are the most commonly reported categories of endometriosis-related pain (Montanari et al., 2019). In a cross-sectional Italian study, Facchin et al. (2015) compared these categories of pain specifically with reference to their impact on endometriosis-specific HRQoL. Non-menstrual related pelvic pain was the most significant predictor of poor HRQoL, affecting both physical and mental HRQoL domains. Dysmenorrhea predicted physical HRQoL only, with no significant impact on mental health components. Dyspareunia and dyschezia had no influence on HRQoL. It must be noted that the participants of this study reported generally good HRQoL, although HRQoL was lower in individuals with symptomatic endometriosis than in asymptomatic controls and a general population sample, implying that any disparity in HRQoL scores between the groups is likely to arise from endometriosis-related symptomology such as pain. However, it is important to note that Facchin et al.'s (2015) study included only White individuals, therefore the transferability of these findings to the wider population is questionable. Additionally, the study does not specify how many participants experienced dyspareunia and dyschezia, which, although common, are less widely experienced than endometriosis-associated pelvic pain. As it is unknown how many participants experienced these categories of pain, it is unclear whether the results showing no relationship between dyspareunia, dyschezia and HRQoL are representative of the wider population. Indeed, contrary to Facchin et al.'s (2015) findings, an American survey-based study by Schneider et al. (2020) reported that dyspareunia is directly associated with decreased HRQoL in both physical and mental QoL domains.

Although dyspareunia was a source of adverse HRQoL for individuals both with and without endometriosis, this effect is stronger for those with endometriosis, suggesting that pain associated with sexual activity impairs HRQoL both directly and indirectly by triggering psychosocial mechanisms that further impede HRQoL for those experiencing endometriosis. Correspondingly, in a qualitative account of the impact of dyspareunia on the lives of people living with endometriosis in England, Denny and Mann (2003) emphasised the negative impact of dyspareunia on sexual functioning and highlighted a significant negative impact on participants' relationships with their partners. Dyspareunia was further associated with negative self-esteem, fuelled largely by feelings of inadequacy and shame. This effect was strongest in younger individuals. However, Schneider et al.'s (2020) study focussed solely on adolescents and young adults experiencing dyspareunia, therefore the acquired results may not be generalisable to older individuals with endometriosis. Nonetheless, further research has corroborated Scheider et al.'s (2020) findings, demonstrating a link between endometriosis-related dyspareunia and impaired HRQoL across a variety of age ranges (Shum et al., 2018).

At the time of writing, no literature on the impact of endometriosis-related dyschezia was identified. Research to address this gap in the literature will offer further insight into the experience of pain in endometriosis, and the impact of specific categories of pain on HRQoL.

In terms of general pain, multiple studies have sought to determine the influence of pain and endometriosis-related symptoms on HRQoL by measuring HRQoL prior to and following surgery for endometriosis (Comptour et al., 2019; Gortazar de Las Casas et al., 2022; Riiskjær et al., 2018; Setälä et al., 2012). Several studies have observed that effective surgery resulting in endometriosis-related pain reduction prompts an increase in HRQoL (Comptour et al., 2019; Gortazar de Las Casas et al., 2022; Riiskjær et al., 2018; Setälä et al., 2012). For example, a meta-analysis of 38 studies (Arcoverde et al., 2019) reported that, for all types of endometriosis (see chapter 1 section 1.3.1), the mental health components of HRQoL were significantly improved following surgery to excise or ablate endometriosis lesions. All dimensions of HRQoL were improved following surgery for deep infiltrating endometriosis, including functioning, physical health, bodily pain, and emotional processing. This effect appears to be long-lasting, with several longitudinal studies observing stable HRQoL scores in the majority of patients following complete endometriosis surgery (Byrne et al., 2018; Comptour et al., 2019; Turco et al., 2020). Comptour et al. (2020) broke down this effect, reporting that 53-67% of patients experienced an improvement in HRQoL following laparoscopic surgery to remove endometriosis lesions, an effect that remained stable over the course of 36 months. Only 5-11% did not experience any change in HRQoL following surgery. Roughly a third of patients experienced a significant improvement in pain following surgery, whilst a third experienced persistent pain symptoms. However, within 60 months post-surgery, 40-50% of individuals diagnosed with endometriosis are likely to experience pain recurrence (Horne & Saunders, 2019) which may prompt a subsequent decline in HRQoL at the 5-year mark. Therefore, longitudinal research is required to assess the longer-term impact of endometriosis surgery on pain and HRQoL domains. Due to the high recurrence rate of endometriosis-related pain, many individuals require multiple surgeries to reduce endometriosis-related pain and symptom severity (Saraswat et al., 2018) however at the time of writing there is little research on the impact of multiple surgeries for pain management and HRQoL in endometriosis. Nonetheless, one study did report that undergoing a single surgery at an older age was associated with better HRQoL, whilst multiple reoperations were associated with poor HRQoL including higher self-reported bodily pain (Vannuccini et al., 2019).

It should be noted that surgery may positively influence alternate factors alongside pain, such as functioning, body image and perceptions of control, which may also impact endometriosis-related QoL (Chaman-Ara et al., 2017; Jones et al., 2004; Van Niekerk et al., 2022). Consequently, increases in HRQoL through surgery cannot be wholly attributed to pain reduction. Relatedly, Abbott et al. (2004) found that placebo surgery was effective in improving the symptoms of endometriosis in 32% of their sample, compared to 80% of those undergoing surgical procedures to extract endometriosis lesions. There was an overall increase in HRQoL in both the surgery and placebo group, although HRQoL was most improved for those who had undergone surgery. This indicates that pain and endometriosis symptomology do not solely predict HRQoL outcomes in this population. However, it should be noted that the study included only 39 individuals with endometriosis, therefore the transferability of the results is uncertain.

To disentangle the impact of endometriosis-related pain on HRQoL from alternate endometriosis-specific and psychosocial factors, it is useful to consider the impact of chronic pelvic pain (CPP) without endometriosis on HRQoL. CPP is characterised by enduring pelvic pain existing for more than 6 months (Dydyk & Gupta, 2022). Research has generally shown that HRQoL is similarly impaired in both CPP and endometriosis (Lorençatto et al., 2006; Tripoli et al., 2011; Warzecha et al., 2020), implying that pain is the most prominent driver of endometriosis-related QoL. In a meta-analysis incorporating 99,614 participants, Gambadauro et al. (2019) concluded that those living with endometriosis and those experiencing CPP both had similar rates of depression, yet individuals with symptomatic endometriosis showed higher levels of depression than those with asymptomatic endometriosis. This implies that pain is a greater determinant of HRQoL and wellbeing than experiencing endometriosis alone. However, although CPP is characterised by pain, other psychosocial factors are likely to play a role in determining HRQoL and wellbeing in this population. For example, it is likely that many individuals struggle with a lack of answers and/or treatment available for their pain. Individuals with endometriosis often describe the anxiety and depression they experienced prior to diagnosis, fuelled by uncertainty surrounding their symptoms (Denny, 2009). Such uncertainty is likely to be experienced by those with CPP also, subsequently influencing their wellbeing and HRQoL. Furthermore, as described in chapter 1, it is thought that up to 60% of endometriosis cases are undiagnosed (Morassutto et al., 2016), and it is therefore likely that some in the CPP comparison groups have an underlying condition such as endometriosis. There is no way to rule this possibility out due to the prevalence of missed cases and misdiagnosis in endometriosis as described in chapter 1 (Simko & Wright, 2022; Tirlapur et al., 2015). The appropriateness of comparing CPP and endometriosis to gain an insight into the impact of pelvic pain alone on HRQoL is therefore unclear.

Conversely, a small collection of literature has detected some differences in HRQoL between those experiencing CPP and those experiencing endometriosis, implying that mechanisms beyond pain predict HRQoL in endometriosis. For example, in an Italian cross-sectional study of quality of life in individuals with and without endometriosis, Centini et al. (2013) found that, although people experiencing CPP and those experiencing endometriosis demonstrated negative HRQoL, there was a greater impact on HRQoL for individuals experiencing endometriosis. Thus, at present, the question of whether those with endometriosis have worsened HRQoL compared to individuals experiencing CPP remains unanswered due to contradictory results in the available literature, and uncertainty surrounding the source of the CPP experienced by the individuals recruited within such studies.

Ultimately, pain appears to be a major driver of HRQoL in endometriosis, as is the case in other conditions characterised by chronic pain such as rheumatoid arthritis (Matcham et al., 2014), fibromyalgia (Gormsen et al., 2010), and chronic back pain (Ge et al., 2022). The mechanisms by which pain impacts HRQoL and the extent to which pain impacts HRQoL cannot currently be deciphered from the existing literature. However, it is likely that alternate endometriosis-specific factors including psychosocial elements play a role in determining HRQoL for those experiencing endometriosis. Additionally, it is probable that pain and HRQoL operate in a cyclical manner, with pain fuelling HRQoL detriments, and decreased HRQoL worsening pain perception. Moreover, pain is likely to affect HRQoL directly, but also indirectly, for example through driving functioning detriments which have their own unique impact on HRQoL.

2.4.3 Functioning

Functioning detriments are widely associated with endometriosis (Facchin et al., 2021; Jones et al., 2004; Nnoaham et al., 2011). Functioning detriments refer to issues performing essential and/or meaningful tasks (Facchin et al., 2021). In endometriosis, they are often driven by pain but may also be attributable to alternate endometriosis-specific factors such as heavy menstruation, bloating, fatigue, and negative body image (Barbara et al., 2017; Facchin et al., 2021). Day-to-day physical functioning is impaired by endometriosis (Lozano-Lozano et al., 2021), with many reporting issues with mobility as a result of their condition, including problems with sitting, standing and walking (Jones et al., 2004). Following qualitative interviews with 24 UK-based individuals experiencing endometriosis, Jones et al. (2004) identified physical functioning as a significant factor contributing to decreased HRQoL and wellbeing. Daily functioning is a key outcome in the physical health domain of many HRQoL measures due to its impact on the everyday lives of individuals living with chronic conditions. In endometriosis, detriments to physical functioning are often associated with depressed and anxious mood (Jones et al., 2004; Laganà et al., 2022). Beyond day-to-day physical functioning, functioning detriments are often split into three categories: i) sexual functioning; ii) social functioning; and iii) work functioning.

2.4.3.1 Sexual functioning

Individuals with endometriosis often report an adverse impact on their sexual desire, arousal, enjoyment, and frequency of sexual activity (Facchin et al., 2021; Melis et al., 2015; Montanari et al., 2013; Pluchino et al., 2016; Rossi et al., 2020). Detriments to sexual functioning are often attributed to endometriosis-specific symptoms such as dyspareunia, fatigue, negative body image, and bloating (Barbara et al., 2017; De Graff et al., 2016; Facchin et al., 2021; Pluchino et al., 2016). Reduced sexual functioning has a detrimental impact on psychological distress and HRQoL (Facchin et al., 2021; Melis et al., 2015; Montanari et al., 2013; Pluchino et al., 2016; Rossi et al., 2020). In a cross-sectional Italian study, Melis et al. (2015) reported that, compared to a control group without endometriosis, participants living with the condition experienced increased pain during sexual intercourse and more substantial pain following penetrative intercourse. Participants with endometriosis reported significantly lowered HRQoL in all domains compared to the control group, and demonstrated body dissatisfaction which was correlated with the mental health domain of HRQoL. Increased sexual desire, arousal, orgasm, and satisfaction were related to more positive self-reported mental health outcomes. However, Melis's (2015) study included only 40 participants with endometriosis, which may limit the generalisability of the results. Nonetheless, the findings of the study are corroborated by several other papers, including qualitative accounts of the impact of reduced sexual functioning on HRQoL and wellbeing. For example, individuals with endometriosis often describe a sense of guilt, shame and inadequacy arising from reduced sexual functioning, leading to low self-esteem and reduced HRQoL (Denny & Mann, 2007; Facchin et al., 2021). Facchin et al. (2021) synthesised the available qualitative literature on dyspareunia and sexual functioning in endometriosis, identifying a significant and detrimental impact of dyspareunia on psychological health and QoL elements. Participants often described a sense of lost femininity and self-esteem through sexual dysfunction, and perceived associated, adverse effects on their relationships. Despite the substantial negative impact of sexual dysfunction on their HRQoL, participants described a reluctance to openly discuss sex both in medical and non-medical settings, constituting a barrier to support. Some participants had found ways to work around reduced sexual functioning, by identifying and practicing ways to engage in sexual activity without penetration, for example. This in turn reduced negative emotions such as guilt and shame, highlighting the positive impact that support to reframe definitions and perceptions of sexual activity may have on the lives of individuals experiencing endometriosis with sexual dysfunction. Importantly, all qualitative studies included in Facchin et al.'s

(2015) review were deemed to be of moderate to high quality. However, notably, there was a lack of reflection from researchers on their positionality, expertise and previous experience as a potential source of bias within the studies reviewed.

It must be noted that there are differences in the way in which sexual functioning detriments manifest in people experiencing sexual dysfunction along with endometriosis. For example, an Italian cross-sectional study of 110 individuals with and without endometriosis identified that, despite increased pain and discomfort associated with sexual activity, those living with endometriosis experienced no loss of sexual desire (Rossi et al., 2008). However, this study included only 55 individuals with endometriosis and in broader scale research the opposite effect has been identified, with reports that sexual desire is indeed impaired by the symptoms of endometriosis (Melis et al., 2015; Rossi et al., 2020). Reduced desire to engage in sexual activity may be indicative of coping strategies aimed at self-preservation. For example, it is reasonable to assume that withdrawal from sexual activity is perceived as a means of reducing pain and increasing wellbeing as a result. However, from a mental health perspective, it appears that such strategies are counterintuitive. For example, Melis et al. (2015) identified an inverse correlation between sexual desire and depression in individuals with endometriosis – that is, increased sexual desire was associated with a decrease in depression and vice versa. Therefore, strategies to increase sexual desire and pleasure may lead to improved mental health and, subsequently, increased HRQoL for many experiencing endometriosis with sexual functioning limitations.

In keeping with the heterogenous experience of endometriosis-related sexual dysfunction, there appears to be a worsened impact on sexual functioning for those with advanced stages of endometriosis, such as DIE (Melis et al. 2015). At the time of writing there is little research comparing the different stages of endometriosis on their impact on sexual functioning and HRQoL. However, DIE has been associated with a higher risk of dyspareunia, reduced frequency of sexual intercourse, and less enjoyment of sexual activity (Ferrero et al., 2005). Future research is required to directly assess the impact of sexual dysfunction on HRQoL in different endometriosis sub-types. Research has also linked infertility with reduced sexual functioning (Monga et al., 2004; Starc et al., 2019), although this link is not well-studied in the context of endometriosis. Furthermore, perhaps unexpectedly, one small-scale study reported that fertile individuals with endometriosis actually experienced more detrimental psychological and functional outcomes than those with infertility, including reduced sexual functioning. This effect was theorised to be associated with higher levels of support and understanding offered to individuals with infertility. However, this study included few participants and is contrary to a wide body of literature linking infertility with reduced sexual functioning and reduced HRQoL compared to fertile controls (Bakhtiyar et al., 2019; Chachamovich et al., 2010), so the accuracy of its conclusions remains unclear. Future research should therefore seek to disentangle the relationship between sexual functioning, infertility and HRQoL in the context of endometriosis.

Support from intimate partners, sexual therapy, and identifying alternate means of engaging in sexual activity appear to be protective factors against the impact of sexual dysfunction in HRQoL (Facchin et al., 2021). Due to the significant negative impact of reduced sexual functioning on the HRQoL of those living with endometriosis, it may be beneficial to develop and trial interventions targeting this specific element of experiencing endometriosis. The extant literature suggests that body image and infertility may potentially mediate the relationship between sexual functioning and HRQoL, although further research is required to aid understanding of the mechanisms underlying this association.

2.4.3.2 Social functioning

Endometriosis is often linked to adverse impacts on social functioning (Jones et al., 2004; Moradi et al., 2014). For example, individuals with endometriosis frequently describe withdrawal from social settings as a direct result of their condition, often fuelling feelings of isolation (Grogan et al., 2018). Social withdrawal may be associated with endometriosis-specific symptoms, such as pain, digestive issues, and fatigue (Gao et al., 2006; Jones et al., 2004), but it is likely that widespread misunderstanding of the condition further fuels isolation by impacting on social support and the extent to which individuals feel comfortable to openly discuss their experiences (Moradi et al., 2014). A meta-analysis by Gao et al. (2006) identified social functioning as one of the most impacted areas of QoL in individuals with endometriosis, illustrating the significant impact of endometriosis on the social lives of individuals living with the condition. However, multiple QoL measures were utilised across the studies reviewed and there are disparities in the questions included in each QoL and HRQoL measure. For example, the Short Form-36 (SF-36; Anderson et al., 1996) asks participants to rate the extent to which their condition has limited their social activities, whereas the World Health Organisation's Brief QoL measure (WHOQOL-BREF; 1998) assesses social functioning by asking participants to rate their satisfaction with their personal relationships and support from friends. Therefore, the extent to which social functioning can be compared between studies employing diverse QoL measures is questionable, since different tools may measure alternate underlying variables, such as social support (i.e., perceptions and utilisation of available support resources) or social engagement (i.e., active participation in social activities or events). Nonetheless, a wide-ranging report on endometriosis, prepared by the UK parliament in 2020, echoed Gao et al.'s (2006) findings (APPGE, 2020), reporting that almost a quarter of respondents (24%) never or seldom felt able to participate in social events due to their endometriosis. Furthermore, only 33% had felt able to participate in social events often or very often, illustrating the detrimental impact of endometriosis on the social lives and relationships of those experiencing the condition. Additionally, in a cross-sectional survey-based study, Sullivan-Myers et al. (2021) reported a link between social functioning detriments and psychological distress, including low mood and anxiety amongst individuals with endometriosis in Australia.

Despite a well-established link between adverse social functioning and endometriosis, quantitative research at the time of writing provides little information on the impact of social functioning detriments on the lives of individuals experiencing endometriosis. Qualitative research, however, offers a rich account of the mechanisms underlying limited social functioning and the consequences of reduced social functioning for those diagnosed with endometriosis. For example, qualitative research paints withdrawal from social events as a widely used coping strategy aimed at reducing pain and discomfort by avoiding unnecessary social contact. However, individuals experiencing endometriosis often describe a negative impact of this coping strategy on their friendships, including increased emotional distance and loss of friendship as a consequence of limiting social contact (Grogan et al., 2018). Therefore, social withdrawal reduces the opportunity for social support, a well-established protective factor against depression and anxiety (Alsubaie et al., 2019; Grey et al., 2020; Szkody & McKinney, 2019), and heightens the risk for isolation, an important risk factor for adverse mental health consequences (Almeida et al., 2021; Sharma et al., 2020). Social support is a significant predictor of HRQoL in several conditions (Cassarino-Perez & Dell’Aglio, 2014; Leung et al., 2014) including endometriosis (Guillemot et al., 2023).

The existing literature therefore indicates that endometriosis exerts a pervasive, negative impact on the social lives and relationships of individuals experiencing the condition. Future research may aim to determine strategies to improve social functioning and alleviate feelings of isolation. As pain and functioning detriments are often the cause of reduced social contact, it would be particularly useful to ascertain the impact of online support compared to face-to-face support on HRQoL and isolation in endometriosis, following a shift in support trends due to the COVID-19 pandemic.

2.4.3.3 Work functioning

Individuals experiencing endometriosis often report a negative impact on their career, employment, and academic achievements due to the symptoms associated with the condition (Facchin et al., 2019; Hansen et al., 2013; Nnoaham et al., 2011). A report published on endometriosis by the UK parliament (APPGE, 2020) stated that 55% of those surveyed had to take time of work often or very often, 38% felt restricted in the roles they could take, and 38% were concerned about potentially losing their jobs. Additionally, 35% of individuals diagnosed with endometriosis had experienced financial hardship as a result of their employment status. Relatedly, in a cross-sectional Italian survey-based study, Facchin et al. (2019) observed that individuals were more likely to be unemployed if they had symptomatic endometriosis, compared to asymptomatic controls and the general population. Unemployment was correlated with greater bodily pain. This was a wide-scale study incorporating 630 individuals both with and without endometriosis. However, important factors that may contribute to unemployment such as socioeconomic status and the availability of employment in the area of study, as well as the presence of co-morbidities, were not considered in Facchin et al.'s research, which should be recognised as a limitation.

Generally, research has demonstrated that people in full-time employment have better overall QoL and mental wellbeing than unemployed individuals (Carlier et al., 2013; van Rijn et al., 2016). Furthermore, the nature of employment has a significant impact on QoL and wellbeing (ter Hoeven & van Zoonen, 2015). For example, individuals reporting better work-life balance and engaged in flexible working practices report better QoL (Haar et al., 2014). Therefore, individuals experiencing endometriosis and in flexible employment may experience a reduced impact on their work functioning resulting in reduced adverse QoL consequences. No research examining different types of employment and HRQoL in the context of endometriosis was identified at the time of writing, however due to the impact of endometriosis on the career trajectories and opportunities of those experiencing the condition, this is an important area for future research.

Endometriosis has an impact not only on employment status, but also on absenteeism and presenteeism at work. In a cross-sectional survey-based study, Hansen et al. (2013) reported that Danish individuals with endometriosis took more sick days, faced more disturbances at work, and perceived lower work ability than a control group of individuals without endometriosis. Importantly, higher absenteeism and presenteeism was associated with feelings of depression. Nnoaham et al. (2011)

quantified these effects in a large-scale study incorporating individuals experiencing endometriosis across ten countries. It was found that each participant lost an average of 10.8 hours of work per week due to the impact of endometriosis on their work effectiveness. Furthermore, participants with endometriosis demonstrated lower HRQoL scores than those without, specifically in the physical health domain, which impeded their effectiveness at work. It is likely that work effectiveness and physical HRQoL scores operate in a cycle, in which lower physical HRQoL negatively impacts productivity and absenteeism at work, fuelling further detriments to physical HRQoL, although further research is necessary to confirm this potential link. Additionally, it has been suggested that reduced work functioning may impact HRQoL indirectly, by increasing the risk of depression and sexual dysfunction in the context of endometriosis (Gonzalez-Mesa et al., 2021). Furthermore, in qualitative work, participants often describe feelings of powerlessness and hopelessness connected to their employment status (Jones et al., 2004; Márki et al., 2022; Moradi et al., 2014), reflecting the significant negative impact of endometriosis on the life trajectories and mental health of those experiencing the condition.

2.4.4 Healthcare experiences

Within healthcare settings, individuals with endometriosis face barriers to support including diagnostic delays, ineffective treatment and, often, strained relationships with their medical team (Cox et al., 2003; Young et al., 2020). Studies examining the impact of negative medical experiences on HRQoL are lacking at the time of writing, however a small collection of literature has investigated the impact of common experiences within medical settings, for example invalidation and delayed diagnosis, on the wellbeing of individuals experiencing endometriosis. For example, after seeking medical support for their symptoms, individuals with endometriosis widely report the minimisation and dismissal of their symptoms within healthcare environments (Grundström et al., 2023), leading to a sense of invalidation and, ultimately, delayed diagnosis of endometriosis (Cox et al., 2003; Evans et al., 2022; Van Der Zanden et al., 2020).

In a survey-based study of 427 individuals with endometriosis in Sweden, Grundström et al. (2023) reported that healthcare experts provided the highest level of invalidating communication, whilst family members and friends provided the highest level of validating communication in relation to endometriosis symptom disclosure. The type of communication received was directly linked to HRQoL, with invalidation in medical settings predictive of worsened HRQoL, and validation exerting a protective effect on HRQoL. However, the study uses the ENDOCARE questionnaire to measure the patient-centredness of care. As individuals are required to recall their endometriosis care across their lifetime in this questionnaire, there is a high risk of recall bias. Nonetheless, the findings of Grundström et al (2023) were corroborated by a cross-sectional survey-based study (Bontempo 2022), which observed a negative relationship between invalidation within medical settings and self-esteem, suggesting that the dismissal of an individual’s symptoms has a direct, negative impact on the way they view themselves. Additionally, individuals who felt invalidated by healthcare professionals after seeking support for their endometriosis symptoms reported a higher incidence of depressive symptoms. Diagnosis therefore often provides relief for individuals with endometriosis, bringing with it a sense of validation and a corresponding increase in their emotional wellbeing (Ellis et al., 2022). However, Facchin et al. (2017) observed that individuals who had been more recently diagnosed with endometriosis experienced higher anxiety compared to individuals with a more longstanding diagnosis. This indicates that the sense of relief derived from an endometriosis diagnosis is short lived, rapidly giving way to a sense of anxiety surrounding the future and life with endometriosis.

Additionally, endometriosis is associated with lengthy diagnostic delays (see chapter 1, section 1.3.3). Diagnostic delays appear to exert a long-lasting impact on HRQoL. For example, in an Australian survey-based study, Gallagher et al. (2018) reported that increased diagnostic delay was associated with poorer HRQoL outcomes in adolescents and young adults aged under 25 years. Specifically, individuals experiencing diagnostic delays of over 3 years experienced impairments to their physical HRQoL, for example physical functioning and pain, but not their mental HRQoL. Furthermore, in a study including all age ranges, endometriosis-related diagnostic delays were also associated with reduced physical HRQoL (Nnoaham et al., 2011), implying that delayed diagnosis directly and negatively impacts elements such as daily functioning and disability status, but not mental wellbeing. However, at the time of writing there is limited research examining the impact of diagnostic delay on HRQoL, restricting the strength of the conclusions that can be drawn from the current literature. Where it is measured, diagnostic delay tends to be considered as secondary variable, so some of the potential impact of diagnostic delay on wellbeing outcomes may be lost. Future research may therefore wish to examine diagnostic delay as a primary outcome variable to ascertain the relative impact of this factor on wellbeing and HRQoL.

More generally, the existing literature widely indicates that navigating the healthcare system is a source of frustration and prompts negative emotions for many experiencing endometriosis. Across qualitative literature, participants frequently outline the detrimental impact of their interactions with medical professionals on their mental health and wellbeing, with these effects often described as enduring (Young et al., 2015). However, there is currently limited research examining the impact of a range of common medical experiences on HRQoL specifically, including invalidation and symptom minimisation within healthcare settings. Nonetheless, it must be noted that, at the time of writing, work is ongoing to conceptualise and measure invalidation as experienced by individuals with endometriosis (Bontempo, 2023) to ensure that this important facet of experiencing endometriosis may be captured in quantitative research.

Notably, no research pertaining to the impact of endometriosis misdiagnosis on HRQoL outcomes was identified. In a US-based study of 758 patients with medically confirmed endometriosis, 75.2% of individuals experienced misdiagnosis with a physical and/or mental health condition (Bontempo & Mikesell, 2020), illustrating the pervasiveness of misdiagnosis in this population. It would therefore be beneficial to ascertain the potential long-term psychological impact of misdiagnosis within this population. However, the omission of these factors in quantitative research may reflect a lack of standardised tools to measure these variables, and therefore additional research could endeavour to establish valid and reliable measures to capture this information. Qualitative research has linked misdiagnosis to deteriorations in trust in medical professionals (Fernley, 2021) and frustration within healthcare environments (Moradi et al., 2014), however a link to HRQoL and/or wellbeing variables has yet to be firmly established. Therefore, future research should endeavour to establish whether there is a link between misdiagnosis and HRQoL in this population.

2.4.5 Infertility and subfertility

Infertility is thought to affect 30-50% of individuals experiencing endometriosis (Meuleman et al., 2009). Furthermore, up to 50% of individuals assigned female at birth presenting with infertility have endometriosis (Vitale et al., 2017). Although infertility has been linked to endometriosis, it is as yet uncertain whether this is a cause-and-effect relationship. It is also unclear whether individuals experiencing endometriosis are indeed at heightened risk of infertility, defined as an inability to become pregnant following 12 months of unprotected sexual intercourse, or if there is a greater risk of subfertility, defined as an extended delay in the onset of pregnancy (Stellar et al., 2016). Nonetheless, for individuals looking to conceive naturally, fertility problems are associated with a significant negative impact on mental health and wellbeing (Hi-Kwan Luk & Yuen Loke, 2016; Dadhwal et al., 2022). Furthermore, infertility is linked to poor HRQoL specifically for those diagnosed with endometriosis (Heng & Shorey, 2022; Vitale et al., 2017). There is currently limited quantitative research on the impact of infertility on HRQoL in the context of endometriosis, however qualitative research provides a rich account of how infertility and IVF treatment impact the QoL of individuals experiencing endometriosis (Heng & Shorey, 2022; Young et al., 2015). For example, in a UK-based qualitative study, Jones et al. (2004) observed that, amongst individuals experiencing fertility problems alongside endometriosis, there was a sense of inadequacy and shame, alongside perceptions of being “an incomplete woman” due to infertility. Several participants disclosed feelings of anxiety and depression related to their fertility problems, with many describing issues in their romantic relationships due to difficulties with conception. Additionally, a mixed methods investigation into infertility-specific QoL in individuals experiencing endometriosis (Zarbo et al., 2022) found that assisted reproductive therapies were poorly tolerated and decreased HRQoL by increasing feelings of powerlessness and guilt. The intolerance of assisted reproductive therapies was further associated with increased bodily pain. Through qualitative interviews, participants also noted a discrepancy between their identity as someone who has been unable to conceive, and their internalised ‘ideal’ or ‘cultural’ identity in which they can carry children, often leading to distress. Previous miscarriage further mapped onto adverse HRQoL outcomes in this population. Although this study illuminates our understanding of the impact of potential infertility on the wellbeing of individuals experiencing endometriosis, the quantitative element of this study involved only 22 participants drawn from a clinical sample, and therefore it is not possible to generalise these findings to the wider population. It would be beneficial for future research to employ larger-scale surveys to reach more individuals with endometriosis and associated fertility problems. However, as previously stated, there is no clear mechanism by which endometriosis impacts fertility, so it is uncertain whether the association between endometriosis and infertility/subfertility represents a cause and effect. Therefore, further research is required to clarify this before any consequences of infertility on HRQoL can be fully attributed to the experience of endometriosis. Additionally, at the time of writing there is no research on the impact of endometriosis-related fertility on the HRQoL of people for whom fertility is not an issue or a priority (for example, those who do not wish to conceive, or those who have had no issues with conceiving). This is important because many individuals are diagnosed with endometriosis only after they approach medical services with issues surrounding their fertility (Young et al., 2016). Therefore, there are likely to be further delays in diagnosis for those not seeking support with their fertility, which may negatively impact HRQoL (Cox et al, 2003). Future research should address this by exploring the HRQoL impact of infertility for different groups (e.g., for those who would like to conceive naturally, those who have conceived naturally, and those who do not want to conceive naturally). Qualitative research of this kind would be particularly beneficial to provide a rich insight into the impact of infertility on the lives of a diverse range of individuals experiencing endometriosis, sharpening understanding of the ways in which endometriosis-associated factors such as infertility may impact on HRQoL.

2.4.6 Body image and self-esteem

There is a well-established link between endometriosis and poor body image (Melis et al., 2015; Van Niekerk et al., 2022). This relationship is thought to be influenced by endometriosis-specific symptoms such as bodily pain, bloating, heavy menstruation, and digestive issues (Sayer-Jones & Sherman, 2022). Poor body image is related to an increased risk of depression and lowered HRQoL in people living with endometriosis (Sullivan-Myers et al., 2021), with qualitative work indicating that those with poor body image experience shame, isolation, and perceived threats to their relationships (Van Niekerk et al., 2022). For example, in an Australian-based study, Sayer-Jones and Sherman (2022) examined body image across 40 in-depth interviews with individuals experiencing endometriosis. Many participants described feelings of shame towards their bodies, causing them to actively hide their bodies under baggy clothes and to miss social events. Participants described embarrassment around specific endometriosis symptoms such as bloating, which for many caused distress and feelings of unattractiveness. This, in turn, had an impact on their sexual functioning and lowered their confidence, often impacting on participants’ intimate relationships. Additionally, Van Niekerk et al. (2023) examined the impact of body compassion, a specific element of overall body image, on the HRQoL of people experiencing endometriosis across Australia. Higher self and body compassion were associated with increased HRQoL in both physical and mental domains. Furthermore, familiarity with one's own body is associated with increases in both physical and mental HRQoL (Van Niekerk et al., 2022). Therefore, incorporating therapeutic approaches such as body-compassion and incorporating body familiarity techniques into endometriosis care may support the QoL of individuals experiencing endometriosis.

Body image impacts endometriosis-specific HRQoL elements directly, but also indirectly by influencing additional psychosocial mechanisms. In an Australian-based longitudinal study over 2 months, Pehlivan et al. (2022) observed that body image directly predicted depression in individuals experiencing endometriosis, but also influenced self-esteem. Self-esteem did not have a direct impact on depression, but acted as a mediator between body image and depression. Research has demonstrated that high levels of self-esteem can enhance the ability to cope with chronic conditions, often leading to improvements in mental health and pain perception (Mann et al., 2004; Shaygan & Karami, 2020). However, contrary to Pehlivan et al.'s (2022) findings, an Italian survey-based study by Facchin et al. (2017) reported a direct impact of both general self-esteem and body esteem on psychological outcomes including anxiety, depression and rumination in a group of individuals with endometriosis. As self-esteem increased, adverse mental health impacts decreased. However, this study did not incorporate a control group, which is of particular importance considering the current trends in self-esteem. For example, the Mental Health Foundation (MHF; 2019) reported that over one third of adults experienced low mood due to their body image, whilst one in five felt shame or disgust related to their bodies. Shame associated with body image increases for adolescents and young adults, with 31% feeling ashamed of their bodies (MHF, 2019). Individuals identifying as female are more likely to experience low self-esteem than those identifying as male (Bleidorn et al., 2016). Therefore, the inclusion of a control group is essential in research on self-esteem and body image, to determine whether there is an increased risk for low self-esteem and negative body image amongst individuals experiencing endometriosis. Nonetheless, recent research has employed control groups and corroborated the findings of Facchin et al. (2017). For example, Volker and Mills (2022) reported that those living with endometriosis in Australia experience lower appearance satisfaction and poorer body image than a general population sample. Similarly, Geller et al. (2021) compared healthy controls and individuals experiencing endometriosis within Israel on body image, depression and anxiety, finding that body image was poorer and self-criticism higher in the endometriosis group. Subsequently, poorer body image and higher self-criticism predicted a greater likelihood of anxiety and depression. However, these studies do not directly demonstrate the impact of poor body image on HRQoL domains, so further research is needed to explore this potential link further.

Despite the clear negative impact of endometriosis on the body image of individuals experiencing the condition, research trialling interventions such as yoga, acupuncture, dietary supplementation, and herbal medicine generally does not measure body image pre and post treatment (Falconer et al., 2022). Therefore, the effectiveness of interventions for increasing body confidence in this population cannot yet be gauged. Furthermore, the current literature assessing the potential link between body image and endometriosis-related QoL either focusses on cis-gendered individuals identifying as women, or does not provide details pertaining to the number of cis-gendered and non-gender conforming individuals included. This is problematic due to the additional distress potentially faced by individuals who do not conform to the gender they were assigned at birth. To exemplify, due to the incongruity between their biological sex and gender identity, non-binary and transgender individuals often experience gender dysphoria, which can lead to depression, anxiety, poor self-esteem and, in extreme cases, suicidality (Garg et al., 2022). Therefore, future research should aim to examine body image from a range of perspectives including non-gender conforming individuals experiencing endometriosis.

2.4.7 Self-efficacy

Albert Bandura (1996, p.2) defined self-efficacy as the “belief in one's capabilities to organize and execute the courses of action required to manage prospective situations.”. Specific to health, self-efficacy relates to the extent to which an individual perceives control over their health and their ability to complete health-oriented tasks (Bandura, 2004). The World Health Organization promotes the active self-management of chronic diseases (Slama-Chaudry et al., 2019). Self-efficacy aids self-management by instilling the confidence required to complete the tasks essential to the self-management of health. Higher self-efficacy has been linked to increased goal setting, greater commitment to achieving health-oriented goals, and increased belief in the ability to achieve goals and improve health status (Bandura, 2004). Furthermore, individuals experiencing chronic disease but with high self-efficacy seem to cope more effectively with bodily pain (Bandura et al., 1987). Self-efficacy has been linked to HRQoL in endometriosis (Facchin et al., 2017; Rees et al., 2022). A systematic review prepared by O’Hara et al. (2021) reported that increased self-efficacy predicted better physical HRQoL in people with endometriosis, suggesting that individuals with high self-efficacy may more effectively manage their pain and endometriosis-specific symptoms. Furthermore, higher self-efficacy was associated with improved mental HRQoL, including symptoms of anxiety and depression. A UK-based cross-sectional questionnaire study by Rees et al. (2022) focussed specifically on pain self-efficacy, relating to a person's belief in their ability to complete tasks despite the pain they experience. Echoing O'Hara et al.'s (2021) findings, pain-specific self-efficacy was related to physical HRQoL, mental HRQoL, and social functioning in those with endometriosis. Specifically, higher pain self-efficacy predicted more positive HRQoL outcomes. Facchin et al. (2017) focussed on emotional self-efficacy in endometriosis, relating to an individual's confidence in managing negative emotions related to their condition. They found that individuals with high emotional self-efficacy experienced significantly less psychological distress than those with lower emotional self-efficacy. It is possible that low self-esteem and low self-efficacy encourage self-criticism and a negative emotional response which underlies adverse HRQoL outcomes. Qualitative work specifically focussed on self-efficacy would aid understanding of the mechanisms underlying the relationship between self-efficacy and HRQoL outcomes, however at the time of writing no qualitative work of this nature was identified.

There is a need for additional research to further explore the relationship between self-efficacy and endometriosis. However, the existing literature suggests that improvements in self-efficacy may increase HRQoL for those experiencing endometriosis (e.g., Orr et al., 2023). One day workshops have been enough to improve self-efficacy for individuals experiencing symptoms common to endometriosis, such as pain related to sex (Orr et al., 2023), so there are clear benefits to creating and trialling similar interventions for individuals experiencing endometriosis. However, the incurable and complex nature of endometriosis presents unique challenges to altering self-efficacy, in that for some people, treatment is ineffective which has implications for their perceived control over endometriosis. Therefore, some individuals may get more benefit from self-efficacy focussed interventions than others.

2.4.8 Coping

Coping strategies are linked to HRQoL in a range of chronic conditions, including multiple sclerosis (Cerea et al., 2021), Parkinson's disease (Libermann et al., 2020), and HIV (Rzeszutek 2018). Adopting proactive, problem-focussed coping strategies generally predicts higher HRQoL in all domains (Fairfax et al., 2019; Guan et al., 2020), whereas avoidant and/or passive strategies can magnify stress, leading to decreased HRQoL (Li et al., 2022). Research has identified similar effects in the context of endometriosis (González-Echevarría et al., 2019; Roomaney & Kagee, 2016). For example, in a review of the existing literature, Zarbo et al. (2018) described several coping strategies adopted by individuals experiencing endometriosis, including emotion suppression, pain catastrophising, seeking social support, and self-management. Emotion suppression appeared to heighten catastrophising, which itself was linked with worsened mental health outcomes. Emotional and avoidant coping styles predicted adverse mental health outcomes, whilst adaptive, rational coping styles were related to more positive mental health effects. Similarly, in a Danish cross-sectional study, Eriksen et al. (2008) reported that rational, detached coping styles were correlated with lower anxiety and depression, whilst avoidant, emotion-driven coping styles were associated with higher self-reported anxiety and depression for individuals experiencing endometriosis. Conversely, in a survey-based study from the UK, Rees et al. (2022) identified no link between coping style and physical or mental HRQoL domains in this population. However, Rees et al. (2022) used a questionnaire specific to coping with pain, whereas Eriksen et al. (2008) utilised a generic measure of coping style in their study. Therefore, Rees et al.'s (2022) results don't necessarily refute those of Eriksen et al. (2008), but suggest that pain-specific coping is unrelated to HRQoL outcomes. Indeed, Guillemot et al. (2023) reported that stress-specific coping styles predicted HRQoL, with problem-focussed strategies such as seeking support enacting a positive effect on endometriosis-specific HRQoL. Furthermore, using a generic measure of coping styles, González-Echevarría et al. (2019) identified a link between maladaptive coping strategies such as social withdrawal and self-criticism and reduced HRQoL in endometriosis. Pain-focussed coping styles may not be related to HRQoL in endometriosis due to the limited options available to lessen the pain arising from the condition, whereas stress-focussed and generic coping strategies may influence HRQoL by addressing broader emotional and psychological factors, thereby contributing to a more comprehensive improvement in overall well-being. It should be noted that the broad range of coping questionnaires employed by researchers examining endometriosis and coping may limit the comparisons that can be made amongst studies into endometriosis-related HRQoL and coping.

It is likely that coping strategies are influenced by the severity of symptoms and the subsequent impact of endometriosis on the lives of individuals experiencing the condition. One commonly used framework for understanding the role of coping in the context of chronic illness is the Common-Sense Model of Self-Regulation (CSM-

SR; Leventhal et al., 1997). This theory posits that coping mechanisms are dictated by individuals' perceptions of their illness.

2.4.9 Illness perceptions

IPs refer to the way in which a health threat or condition is perceived by the person experiencing it (Leventhal et al., 1997). They are theorised to influence coping style and emotional/behavioural responses to a health threat (Leventhal et al., 2016), and include aspects such as the perceived consequences, timeline, and control associated with experiencing a health condition or threat. The following chapter of the current thesis provides a more detailed overview of the CSM-SR and IPs (see chapter 3). There is limited research directly examining IPs in the context of endometriosis, however IPs influence HRQoL in several health conditions including fibromyalgia (van Wilgen et al., 2008), irritable bowel disease (Rochelle & Fidler, 2013) and arthritis (Hyphantis et al., 2013). At the time of writing, only one paper has incorporated IPs in a study of endometriosis and HRQoL. Barberis et al. (2023) assessed the relationship between trait emotional intelligence, IPs, and endometriosis-specific HRQoL. IPs were directly linked to HRQoL, and indirectly related to HRQoL by acting as a mediator between trait emotional intelligence and HRQoL. However, the study only incorporates 5 categories of IPs (consequences, timeline, identity, concern, and emotional response), as opposed to the 9 categories outlined by Broadbent et al. (2006; see chapter 3, section 3.2 for a more detailed description of IP categories) in the Brief Illness Perceptions Questionnaire. Therefore, important IPs such as treatment and personal control are missed in this study. Furthermore, the authors make no distinction between the IPs measured, combining the scores of participants on all items to create on overall "illness perception” variable. Although this offers a generic overview of how positively or negatively participants view their condition, it would be useful to ascertain the relative impact of specific IPs on HRQoL as well as the combined effect. Moreover, there are issues with the transformation of the HRQoL scale used within this study. According to the EHP-30 manual (Jones et al., 2001), participants’ HRQoL should be expressed as a percentage between 0-100. Barberis et al. (2023) have instead produced a scale ranging from 0-120, which may impact on results as the measure has not been scored in line with official instructions. Nonetheless, this study provides the first quantitative evidence that IPs may be related to endometriosis-specific QoL, although additional research is required to provide further clarification on the way in which IPs impact HRQoL in the context of endometriosis.

Qualitative work provides clues that certain IPs, particularly control and the perceived consequences of endometriosis, impact mental health and HRQoL. For example, Jones et al. (2004) identified a sense of powerlessness attributed to endometriosis, and outlined the many perceived and actual consequences of endometriosis on the life trajectories of individuals experiencing the condition. Perceived consequences included damaged relationships, missed employment and educational opportunities, and reduced body confidence. Roomaney and Kagee (2016) echoed these findings, suggesting that endometriosis exerts a pervasive and wide-ranging impact on the lives of those experiencing the condition, leading to a sense of feeling “trapped” and helpless against the condition.

In short, there is limited research on IPs and HRQoL in endometriosis. As IPs are related to health and wellbeing outcomes in a range of alternate chronic conditions, IPs in the context of endometriosis constitutes an important area for future research. Establishing whether IPs, and if so, which IPs, influence HRQoL in endometriosis would allow for targeted psychological interventions to be designed to support the HRQoL and wellbeing of individuals experiencing endometriosis.

2.4.10 Summary of literature

In short, the existing literature outlined within this overview details several factors that may underlie HRQoL in the context of endometriosis, including demographic variables such as age, the medical experiences of individuals diagnosed with the condition, and various psychosocial factors such as body image, self-efficacy and coping styles. Strong evidence implicates pain as underlying the relationship between endometriosis and poor HRQoL, however comparisons with alternate conditions associated with pelvic pain (e.g. CPP) have observed worsened HRQoL in individuals with endometriosis. Additionally, in the absence of a cure or effective pain relief for endometriosis, it is essential to uncover the alternate factors associated with endometriosis-related QoL in this population with a view to increasing available support options and supporting HRQoL. There is a growing literature base examining the impact of several factors on the lives of individuals experiencing endometriosis. However, one factor that has yet to receive adequate research attention are IPs, which are related to HRQoL and wellbeing outcomes in a range of chronic conditions.

2.5 Methodological considerations

In examining the factors related to endometriosis-related QoL, it is crucial to consider the underlying methodological foundations of the existing literature. Across the research incorporated into the current literature overview, there is significant disparity in the methodologies adopted by researchers, as well as methodological limitations common to the existing literature in this area. This section of the current thesis will briefly summarise these aspects.

2.5.1 Measurement of HRQoL

As stated at the outset of the current chapter, researchers have adopted various measures to assess HRQoL, resulting in significant variability in how HRQoL and its components are gauged in endometriosis research. Some studies use generic QoL and HRQoL measures, whilst others adopt endometriosis-specific HRQoL instruments. This poses a challenge due to differences in the factors measured between generic QoL measures condition-specific assessments. For example, the EHP-30, based on interviews with individuals living with endometriosis, examines factors specific to endometriosis that may impact wellbeing, such as dyspareunia, powerlessness, and work functioning, whilst more generic measures of HRQoL, such as the Short-Form 36 (SF-36), measure more general aspects of experiencing ill-health such as disability, functioning, and mental wellbeing. Therefore, the extent to which the findings of studies incorporating different measures of HRQoL may be compared is uncertain. To circumvent this issue, it has been recommended that future research employs condition specific measures of HRQoL, such as the EHP-30 for endometriosis research (Bourdel et al., 2019). However, it should be noted that the SF-36 has been validated for use in the context of endometriosis, and it is believed to encompass the most crucial aspects of health relating to QoL in this population (Stull et al., 2014).

2.5.2 Inclusion criteria

The research discussed in the current chapter often varies in terms of its inclusion criteria. For example, some studies consider co-morbidities and exclude participants with multiple conditions (e.g., Facchin et al., 2015), while others do not take co-morbidities into account at all (e.g., Nnoaham et al., 2011). Neglecting to account for co-morbidities can be particularly problematic in studies employing generic HRQoL measures, as it remains unclear whether HRQoL outcomes are directly attributable to endometriosis or if scores are influenced by another underlying condition. The use of condition-specific HRQoL measures may address this issue by directly linking aspects of HRQoL to the experience of endometriosis.

Moreover, pain appears to be strongly related to HRQoL. Although medical and/or surgical treatment is often ineffective in eradicating pain, it does have the potential to reduce pain and endometriosis-related symptoms for many individuals (Becker et al., 2017). Therefore, future studies might consider distinguishing between individuals who have undergone previous medical intervention for their endometriosis and those who have not, to assess the potential impact of medical intervention on HRQoL. However, given that endometriosis is typically diagnosed through surgery, it may be unlikely for patients with endometriosis to have had no previous surgery.

2.5.3 Recruitment strategy

Recruitment for endometriosis research predominantly occurs in clinical settings or through support groups. However, these approaches may lead to an unintended over-representation of individuals experiencing lower QoL and more detrimental wellbeing outcomes. For example, individuals attending endometriosis clinics are often awaiting treatment for their symptoms, potentially contributing to heightened anxiety and distress, as well as increased pain. Similarly, participation in support groups may be indicative of worsened symptomology and mental health outcomes related to endometriosis, prompting increased support-seeking behaviour. On the other hand, recruitment in clinical and support settings may also over-represent individuals with higher QoL and better wellbeing outcomes due to enhanced social support and the adoption of more adaptive coping strategies. As highlighted in section 2.4.8, increased social support is linked to heightened HRQoL (Guillemot et al., 2023).

Despite this, it is evident that the recruitment strategies used within endometriosis research frequently omit individuals with manageable or asymptomatic endometriosis as they are currently under-represented in the existing literature. Future studies should aim to address this gap to ensure a more accurate reflection of the entire endometriosis population. However, this presents a challenge, as the number of individuals living with manageable and/or asymptomatic endometriosis remains unknown.

2.5.4 Demographics

Various demographic variables have received little attention in the research included within this overview. For example, despite evidence suggesting that endometriosis symptoms can persist beyond menopause (Secosan et al., 2020), individuals experiencing the menopause are notably absent from endometriosis research. Consequently, our understanding of the enduring impact of endometriosis and its subsequent effects on HRQoL throughout the lifespan is limited. Future research should address this gap. However, when conducting such studies, it is imperative to consider the influence of menopause on HRQoL, as the menopause itself is associated with an elevated risk of depression and adverse mental health outcomes (Vivian-Taylor & Hickey, 2014).

Moreover, there is a notable gap in research regarding the influence of cultural and ethnic backgrounds on HRQoL in endometriosis. This gap may be attributed to the often-observed demographic homogeneity in participants recruited for endometriosis studies, particularly in high-income countries like the UK, USA, and Australia, where predominantly white, cis-gender individuals in their early 30s with a university education are included (Kuohung et al., 2002; Rush & Misajon, 2018; Soliman et al., 2017). This sampling bias has contributed to the misconception that certain racial and ethnic groups, including Black and Hispanic individuals, are less likely to experience endometriosis compared to White individuals (Bougie et al., 2022). Additionally, the generalisability of findings from the existing literature to individuals from diverse ethnic backgrounds is uncertain. Future research efforts should prioritise inclusive recruitment strategies to better understand how endometriosis impacts individuals across various ethnic groups.

2.5.5 Longitudinal research

At the time of writing, there is limited longitudinal research on endometriosis-related HRQoL. Therefore, it is not generally possible to track the trajectory of HRQoL in this population. Cross-sectional research provides a snapshot of the factors underlying endometriosis-specific HRQoL, however it cannot offer a cause and effect. By tracking variables over time, future research may offer further insight into the trajectory of the mechanisms underlying HRQoL in the context of endometriosis. Additionally, longitudinal research may determine the predictive validity of various factors that may underpin HRQoL in this population.

2.6 Discussion and future directions for endometriosis and HRQoL literature

Collectively, the literature incorporated within the current chapter outlines the largely negative impact of endometriosis on HRQoL. The relationship between endometriosis and HRQoL appears to be influenced by several distinct and overlapping factors, including endometriosis-specific symptoms such as pain, functioning detriments, and several psychosocial factors. Pain appears to have the most profound impact on HRQoL independently, but also indirectly through impacting on factors that further contribute to the deterioration of HRQoL, including functioning detriments, self-esteem, and self-efficacy. However, the current literature examining endometriosis-related pain as a predictor of HRQoL does not provide a coherent account of the extent to which pain influences HRQoL and psychological distress. This may be explained by the heterogeneous nature of endometriosis, meaning that some people experience worsened pain than others. Therefore, it may not be possible to quantify the extent to which pain worsens HRQoL. Furthermore, pain may emerge as the most significant predictor of HRQoL in part due to the relative lack of research pertaining to alternative factors which may exert an influence on HRQoL. The focus on clinical factors and their relation to HRQoL demonstrates an over-reliance on a medical model of endometriosis, rather than the employment of integrated care including the measurement of psychosocial outcomes. The provision of multifaceted care for endometriosis is recommended in several endometriosis research papers (e.g., Evans et al., 2022; Van Niekerk et al., 2023; Young et al., 2015), however, it appears that these recommendations are, at the time of writing, far from everyday practice.

A somewhat surprising observation stemming from the literature included within this overview is the lack of a consensus relating to the impact of infertility on the HRQoL of individuals experiencing endometriosis. Fertility is complex in the context of endometriosis, and the prevalence and likelihood of infertility in individuals experiencing endometriosis is currently unknown. This complexity is reflected in the often contradictory results observed throughout the current literature overview. That infertility is frequently associated with endometriosis without strong evidence of a relationship means that medical treatment is often focussed on fertility preservation and/or restoration, to the extent that endometriosis is often deemed a reproductive condition. This is likely to increase medical delays for individuals for whom fertility is not a priority and/or concern, as many individuals receive a diagnosis only after they have approached healthcare services for fertility support. Qualitative research focussed on fertility and recruiting different groups of individuals, for example, those experiencing infertility, those with no fertility problems, and those for whom fertility is not a concern, would be beneficial to further probe the potential relationship between fertility and HRQoL in this population.

Based on the literature outlined within the current chapter, some recommendations for future research can be made. It is clear that endometriosis has a detrimental effect on HRQoL, however, further research is required to aid understanding of the mechanisms by which psychosocial factors such as coping, body image, sexual functioning, and medical experiences impact on the HRQoL of people experiencing endometriosis. Longitudinal research employing condition-specific HRQoL measures would be particularly beneficial to gauge the long-term impact of endometriosis-related symptoms and psychosocial factors on HRQoL. A lack of diversity in the participants recruited for endometriosis-related research was observed within the current overview, casting doubt on the generalisability of the observed results. This inequality means that people from Black and ethnic minority backgrounds may have vastly different experiences within medical settings compared to individuals from White backgrounds which are as yet unknown. The relative exclusion of individuals from Black and ethnic minority backgrounds, albeit a common issue across social research generally, means that their experiences are not fully captured. Researchers may seek to rectify this by using targeted recruitment strategies and working to engage diverse communities in their research.

Individuals who do not conform to their birth gender also experience barriers and discrimination within support settings (Cicero et al., 2019). It is important therefore that their voices and experiences are heard and considered in future research. Qualitative research may shed a light on the experiences of non-gender conforming and transexual individuals living with endometriosis, leading to a deeper understanding of the barriers faced by these individuals and how these issues may be circumvented.

The current chapter also identified several factors that may impact on endometriosis-related HRQoL but have not yet been considered within the existing research. For example, the experience of multiple hospital visits and misdiagnoses are yet to receive extensive research attention, particularly from a quantitative perspective. Additionally, working environments and employment-related practices have not yet been considered in terms of their relation to HRQoL, despite the impact of work-related functioning detriments on HRQoL. It would be particularly beneficial to assess the impact of the COVID-driven shift to hybrid working on the wellbeing of individuals experiencing endometriosis and chronic pelvic pain. Notably exempt from the research is the impact of IPs, which are key predictors of HRQoL in several alternate chronic conditions (Hyphantis et al., 2014; van Wilgen et al., 2008). Therefore, future research may endeavour to assess the extent of the relationship between IPs and endometriosis-related HRQoL, with a view to increasing support options for those affected by the condition.

The findings of the current overview of the literature align with previous research which has highlighted the need for an interdisciplinary approach to endometriosis treatment, involving both medical and psychosocial perspectives and interventions. However, as stated in section 2.3, this overview did not take a systematic approach, meaning that an account of potential biases across the studies included cannot be given. Additionally, it is possible that some relevant research was missed in the construction of this overview, and this should be kept in mind when considering the content and conclusions of the current literature overview.

2.7 Chapter summary

The current chapter provided an overview of the literature related to the factors underlining detriments to endometriosis-related HRQoL. First, a distinction was made between QoL and HRQoL, and condition-specific measures of HRQoL were discussed. The approach adopted by the current review was next outlined. An overview of the factors potentially related to endometriosis-specific HRQoL including endometriosis-specific symptoms, functioning detriments, medical experiences, demographics and psychosocial variables was next provided. Methodological considerations including methodological limitations were presented, followed by suggestions for future research in this area. The following chapter will provide an overview of the literature related to IPs and HRQoL across a range of health conditions.

CHAPTER 3

An overview of the impact of illness perceptions on health and wellbeing outcomes

3.1 Introduction

The current chapter considers the relationships between IPs and various health and wellbeing outcomes such as health-protective behaviours, QoL, anxiety, and depression across a range of chronic conditions. By considering these elements, the current chapter aims to illuminate the gaps in the literature, and to make a case for exploring IPs in the context of endometriosis. Firstly, the common-sense model of self-regulation is briefly outlined, with a particular focus on IP dimensions (3.2). Subsequently, the approach adopted for the present overview is described (3.3). The central element of the current chapter, a critical overview of the literature on IPs and their relation to various health and wellbeing factors is next presented (3.4), followed by a broader discussion of the current literature including future research directions (3.5). Finally, the chapter is summarised (3.6).

3.2 The Common-Sense Model of Self-Regulation

The Common-Sense Model of self-regulation (CSM-SR) is a theoretical framework that seeks to explain how individuals perceive and respond to health threats or medical conditions (Leventhal et al., 2016). The model theorises that, when individuals encounter a health threat or condition, they experience a cognitive and emotional process involving 5 key components (Leventhal et al., 1997):

i) Stimuli: The individual encounters a health threat or condition.

ii) IPs: Cognitive representations of the stimuli are formed, including perceptions of the consequences, controllability, causation, and the timeline of the health threat or condition. These cognitions may be informed by lay information stored in memory, external information relating to the health threat, and the symptoms experienced.

iii) Emotional representation: Simultaneously, an emotional response to the stimuli is experienced.

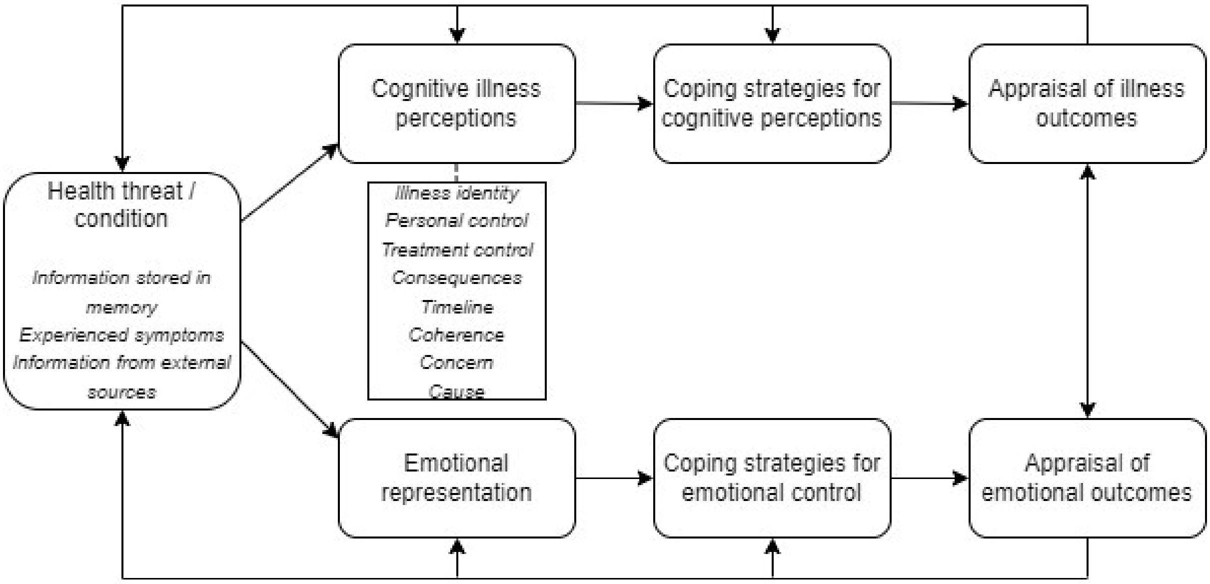
iv) Coping: IPs and emotional representations inform coping strategies for both the health threat and the emotional impact of encountering the stimuli.

v) Appraisal: Through a process of ongoing appraisal, the effectiveness of coping strategies is assessed which, subsequently, influences responses to the stimuli including behaviours, IPs and emotional representations, creating a continuous cycle.

The CSM-SR positions IPs and emotional representations as dynamic and unfixed due to this ongoing process of appraisal (Leventhal et al., 2016). Figure 3.1 illustrates this process.

Figure 3.1

The Common-Sense Model of Self-Regulation (Leventhal et al 2016)



Given the pivotal role of IPs in shaping coping responses and influencing health-related outcomes, research has focussed on defining and measuring the various dimensions of IPs following the inception of the CSM-SR. According to Weinman et al. (1996), IPs encompass 5 distinct components:

i) *Consequences*: the perceived outcomes and effects associated with experiencing the condition

ii) *Control*: an individual's perception of their ability to influence and manage the health threat

iii) *Timeline*: the expected duration of condition-specific symptoms

iv) *Identity*: the symptoms and characteristics attributed to the condition

v) *Cause*: Causal attributions associated with the health threat

Subsequently, understanding of IPs has evolved and, resultantly, the number of IP dimensions expanded. Notably, Moss-Morris et al. (2002) conducted a comprehensive review of the existing IP dimensions and employed factor analysis to refine the model. Their research resulted in refinement of IPs, including the division of the control dimension into two distinct components: personal control and treatment control. Additionally, the updated model introduced illness coherence and concern as new IP dimensions, and it was recommended that emotional representation be assessed alongside IPs. These IP dimensions are reflected in figure 3.1. This work culminated in the development of the ‘Revised Illness Perceptions Questionnaire’ (IPQ-R; Moss-Morris et al., 2002), which, along with its abbreviated version, the ‘Brief Illness Perceptions Questionnaire’ (B-IPQ; Broadbent et al., 2006), currently stands as the most widely employed measure of IPs.

Extensive research on a range of health conditions has sought to ascertain the influence of IPs on a wide range of outcomes, including HRQoL (Foxwell et al., 2013; Knowles et al., 2020), depression (Cannon et al., 2022), anxiety (Dempster et al., 2015), as well as health promotion behaviours including medication adherence (Shiyanbola et al., 2018). This body of literature has been instrumental in the development of interventions aimed at addressing IPs in people with a range of conditions, such as myocardial infarction (MI; Sararoudi et al., 2016), type 2 diabetes (Alyami et al., 2016), and chronic back pain (Siemonsma et al., 2013).

The current overview of the literature aims to assimilate and critically evaluate the literature relating to the impact of IPs on health and psychosocial outcomes.

3.3 Approach of the current review

Mirroring the approach outlined in chapter 2 (section 2.3), this overview aims to provide a broad summary of the research surrounding the impact of IPs on health and wellbeing outcomes. As with the previous literature overview, this approach is not intended to be exhaustive, but to provide a synopsis of the key themes emerging from the literature base. It is intended to demonstrate to the reader the gaps in the literature, and to provide some context to the research questions, particularly in relation to the adoption of the CSM-SR in this context. Systematic reviews on the topic of IPs and health and wellbeing outcomes have previously been carried out and are referenced throughout the current chapter, however a key systematic review on this topic was conducted by Dempster et al. (2015) as part of their meta-analysis in IPs and outcomes.

Broadly, the approach taken within this overview was as follows:

i) Identification of topic of interest following first literature overview (see chapter 2)
ii) Broad searches conducted on several databases (including Google Scholar, Web of Science, APA PsycInfo, and the University of Strathclyde's SuPrimo database)
iii) Search terms narrowed as key factors emerged
iv) Paper structured in coherent order according to prevalent themes
v) Critical overview of identified factors
vi) Formulation and revision of key research questions

The key question underpinning the current overview was: How do IPs impact health and wellbeing outcomes?

As outlined in chapter 2 (section 2.3), a broad overview is advantageous in that it covers a broad range of research and allows for a flexible approach in the presentation of the literature. It is particularly useful in scenarios where a broad overview is required, but time and/or resources are limited. However, several potential limitations arising through the adoption of this approach, rather than a more systematic method, should be kept in mind when reading the following overview. These are described in chapter 2 (section 2.3.), but, broadly, they lack the rigour, completeness, and credibility of systematic reviews. Therefore, the following overview of the literature should not be read as an exhaustive account of the literature on IPs and outcomes, but as a broad summary of the key themes and trends emerging from the available literature base.

3.4 The impact of IPs on health and wellbeing outcomes

IPs are associated with health and wellbeing outcomes across a range of health conditions, including breast cancer (Fanakidou et al., 2018), irritable bowel syndrome (IBS; Knowles et al., 2017) and fibromyalgia (Homma et al. 2018). Generally, more positive IPs relate to more positive outcomes, and negative IPs result in more negative health and wellbeing experiences (Dempster et al., 2015). IPs have been linked to health directed behaviours (Shiyanbola et al., 2018), health outcomes, HRQoL (Knowles et al., 2020), mental distress (Rochelle & Fidler, 2012) and coping strategies (Woodhouse et al., 2018). This section of the current chapter will critically evaluate the evidence associated with each of these factors, followed by an evaluation of the effectiveness of IP-based interventions.

3.4.1 Medication adherence and health-orientated behaviours

IPs have been linked to health orientated behaviours, including medication adherence, attendance at healthcare clinics and participation in risky health behaviours (Shahin et al., 2022). This is an important area of study due to the potential for further health complications linked to risky health behaviours and non-attendance at healthcare appointments.

IPs have been found to predict medication adherence in several conditions, including type 2 diabetes (Shiyanbola et al., 2018), asthma (Kosse et al., 2020), and HIV (Weiss et al., 2016). In a survey-based study from the US with individuals experiencing type 2 diabetes, Shiyanbola et al. (2018) observed that negative IPs, for example negative perceptions of the consequences and emotional impact of the condition, predicted lower medication adherence. Additionally, as concern around the condition lessened, so too did adherence to prescribed medication. Interestingly, the relationship between negative IPs and medication adherence was mediated by health literacy, or the degree to which individuals feel able to use and understand information to make informed decisions regarding their health (Berkman et al., 2010). To exemplify, for individuals with high levels of health literacy, threatening IPs did not predict lessened medication adherence, as was the case for individuals with low and moderate levels of health literacy. This suggests that health literacy is a protective factor against the negative impact of IPs on medication adherence in type 2 diabetes.

Concern was again identified as a key predictor of medication adherence in a Netherlands-based study on IPs and health outcomes in asthma (Kosse et al., 2020). The higher the level of concern, the more likely individuals were to take their prescribed medication. Additionally, participants’ level of coherence, or self-reported understanding of the condition, was strongly and positively related to medication adherence. Coherence itself is strongly aligned with health literacy (Walters et al., 2020), indicating that the higher the understanding of an experienced condition, the higher the adherence to prescribed medication. This is in line with the findings of Shiyanbola et al. (2018), suggesting that the relationship between IPs and medication adherence is likely to be mediated by health literacy regardless of the health condition under investigation. However, it is important to note that health literacy not only captures knowledge around the condition, as with the coherence IP dimension, but also refers to aspects such as confidence in using and understanding this information (Berkman et al., 2010). Thus, whilst coherence and health literacy are naturally interconnected, there are differences in the underlying concepts being measured, making direct comparisons challenging.

Amongst the existing research observing a relationship between IPs and medication adherence, there is some disagreement as to the direction of this relationship. For example, in a scoping review of IPs and medication adherence in type 2 diabetes, Alharbi et al. (2023) observed that those with more positive IPs were more likely to adhere to their prescribed medication. To exemplify, individuals with type 2 diabetes who reported positive perceptions relating to personal and treatment control, optimism surrounding the consequences of experiencing their condition, and strong coherence of type 2 diabetes were most likely to adhere to their medication. This observation corroborates Shiyanbola et al.’s (2018) aforementioned findings. Conversely, in a cross-sectional survey-based study on hypertension by Rajpura et al. (2014), individuals who viewed their condition as a threat through holding negative IPs were more likely to adhere to their medication than those with more positive perceptions of their condition. The variance in these findings suggests that the impact of IPs on health behaviours is not universally applicable, but rather individualised based on the unique experiences of the individual facing the health threat as well as the specific condition under examination. Furthermore, collectively these findings suggest that, when studying IPs, it may be beneficial to split IPs into threat-based IPs, such as perceptions of the symptoms, consequences, concern, and emotional representations of the experienced condition, and protective IPs, such as perceptions around the level of control, coherence, and timeline of the condition. Making this distinction may allow researchers to ascertain which types of IPs exert the greatest impact on medication adherence, offering opportunities to develop targeted interventions accordingly. In the same vein, it is important that researchers avoid creating one composite IP score which does not allow for recognition of the unique impact of each IP dimension on health and wellbeing outcomes.

Additionally, researchers have suggested that IPs operate in parallel with treatment beliefs to predict health-oriented behaviours such as medication adherence (Thomson et al., 2020). For example, survey-based research on IPs and medication beliefs in people who had experienced stroke in China (Ruksakulpiwat et al. 2020) found that concerns around the harmful effects of prescribed medication and negative IPs were significantly related to non-adherence to treatment. This is corroborated by Sangsongrit et al. (2014), who found that medication beliefs were the strongest predictors of medication adherence in this population, followed by IPs. It is likely that IPs are informed by lay medication beliefs, which in turn modify medication beliefs in an ongoing cyclical process. For example, as coherence grows, treatment beliefs are likely to change, and this may subsequently influence perceptions surrounding the consequences and control associated with the experienced health condition. Therefore, treatment beliefs and IPs are intrinsically intertwined, and it is potentially difficult to disentangle the relative impact of each of these factors. Additionally, treatment beliefs are likely to differ significantly between conditions. For example, beliefs surrounding the effectiveness of medication are likely to be less positive in a condition for which there is no cure compared to a curable health threat, potentially leading to greater levels of non-adherence to treatment. To exemplify, in a survey-based cross-sectional study, Nicklas et al. (2010) observed high levels of concern relating to the effectiveness of pain relief in a cohort of individuals experiencing chronic, non-malignant pain in Glasgow. Levels of concern predicted higher levels of non-adherence. However, when concern relating to taking prescribed medications was coupled with negative perceptions of the consequences of experiencing chronic pain, this effect diminished, and medication adherence rose. This suggests that perceiving negative consequences associated with pain is a stronger driver of adherence to prescribed medication than negative treatment beliefs. However, the causal direction of the relationship between the perceived consequences of a health threat and medication adherence is as yet unclear, with some researchers suggesting that the perceived consequences of a health condition may be a product of medication adherence rather than an instigator of it (Nicklas et al., 2010).

IPs have been linked to preventative as well as restorative health-orientated behaviours. For example, in a survey-based study, Chong et al. (2020) observed that more positive IPs surrounding COVID-19 increased adherence to precautionary measures such as hand-washing and physical distancing amongst Hong Kong-based adults. This relationship was mediated by avoidance-based coping, including denial, self-blame and rumination. The authors suggest that transparency, and providing regular, accurate and concise information about an unfolding health threat can positively shape IPs and coping strategies, potentially increasing adherence to government legislation and guidelines. However, this study only measured three dimensions of IPs as outlined in the CSM-SR, consequences, timeline, and concern.

Therefore, further research incorporating the full spectrum of IPs may be beneficial in this context.

In sum, IPs influence health-orientated behaviours, including adherence to treatment and medical advice. However, the current literature clearly suggests that there are mediating factors that operate alongside IPs to produce health-orientated behaviours, such as health literacy and treatment beliefs. Shahin et al. (2022) compiled a review of the factors influencing medication adherence, including health literacy, medication beliefs, cultural beliefs, self-efficacy and spiritual beliefs. Therefore, an individualised approach to encouraging compliance with medical advice and treatment may be beneficial. The cause dimension of IPs is rarely considered in the literature on health-related behaviours, and future research should address this.

3.4.2 Health-related outcomes

Alongside medication adherence, IPs are associated with a range of health-related outcomes including pain and functioning. For example, in a UK-based longitudinal survey study on orofacial pain and IPs, Penlington et al. (2019) observed an increase in pain and disability directly attributed to negative IPs. When this effect was further probed, the perceived consequences of experiencing orofacial pain significantly predicted outcomes in terms of self-reported pain and functioning detriments, over and above the effect of anxiety, depression, and other IPs. Furthermore, Galli et al. (2010) identified low perceptions of personal control and anticipating a chronic timeline associated with orofacial pain as predictive of pain, disability, and mental distress. Nonetheless, perceived consequences remained the largest predictor of outcomes, corroborating Penlington et al.’s (2019) findings. However, the strong relationship between perceived consequences and outcomes in this context may indicate tautology. For example, whilst perceived consequences predict health-related outcomes such as pain and disability, they may also be viewed as an outcome of experiencing a health condition characterised by chronic pain. To exemplify, one question within the most widely used measure of IPs, the IPQ-R (Moss-Morris et al. 2002) asks, “to what extent do you think your illness has serious consequences for your life?”. When asked this question in the context of chronic pain, individuals are likely to consider their level of pain and disability-related functioning in formulating their answers. Additionally, the question “to what extent does your illness have consequences for your ability to work?” is directly related to functioning and disability, suggesting some crossover between the consequences IP domain and outcomes such as pain and disability. Nonetheless, IPs, including consequences, perceptions of control and the timeline around pain, are key predictors of worsened pain in various conditions including chronic back pain (Foster et al., 2008) and complex regional pain syndrome (Antunovich et al., 2021).

Moreover, emerging evidence suggests that IPs may extend beyond health-related outcomes to predict survival. For example, in a US-based study involving individuals undergoing haemodialysis, Chilcot et al. (2011) identified significant relationships between IPs and mortality. After controlling for factors such as demographics, co-morbidities, and levels of depression, perceptions surrounding treatment control remained a key predictor of survival. This implies that a higher level of perceived control surrounding dialysis treatment may be associated with a lower risk of mortality. However, it is important to note that in Chilcott’s (2011) survival models, data on blood pressure and medication were not collected and controlled for, despite these variables potentially being predictors of survival in this population. Nonetheless, in a systematic review of the literature, French et al. (2006) also found a link between IPs and mortality, this time in individuals with heart conditions. By analysing the literature on IPs and attendance at cardiovascular rehabilitation clinics following a cardiac event, they found that more positive IPs were associated with higher attendance at these clinics, which, in turn, predicted lower mortality. Specifically, more positive perceptions around the curability of the condition, its associated consequences, and a greater understanding of the condition were associated with higher clinic attendance. However, it must be noted that the sample size incorporated into French et al.'s meta-analysis was fairly small, so although IPs seem to predict cardiac clinic attendance, the strength of this prediction is uncertain. Nonetheless, combined, these findings suggest a potential connection between positive IPs and lower mortality through engagement in health-promotion strategies, including attendance at healthcare clinics.

Overall, there is evidence of a link between IPs and health-related outcomes such as pain and disability, indicating that the positive reframing of IPs may support increased health and wellbeing. Moreover, limited but compelling evidence suggests a relationship between IPs and mortality, warranting further investigative research across a range of health conditions.

3.4.3 Health-related Quality of Life

Alongside health behaviours and outcomes, IPs are strongly linked to HRQoL (Ackigoz et al., 2023; Cai et al., 2023; Hill & Frost, 2022; Sararoudi et al., 2016; Sigit et al., 2022; Tu et al., 2022; Vaske et al., 2017). Regardless of the condition under investigation, individuals harbouring negative IPs are consistently found to experience decreased HRQoL compared to those with more positive representations of their illness (Dempster et al., 2015). For example, in a comprehensive review of IPs in coronary heart disease (CHD), Foxwell et al. (2013) highlighted a consistent association between negative IPs and reduced physical HRQoL. Along with the combined impact of IPs, the influence of specific IPs on CHD-specific HRQoL was examined. It was observed that attributing a greater number of symptoms to CHD, perceiving more severe consequences, and envisioning a longer timeline related to the condition significantly contributed to decreased HRQoL. However, importantly, across the studies reviewed by Foxwell et al. (2013), several QoL and mood measures were employed, limiting the comparisons that may be made between studies due to differences in the conceptualisations of the underlying constructs. Nonetheless, in survey-based research on irritable bowel disease (IBD) in the UK by Rochelle and Fidler (2013), the perceived consequences and timeline associated with IBD also emerged as the strongest predictors of overall QoL in this population. Additionally, in studies involving individuals with fibromyalgia and irritable bowel syndrome (IBS), specific IPs such as the perceived consequences related to the condition, symptom identity, and emotional representation of the condition were directly linked to HRQoL (De Gucht, 2015; Glattacker et al., 2010). Furthermore, in US-based survey research on Lyme's disease, Hill et al. (2022) also observed a strong association between specific IPs such as perceived consequences and symptom identity and HRQoL. Collectively, these findings suggest that specific IPs, particularly those related to the anticipated timeline, the symptom identity, and perceived consequences of a health condition, exert the strongest influence on HRQoL, regardless of the health condition under investigation.

However, the conditions described above are largely characterised by their long-term, incurable nature and limited treatment options. In contrast, individuals experiencing acute and/or potentially curable conditions may hold different IPs that impact their HRQoL. For example, in a longitudinal study conducted by Kaptein et al. (2013), Dutch and Japanese women diagnosed with breast cancer exhibited more negative perceptions surrounding the consequences of their condition compared to a reference group of individuals with diabetes and asthma over the course of 8 weeks. Conversely, they held more positive perceptions relating to the timeline of their condition, reflecting belief in the curability of their condition. Therefore, HRQoL was primarily influenced by IPs such as concern, perceived consequences, and emotional representations rather than the anticipated timeline of the condition. Moreover, this study observed that IPs in individuals with breast cancer were dynamic, aligning with Leventhal et al.'s (2016) claim that IPs change over time in response to cognitive appraisals. Specifically, IPs were susceptible to change based on appraisals of treatment success, subsequently influencing HRQoL outcomes.

In contrast, chronic conditions with limited treatment options and no curability may exhibit more stability, resulting in relatively constant HRQoL. For instance, Rutter and Rutter (2007) measured IPs at 3 different time points in a group of 37 individuals experiencing IBS, an incurable condition characterised by painful stomach spasms, bloating, constipation, and diarrhoea (NHS, 2021). They observed no statistically significant differences in IPs across the 3 time-points, with IPs at time-point 1 successfully predicting HRQoL at time-point 3. However, the particularly small sample size used in this study means that the generalisability of these results may be limited. Nonetheless, a wide-ranging review of IPs in various physical health conditions, including epilepsy, arthritis, IBD, IBS, and heart failure echoed Rutter &

Rutter's (2007) findings by identifying minimal changes in IPs over time (Dempster et al., 2015). This review incorporated individuals with both chronic and acute conditions including breast cancer, casting uncertainty on the dynamic nature of IPs observed in Kaptein et al.'s (2013) aforementioned study.

Nevertheless, the results of a Netherlands-based longitudinal survey on IPs in chronic obstructive pulmonary disease (COPD; Fischer et al., 2010) demonstrated that, with medical support, IPs are indeed dynamic and subject to change. This suggests that the dynamic nature of IPs may stem from treatment and experiences within the healthcare system rather than the curability of the condition itself. Consequently, in the absence of medical intervention, IPs may exhibit more stability, along with HRQoL. However, it should be noted that Fischer et al.'s study included only 87 individuals, so the generalisability of the results is unclear. Nonetheless, their findings underscore the potential for modifying IPs through targeted interventions, even for individuals experiencing long-term and incurable conditions, which have the potential to lead to improvements in HRQoL outcomes.

Whilst there is strong evidence to link IPs to HRQoL, the 'cause' dimension of IPs is often overlooked or studied in isolation from alternate IPs. This is likely, in part, due to the complexity of coding and analysing this dimension, which is typically assessed through free-text responses or by asking participants to select potential causes from a pre-determined list (Moss-Morris et al., 2002). Consequently, making direct comparisons of the impact of perceived cause on HRQoL with other IP dimensions is challenging.

Moreover, as perceived cause is disease-specific, identifying cross-cutting commonalities across the existing literature on IPs and HRQoL is complex.

Nevertheless, in a review of IPs in CHD patients, Foxwell et al. (2013) observed that the majority of studies did not establish a significant link between perceptions of cause and HRQoL. Among the studies that did identify a connection, individuals who perceived stress as the cause of their condition experienced lower HRQoL. Scharloo et al. (2007) echoed these findings, reporting that psychological perceptions of cause, such as stress, contributed to decreased HRQoL in people experiencing COPD in the Netherlands. Similarly, attributing the experience of fibrous dysplasia, a rare bone disorder, to psychological causes resulted in deteriorations in physical and mental HRQoL for those experiencing the condition in the Netherlands (Majoor et al., 2018). However, at the time of writing there is limited research, particularly of a longitudinal nature, exploring the potential relationship between causal attributions and HRQoL. Thus, it is not possible to definitively confirm the existence of such a relationship, and future research should aim to address this gap within the literature.

Qualitative research further emphasises the pivotal role of the consequences and identity IP dimensions in shaping HRQoL outcomes including functioning and mental distress. Additionally, these studies provide further detail on participants' experiences, particularly in relation to the factors underpinning IPs and HRQoL outcomes. For example, in a qualitative exploration of IPs amongst individuals with epilepsy in Ethiopia, Demissie et al. (2021) found that participants' experiences within healthcare settings were intertwined with their IPs. Concerns regarding treatment effectiveness, for instance, often led to dissatisfaction with healthcare providers, leading to apprehension surrounding the consequences of their condition and a decline in HRQoL. Additionally, qualitative research on IPs in individuals with eczema (Rocholl et al., 2021) provides a detailed account of how specific IPs impact the HRQoL of those experiencing the condition. Under the 'consequences' dimension, participants described negative physical, social, economic, occupational, and psychological repercussions stemming from their condition. Each of these factors is closely related to QoL (Haraldstad et al., 2019), shedding light on the mechanisms through which IPs may affect HRQoL.

In summary, it is evident that IPs exert a substantial influence on HRQoL. However, the relative impact of specific IPs on HRQoL may vary depending on the chronicity of the condition experienced. Specific factors such as the response to diagnosis, diagnostic delay, and healthcare experiences may also shape IPs, as indicated by qualitative work, however additional research is required to further understand these factors. Existing literature consistently emphasises the importance of perceived consequences, perceived disease duration and symptomology as primary drivers of HRQoL.

3.4.4 Anxiety and depression

Along with HRQoL, research has consistently linked negative IPs with heightened anxiety (Bierbauer et al., 2022) and depression (Dempster et al., 2015). Negative IPs are associated with deteriorations in mental health, regardless of the condition under investigation (Hagger et al., 2017). For example, in a meta-analysis on IPs in a range of mental health conditions, Cannon et al. (2022) reported that IPs consistently predicted anxiety and depression. Specifically, threat-related IPs including identity, timeline, consequences, and emotional representations were associated with adverse mental health outcomes, whereas protective IPs such as perceptions of control and coherence were linked to more positive outcomes. IPs impacted mental health directly, but also indirectly by influencing self-management techniques including medication adherence.

In terms of individual IPs, a meta-analysis of IPs in several chronic conditions (Dempster et al., 2015) reported that anxiety was most strongly influenced by perceptions of the consequences, the number of symptoms attributed to the condition, and the emotional representation of the health threat. Meanwhile, depression was associated with perceptions of control over the condition as well as the perceived consequences. Additionally, in a review of IPs in CHD, Foxwell et al. (2013) observed that poorer understanding of CHD, perceiving adverse consequences associated with the condition, and negative perceptions of control surrounding CHD exerted the strongest relationships with both anxiety and depression. Attributing negative consequences, a longer timeline and holding negative emotional representations towards long-COVID also predicted health and wellbeing outcomes including anxiety and depression (Bierbauer et al., 2022). Similarly, negative perceptions of the consequences, control and illness identity were the strongest predictors of anxiety and depression in a group of individuals experiencing tuberculosis in Pakistan (Husain et al., 2008). These findings are consistent with the results of a wide-ranging review on IPs produced by Hagger et al. (2017), which indicated that negative perceptions around control, the consequences of a health condition, and illness identity are consistently related to increased psychological distress across the spectrum of health conditions.

Additionally, in a UK-based cross-sectional study on IPs in IBD, Rochelle and Fidler (2013) reported correlations between anxiety and perceived consequences, personal control, illness coherence and emotional representation related to the condition, indicating that more negative IPs predicted increased anxiety. However, when input into a regression model with several other psychosocial factors, no single IP was predictive of anxiety. This indicates that IPs have a combined effect on anxiety but individually, singular IPs do not possess predictive value in this context. Similarly, depression was related to perceptions of the timeline, consequences, treatment control, illness coherence, and emotional representations related to IBD, however when input into a regression model only illness coherence had a significant positive association with depression. This indicates that the more understanding patients have of their IBD, the higher the risk of depression, but no other IP was predictive of depression. Thus, combined IPs appear to be stronger predictors of mental health outcomes than singular IPs, indicating that these perceptions inform one another and act together to produce an overall psychological effect.

Across the existing literature, many studies place perceived consequences and emotional representations as important determinants of anxiety and depression across the full spectrum of chronic health conditions, and this appears to hold true for more acute conditions, such as stroke (Campbell Burton, 2012). In a meta-analysis of psychological distress and IPs in stroke patients, Pai et al. (2019) reported that perceiving negative consequences, a greater number of detrimental symptoms, a longer anticipated timeline, and holding negative emotional representations related to stroke was associated with greater psychological distress. However, contrary to several studies relating IPs to adverse mental health consequences in chronic conditions (Dempster et al., 2015; Foxwell et al., 2013), perceptions of control around stroke were not associated with psychological distress, including depression and anxiety. The control dimension of IPs is strongly associated with self-efficacy (Pai et al., 2019), and alternate research has indicated that self-efficacy is not related to psychological distress or recovery in stroke patients (Molloy et al., 2008), corresponding with the aforementioned findings. Additionally, due to the sudden onset of stroke, IPs surrounding control may take on less significance than IPs surrounding the consequences and symptoms of the condition, potentially resulting in a reduced effect of perceived control on psychological factors. However, contrarily, Jones and Riazi (2011) reported that self-efficacy in stroke patients is in fact related to depression and QoL, as well as treatment outcomes, in a review of 22 papers. The disparity in these findings may relate to the individualised nature of stroke, which has wide-ranging effects on individuals who experience this health threat. For example, although stroke is considered an acute condition, for some individuals the onset of stroke can lead to chronic effects such as physical disabilities and cognitive impairments (Sennfält et al., 2020), whilst for others, the symptoms and consequences of stroke fade rapidly. Thus, disparities in the conclusions drawn by research focussed on IPs and self-efficacy in the context of stroke may be reflective of the heterogeneous and multifaceted experiences of those affected by the condition.

Additionally, across the literature included within this overview, anxiety and depression were often linked to HRQoL (e.g., Hyphantis et al., 2013; Stapersma et al., 2019), indicating that IPs may impact HRQoL directly, as discussed in section 3.4.3, and indirectly, through impacting on mental health outcomes. For example, in a Greek study on IPs and HRQoL in arthritis, anxiety was strongly related to HRQoL in psoriatic arthritis, whilst depression was most strongly associated with physical HRQoL in rheumatoid arthritis (Kotsis et al., 2012). However, this study was cross-sectional and therefore causality cannot be inferred. Nonetheless, it is likely that there is a cyclical relationship between IPs, mental distress, and HRQoL which inform one another throughout the duration of a health condition.

Furthermore, as is the case with HRQoL research, cause is rarely considered in the literature on IPs and mental wellbeing. However, in a Canadian survey-based study, Grace et al. (2005) reported that individuals attributing the onset of acute coronary syndrome to psychological factors such as stress, mental attitude, and emotions experienced higher levels of depression than individuals attributing the cause to alternate factors such as diet and health behaviour. However, in a cross-sectional study on depression in a palliative care population within the UK, the severity of depression was unrelated to any of the attributed causes given by participants (Price et al., 2012). At the time of writing, there is limited research, particularly of a longitudinal nature, examining the cause dimension of IPs and therefore solid conclusions surrounding the relationship between causal attributions and mental distress cannot be drawn.

Finally, the current literature suggests that perceptions of the timeline of an experienced health condition exerts little influence on psychological outcomes such as anxiety and depression (Dempster et al., 2015). Some researchers have identified issues with the validity of the timeline scale used within the IPQ-R and B-IPQ (Chilcot et al., 2012), which may explain this finding. For example, Dempster & McCorry (2012) observed that one item, relating to perceptions that the condition will improve over time, maps onto the ‘treatment control’ dimension of IPs, rather than the ‘timeline’ element, casting doubt on the usefulness of this scale. Nonetheless, timeline, alongside several other IPs including treatment control, have been implicated in alternate wellbeing-related outcomes, such as HRQoL (Dempster et al., 2015), indicating that the two scales measure distinct constructs.

Overall, IPs appear to be strongly linked to anxiety and depression. Despite some differences between conditions, negative perceptions surrounding the consequences of the health threat, as well as negative emotional representations of the experienced condition, appear to have the strongest influence on mental distress. However, the predictive power of each singular IP is uncertain, as demonstrated by regression models indicating that culminative IPs have more predictive power than individual IPs when assessed alongside additional psychosocial factors (Rochelle & Fidler, 2013). Additionally, there is currently a lack of longitudinal research on IPs and psychological distress, so the stability of the relationship between IPs and psychological outcomes is unknown. Future research may aim to address this gap and to determine the longitudinal predictive validity of IPs on psychological outcomes such as depression and anxiety.

3.4.4 Coping strategies

The CSM-SR theorises that IPs indirectly influence mental and physical health outcomes by shaping the coping mechanisms adopted in response to a specific health threat or condition (Leventhal et al., 1997). Several studies have tested this theory by examining coping style as a potential mediator between IPs and various health-related outcomes.

In a wide-ranging meta-analysis, Dempster et al. (2015) examined the relationship between IPs and coping strategies across several physical health conditions, including IBS, alopecia, cancer, and arthritis. Moderate, direct relationships between IPs and outcome variables such as QoL, anxiety and depression were observed. However, within studies that introduced coping styles into their analytical models, this tended to be a stronger predictor of health outcomes than IPs. Notably, avoidant coping strategies exhibited the strongest association with psychological distress. These findings correspond with the CSM-SR, suggesting that IPs play a pivotal role in shaping coping strategies, which subsequently influence health behaviours and outcomes (Leventhal et al., 1997). Therefore, it may be expected that the link between coping and outcomes is stronger than the association between IPs and outcomes. Additionally, several studies on numerous health conditions including kidney disease (Knowles et al., 2014), allergies (Knibb & Horton, 2008), COPD (Vaske et al., 2017), and diabetes (Knowles et al., 2019) correspond with these findings, observing that coping strategies mediate the relationship between IPs and health-related outcomes.

However, alternate research has observed no such effect. For example, in a survey-based study on IPs in Crohn’s disease, Zhang et al. (2016) identified no direct relationship between coping strategies and psychological outcomes or QoL, although coping was predicted by IPs. Furthermore, in a cross-sectional study on IPs in individuals experiencing liver cancer, Fan et al. (2013) observed no mediation effect of coping in the relationship between IPs and overall QoL. This inconsistency in findings may be attributed to different analytical approaches used across the literature. For example, coping has been treated either as a covariate or a mediator across studies, potentially leading to disparities in research findings. Specifically, when coping is treated as a covariate, researchers typically control for its effects to isolate the relationships between other variables. On the other hand, when coping is considered a mediator, it suggests that coping mechanisms are part of the causal pathway between an independent variable and an outcome. Depending on how coping is handled, the interpretation of associations between variables may vary, potentially leading to different conclusions.

Additionally, to test the mediating effect of coping on the relationship between IPs and various outcomes, a regression model is often employed. Many researchers place IPs into the regression model ahead of coping, and in this setup, coping tends to explain little of the variance in outcome scores. Conversely, when coping is entered into a regression model prior to IPs, it explains a much greater proportion of the variance observed amongst participant scores. This phenomenon is known as 'statistical suppression' (Akinwande et al., 2015). When IPs are entered first into the regression model, they might account for shared variance with coping, reducing the apparent relationship between coping and outcomes. Therefore, methodological disparities between studies may, in part, explain the inconsistencies within the literature examining coping style as a mediator between IPs and outcomes. Additionally, the role of coping may take on less importance depending on the condition experienced. For example, in liver cirrhosis, concern and perceptions of the consequences are likely to exert a direct and significant influence on QoL and wellbeing factors which may result in the diminished influence of coping strategies (Dhaliwal et al., 2021).

Amongst the literature that has identified coping as a mediator of the relationship between IPs and health-related outcome variables, there is often disagreement on the nature of the relationship, even across similar conditions. For example, Kantidakis et al. (2021) examined IPs in a cohort of individuals with IBD. They observed a relationship between negative IPs, such as the perception of serious consequences associated with the condition, and maladaptive coping strategies, which underpinned emotional distress. However, importantly, the authors state that the IP dimensions incorporated into this study were 'miscoded', which limits comparisons between the results of this research and others. Nonetheless, in a study of IPs in IBS, Knowles et al. (2017) also observed that negative IPs were associated with maladaptive coping strategies, such as self-criticism and avoidance, which in turn were strongly related to psychological distress. Adaptive coping strategies were unrelated to psychological wellbeing. These results indicate that maladaptive coping is a greater predictor of psychological distress and QoL outcomes than adaptive coping in individuals with IBS and IBD. Additionally, several other studies on IBD and IBS corroborate Knowles et al.'s (2017) findings (Knowles et al., 2013; van Erp et al., 2017; Woodhouse et al., 2017).

However, in a survey-based study including 83 stoma patients, Knowles et al. (2014) observed that more positive IPs predicted the use of adaptive coping strategies, which in turn lessened the risk of depression. This corresponds with evidence which has identified a link between adaptive coping styles and wellbeing in individuals experiencing IBD. For example, in a US-based study, Parekh et al. (2014) reported that, amongst individuals with IBD, the use of adaptive, problem-focussed coping strategies was associated with more positive QoL outcomes. Additionally, Knowles et al. (2011) reported that problem-orientated coping such as positive thinking and forward planning was associated with reduced anxiety and depression, and predicted by negative IPs for individuals with Crohn's disease. However, each of these studies incorporated less than 100 participants, raising questions around the transferability of the results. Nonetheless, given the current disagreement within the literature on coping and QoL, it remains unclear whether adaptive or maladaptive coping styles exert the greatest impact on the relationship between IPs and QoL.

Nevertheless, the outlined evidence strongly suggests that maladaptive strategies are influenced by negative IPs, whilst positive IPs predict the adoption of adaptive, problem-focussed coping styles. Contrastingly, Woodhouse et al. (2018)

found the opposite effect – that negative IPs led to decreased use of maladaptive coping strategies and increased QoL outcomes in individuals with gastroparesis. This study examined IPs as a whole construct, so it is not possible to ascertain the impact of individual IP elements on coping style. However, it is conceivable that negative IPs such as perceptions around the adverse consequences and emotional representations associated with the condition fuelled participants' motivation to change their circumstances, leading to reduced use of maladaptive coping strategies and more positive QoL outcomes. Additionally, without re-examining IPs in this population following this study, it is unclear whether negative IPs were on a downward trajectory, or whether they had significantly improved over time to produce this effect. There is therefore a need for longitudinal research to further disentangle this association.

As is evident, the CSM-SR's theory that coping mediates the relationship between IPs and QoL is corroborated by multiple studies. However, as discussed above, disagreement remains within the current literature as to the nature of this relationship, even amongst studies focussed on similar conditions. The observed disparity in results may be reflective of the use of different measures of coping. For example, studies adopting generic coping measures appear to be more adept at detecting significant associations between IPs, coping, and psychosocial outcomes than disease-specific measures (van der Have et al., 2013). However, disease-specific measures of coping are likely to yield results more closely aligned with the health experiences of participants. Nonetheless, chronic health conditions tend to impact coping in several areas of an individual's life (Cheng et al., 2019), so it may be appropriate to examine coping as a generic construct, particularly in the context of QoL research.

Furthermore, some researchers have suggested that IPs themselves share similarities with coping mechanisms, and therefore measures of IPs may capture elements of coping. For example, Dempster and McCorry (2012) proposed that participant responses to the consequences scale of the IPQ-R may be driven by a process of appraisal during which the individual considers the consequences of their condition in line with the resources available to aid coping with the condition. It is therefore difficult to disentangle perceived consequences from coping strategies, potentially impacting on the strength of the mediating effect observed within the literature. This finding is corroborated by the results of a think-aloud study on IPs in type 2 diabetes, in which participants tended to consider their available coping resources when formulating their response to the consequences sub-scale of the IPQ-R (McCorry et al., 2013). These findings may partially account for the observed differences in the variance explained by coping and IPs depending on the order they are placed within a regression model. Coping may add little predictive power when placed within the model following IPs, as IPs may have already explained a substantial proportion of the variance arising from coping mechanisms.

In summary, IPs appear to be linked to coping mechanisms, as theorised by the CSM-SR. Although much of the literature suggests that coping style subsequently impacts psychosocial outcomes such as depression, anxiety, and QoL, there is some discrepancy within the literature on the strength of this relationship. There is further disagreement as to the mechanisms which underlie this relationship, with some suggesting that, primarily, maladaptive coping impacts psychosocial outcomes, and others indicating that adaptive coping strategies also have a role to play in determining wellbeing. Additionally, there is a lack of longitudinal research which must be rectified to determine the trajectory of the relationship between IPs and coping over time. Increasing understanding of the complex interplay between IPs and coping may inform interventions and future research to support people experiencing chronic health conditions.

3.4.5 Impact of IP-based interventions

IP-based interventions have been used with individuals experiencing several health conditions, including myocardial infarction (MI; Yan et al., 2014), type 2 diabetes (Alyami et al., 2021), and hypertension (Saranjam et al., 2023). Such interventions have often prompted improvements in IPs, particularly around the control and perceived consequences domains (Alyami et al., 2021; Lee et al., 2015). More positive IPs have, in turn, prompted increases in QoL and health promotion behaviours.

IP-based interventions have been trialled with individuals who have experienced MI. In an early randomised control trial by Petrie et al. (2002), 65 MI patients were assigned to a ‘treatment as usual’ group or an intervention group, in which participants received 3 half-hour support sessions with a healthcare professional, designed to alter their IPs. During these sessions, causal attributions of MI, the anticipated consequences of experiencing a heart attack, and the timeline of symptoms was discussed. Participants were provided with an action plan for future health-promotion behaviours, and the condition was discussed in detail to aid coherence surrounding MI. Compared to the control group, participants in the intervention group held more positive perceptions surrounding the consequences and timeline related to their condition. Participants also demonstrated greater understanding of MI, and showed a stronger sense of control around the symptoms associated with the condition. 3 months after the intervention, participants returned to work earlier than those in the treatment as usual group, and demonstrated fewer symptoms of angina. These results were replicated in a longitudinal study spanning 6-months (Broadbent et al., 2009), with participants who received the intervention returning to full-time work earlier than those who did not. Furthermore, participants in the treatment group reported higher perceived understanding of MI, greater intentions to attend rehabilitation sessions, lessened anxiety and reduced need for medical appointments related to their heart condition.

Additionally, Sararoudi et al. (2016) delivered a similar intervention comprising 3 half-hour information sessions with individuals who had experienced MI in Iran. This intervention led to decreased anxiety and depression around experiencing MI, increased QoL, and an earlier return to work compared to those who had not received the intervention. Specifically, patients who received the intervention returned to work on average in 28.7 days, whereas individuals in the control group returned to work in around 46 days. As 3 half-hour sessions appear to be effective for improving IPs in MI, this represents a cost-effective intervention when compared to the potential economic benefits of improved IPs. Additionally, in a pre-post intervention evaluation, Yan et al. (2014) found that 3 telephone support sessions with individuals diagnosed with acute MI also led to more positive IPs compared with the control group. Specifically, they described more positive beliefs surrounding the controllability of the condition, the timeline of MI, and improved physical activity 12 weeks after the intervention. Therefore, telephone support may be as effective as in-person sessions to improve IPs and wellbeing outcomes for individuals who have experienced MI.

Many of the interventions trialled with individuals experiencing MI have focussed on improving health literacy alongside IPs. The research described above suggests that an increase in health literacy leads to more positive IPs (Petrie et al., 2002). For example, receiving information that exercise reduces the chances of a further heart attack is likely to increase intentions to exercise and physical activity, whilst simultaneously reducing pessimism relating to the consequences and controllability of MI. As outlined previously within the current overview of the literature (see section 3.4.1), increased coherence and health literacy is associated with improved health and wellbeing (Dempster et al., 2015). Therefore, it is important that interventions aimed at altering IPs for individuals experiencing MI account for this.

Alongside MI, IP-based interventions have also been trialled with the intention of improving outcomes for individuals experiencing type 2 diabetes. In a review of IPs and type 2 diabetes outcomes, Alyami et al. (2021) reported that interventions based on IPs may lead to improved glycaemic control. However, just two studies reviewed included total IP scores before and after intervention, with only one of these studies indicating a significant change in IPs following the programme (Kasteleyn et al., 2016). Additionally, only one out of four studies indicated changes in perceptions of the consequences of type 2 diabetes following an intervention (French et al., 2008), whilst two out of five identified improvements in perceived control of type 2 diabetes (Keogh et al., 2011; Vos et al., 2018). Changes in coherence surrounding the condition, however, were identified in four out of five studies (Davies et al., 2008; Keogh et al., 2011; Taggart et al., 2018; Vos et al., 2018), corresponding to the notion that increases in health literacy may have the strongest impact on IPs. The review also identified improved glycaemic control following interventions in two studies (Keogh et al., 2011; Taggart et al., 2018).

Importantly, the interventions used within these studies included family members. Family support is important in diabetes care (Pamungkas et al., 2017), and the perceptions of family members can influence how an individual views and manages their type 2 diabetes (Searle et al., 2007). Therefore, by increasing understanding amongst family members, the interventions may have prompted increased familial support, for example by encouraging family members to address their own dietary and exercise habits, leading to improved IPs amongst participants. Furthermore, it should be noted that many of the interventions included in Alyami et al.'s (2021) review did not specifically address IPs, and any change in IPs was often measured as a by-product of these interventions, rather than as a key outcome factor. Therefore, further interventions incorporating IPs as a primary outcome measure would be beneficial to gauge the appropriateness and effectiveness of IP-based interventions in this population.

Additionally, interventions targeting IPs in hypertension have led to improvements in perceived control and coherence of the condition (Theunissen et al., 2003). One intervention evaluation conducted in Iran indicated that positive changes in lifestyle factors, such as diet and exercise, were related to attending an IP-based intervention (Saranjam et al., 2023). Similarly, following an IP-based intervention for COPD patients, participants reported improved perceptions of control over the condition, and more positive health-directed behaviours related to diet, exercise, smoking, and relaxation techniques (Weldam et al., 2017). However, these effects were not enduring, and faded after 9 months. This may reflect the barriers faced by individuals with COPD in committing to lifestyle changes such as increased physical activity. For example, individuals with COPD often experience airflow disruption, muscle impairments, and the need for supplemental oxygen which all impede their ability to undertake physical activity (Cavalheri et al., 2016). Therefore, health-directed behaviours may be more difficult to complete, and perceptions of the consequences and control related to the condition may become more negative. Thus, it is important to consider the nature of the condition alongside any functional limitations as a by-product of experiencing the condition when designing treatment plans.

Aside from chronic conditions, interventions have also aimed to promote positive IPs in acute conditions, such as injury. Lee et al. (2015) found that a hospital-based intervention over two to four hours with individuals experiencing injury in Taiwan led to increased perceptions of control and lessened symptomology compared to a control group, although the long-term effects of this intervention were not captured. Fann et al. (2021) replicated this study, checking in with patients over the course of 12 months. They found that perceptions of control were improved in the intervention group after 3 months, and at 6 months, the intervention group showed more positive emotional representations compared to the treatment as usual group. However, no intervention effects were identified at the 12-month follow-up period. This may indicate that participants had recovered or adjusted to their injury within 12 months after the intervention, which is likely given that the authors estimate that 80% of their participants had moderate rather than major injuries.

IP-based interventions may exert a more significant effect in chronic pain conditions. For example, Siemonsma et al. (2013) provided 10-14 cognitive-based therapy sessions aimed at improving IPs for 156 individuals with chronic back pain in the Netherlands. Following the intervention, participants reported an improvement in their perceptions of the timeline of chronic back pain, their understanding of the condition, the anticipated consequences and perceived controllability of chronic back pain. Individuals who received the intervention also reported improvements in their ability to undertake daily activities compared to the control group. It must be highlighted that this intervention used trained therapists and occurred over a longer timeline compared to the studies described earlier in the current chapter, so comparison between these interventions may not be feasible. However, it is likely that for chronic pain conditions, a longer, more intense intervention course is required due to the relative stability of IPs which may be resistant to change. Further research is required to corroborate this notion.

In sum, IP-based interventions have led to improvements in IPs across several chronic and acute conditions. In some cases, this is an enduring effect which has led to improvements in health-orientated behaviours and, subsequently, overall health status. The greatest evidence of an effect can be seen in the research on MI, which demonstrates that IP-based support coupled with improvements in health literacy can improve IPs and subsequent outcomes. However, overall, there are a lack of trialled interventions which limits the conclusions that can be drawn from the current literature base. Further research is required on the effectiveness of IP-based interventions for chronic, enduring conditions, particularly those causing chronic pain. The observed disparity in the effectiveness of such interventions across the spectrum of health conditions incorporated into the current literature overview indicates that IP-based interventions should be individualised to the condition being targeted and tailored to the symptoms reported by the individual experiencing the health threat.

3.5 Discussion and future research directions

As stated in section 3.3, the current overview of the literature is not systematic in nature, and therefore cannot make statements about any inherent biases within the studies incorporated into this chapter. The current overview should not be read as comprehensive, but as a broad overview of prominent themes emerging from the current literature base. This should be kept in mind when considering the conclusions drawn within this section.

Collectively, the literature outlined within the current chapter highlights the potential for IPs to influence a range of health and wellbeing outcomes, including medication adherence (Shiyanbola et al., 2018), health-related outcomes, QoL (Dempster et al., 2015), mental distress (Cannon et al., 2022), and coping strategies (Kantidakis et al. 2021). The relationships between IPs and health and wellbeing outcomes appear to be underscored by several factors, most prominently health literacy and medication beliefs (Ruksakulpiwat et al. 2022; Shiyanbola et al., 2018). Throughout the literature incorporated into the current chapter, IPs surrounding control, consequences, coherence, and the symptoms associated with a diagnosed condition appear to exert the strongest influence on health and wellbeing outcomes. This notion is reinforced when assessing the impact of IP-based interventions on patient outcomes. For example, interventions aimed at improving IPs by increasing health literacy and providing emotional support tend to prompt improvements in the perceived control and coherence of a health condition, often leading to increased health oriented behaviours and lessened mental distress (Shiyanbola et al., 2018). However, due to the lack of IP-based interventions and evaluations at the time of writing, strong conclusions relating to the effectiveness of such support cannot be drawn. Therefore, researchers may endeavour to design and assess the effectiveness of new IP-based interventions, particularly in chronic, enduring conditions.

Additionally, the literature included within the current chapter indicates that the impact of IPs on mental distress, defined here as anxiety and depression, is fairly uniform across the spectrum of health conditions evaluated. Emotional representations were very often associated with anxiety and depression (Dempster et al., 2015). This observation is perhaps unsurprising, however it also raises the possibility of tautology. For example, the IPQ-R asks participants to specifically rate the extent to which their condition makes them feel depressed, anxious, worried, and upset (Moss-Morris et al., 2002). These symptoms are directly attributable to depression and anxiety, and therefore measures of mental distress and emotional representations are likely to be closely linked in IP research. This may be problematic when considering anxiety and depression as an outcome variable, as the emotional representation subscale may already account for some mental distress. However, anxiety and depression tools measure general low mood and anxiety, whereas the emotional representation scale gauges emotions towards the condition only, which can be beneficial in determining the extent to which emotions surrounding a health condition contribute to overall mood. Nonetheless, the relationship between emotional representations and mental distress should be further explored in future research to determine the appropriateness of measuring emotional representations alongside mental distress.

In addition to mental distress, IPs are also strong determinants of QoL in several conditions (e.g., Ackigoz et al., 2023; Cai et al., 2023; Hill & Frost, 2022). However, QoL appears to be more susceptible to influence from clinical factors, as demonstrated by disparities in the influence of IPs on QoL outcomes across the range of conditions included within the current chapter. Conceptually, QoL accounts for several factors such as physical functioning and health status (see chapter 2, section 2.2), so its sensitivity to clinical factors such as chronicity and diagnostic delay is plausible. There are however some cross-cutting similarities across the full spectrum of health conditions, in that QoL appears to be most strongly associated with perceptions of the consequences of experiencing a health condition, perceived disease duration, and symptomology regardless of the condition. Nonetheless, additional research is required to determine mediating factors in the relationship between IPs and QoL, and to further assess whether this relationship is condition-specific.

Despite some commonalities between IPs across different health conditions, the impact of IPs on health and wellbeing outcomes appears to vary between chronic and acute conditions. For example, IPs appear to be more dynamic in acute conditions, and more stable in chronic conditions. As IPs become more stable, it is likely that they also become less amenable to change. Therefore, IP-based interventions may be most beneficial in the early stages of diagnosis, regardless of the nature of the condition. For both chronic and acute conditions, providing an intervention soon after diagnosis may enhance coherence and health literacy, increasing confidence around managing the condition (e.g., Yan et al., 2014). However, for chronic conditions, longer-term support is most likely required to maintain positive IPs due to the enduring nature of these types of conditions. Several IP-based interventions discussed within the current chapter took a nurse-led approach (Fann et al., 2021; Weldam et al., 2017), so IP-based support may be integrated into healthcare appointments. Additionally, the evidence indicates that telephone appointments may also promote positive IPs (Yan et al., 2014), making this a cost-effective intervention. However, such interventions have yet to be trialled in numerous health conditions, so generalising from the current literature may be problematic, and further IP-based interventions should therefore be designed and trialled. Research should also endeavour to determine the optimum timeframe and circumstances for IP-based support according to different medical conditions.

It is important to consider the methodological aspects of the literature included within the current chapter. Across studies, there were various differences in the measurement of IPs. Most prominently, several papers examined IPs as a singular construct, whilst others assessed the relative importance of each IP dimension in predicting health and wellbeing outcomes. In taking the former approach, it is not possible to ascertain the individual effect of each IP, which can be problematic when designing content for IP-based interventions. One study (Rochelle & Fidler, 2013), for example, identified a collective effect of IPs on mental distress, however there was no significant impact of any single IP on anxiety or depression. Therefore, it is important that future research breaks down IPs into their constituent parts to gain a full understanding of the relationship between IPs and health and wellbeing outcomes.

Furthermore, across the existing literature, the cause dimension of IPs is rarely examined. It is likely that this dimension is overlooked due to the complexity of scoring and difficulty in comparing the relative impact of cause with alternate IPs due to different scoring techniques for this subscale within the widely used measures of IPs. In studies that have examined the impact of cause on health and wellbeing outcomes, there is often no relationship identified between these factors (Foxwell et al., 2013). However, at the time of writing, there is inadequate research on causal attributions and wellbeing outcomes to draw solid conclusions regarding the nature of this relationship. Qualitative research may be beneficial in this case to examine the perceived causes held by individuals experiencing a range of health conditions, which would provide in-depth information on if, and how, causal attributions relate to health and wellbeing outcomes.

Additionally, there is a lack of longitudinal research pertaining to IPs and health and wellbeing outcomes. Cross-sectional research is useful for gauging the relationships between IPs and outcomes, however causation and the nature of the relationships uncovered in this type of work cannot be deciphered without longitudinal study. Employing longitudinally designed research may aid in disentangling the complex relationships between IPs, coping, and outcome variables such as HRQoL and health-directed behaviours. Furthermore, establishing the longitudinal predictive validity of IPs in relation to a variety of health and wellbeing outcomes may support the design of future health-based interventions.

Longitudinal work would be particularly beneficial in unravelling the links between IPs, coping, and various health and wellbeing outcomes, as these relationships remain unclear at the time of writing. However, such uncertainty surrounding these associations may arise from the widespread use of generic coping measures across the IP literature. The majority of papers included in the current chapter employed generic measures of coping, which make no distinction between coping with everyday stressors and coping with health conditions (e.g., COPE questionnaire, Carver et al., 1989), rather than health-specific measures of coping. Generic measures of coping are more susceptible to influence from alternate stressors than health-specific measures. For example, following the outbreak of COVID-19 in 2020, coping styles are likely to have adapted and changed as additional stressors arose, such as national lockdowns (Godor & Van der Hallen, 2021). Therefore, coping styles assessed during the pandemic may not accurately reflect those used in relation to an experienced health condition. This exemplifies the susceptibility of coping styles to change in response to environmental factors out-with health status. Similarly, it is likely that different coping strategies are adopted for different stressors, so the way an individual copes in everyday situations may not be reflective of how they cope with regards to their health condition. Therefore, health specific measures of coping may be more appropriate in capturing information specific to the health condition experienced, and may lead to more uniform results across the literature. However, utilising these measures is not without its drawbacks. For instance, health-related aspects affect several areas of life beyond an individual's health status, including factors such as work, recreation, and wellbeing (Ambrosio et al., 2021). Therefore, health-specific measures may not capture the full extent of coping with the different elements of an experienced health condition. Future research may wish to evaluate the appropriateness of utilising different coping measures in IP-related research.

Whilst there has been ample research into IPs and health and wellbeing outcomes in several conditions, such as CHD, type 2 diabetes, hypertension, and COPD, there are clear gaps in the literature on alternate health conditions. This is particularly evident for women's health conditions, in which IPs have rarely been considered. For example, no research was identified which directly or comprehensively measured IPs as a predictor of health and wellbeing outcomes in menopause, adenomyosis, or endometriosis. The symptoms of endometriosis share some overlap with those of IBS, which has been researched in the context of IPs. Both are chronic, incurable conditions which, for many, can cause significant pain and life disruption (Horne & Missmer, 2022; Shah et al., 2020). Due to this overlap in symptomology, the aforementioned research demonstrating a link between IBS-related IPs and health and wellbeing outcomes (e.g. Knowles et al., 2017) indicate that IPs may also play a role in shaping health and wellbeing outcomes in endometriosis. As adverse QoL and wellbeing outcomes are associated with endometriosis (e.g., La Rosa et al., 2019; Marinho et al., 2018; Vitale et al., 2017), it is particularly important that future research investigates the potential impact of IPs on the lives of individuals affected by the condition. Deciphering whether such a link exists may allow for the creation of IP-based interventions to support the wellbeing of individuals experiencing endometriosis.

3.6 Chapter summary

The current chapter provided an overview of the literature on IPs and health and wellbeing outcomes. Initially, the CSM-SR was outlined, with discussion on the evolution of the IP dimensions over the years. Next, the approach of the current overview was outlined. An overview of the known impact of IPs on health and wellbeing outcomes was next provided, outlining the literature on IPs and health-directed behaviours, QoL, mental distress, and coping strategies. The impact of IP-based interventions was next considered. Finally, a discussion of the findings of the overview, including suggestions for future research was presented. The next chapter will outline the methodology underpinning the present research.

CHAPTER 4

Methods

4.1 Introduction

The present thesis adopts a mixed methods approach, including both qualitative and quantitative elements. For the quantitative component of this project, a longitudinal survey comprising two time points was used, whilst semi-structured interviews were conducted for the qualitative element. The current chapter provides further details on the methodological approach adopted for the current research. First, the philosophical underpinnings of the research are considered (4.2). An account of ethical considerations relevant to the current project is then presented (4.3). Subsequently, details of the quantitative (4.4) and qualitative (4.5) aspects of this project are provided, including information pertaining to participants, data collection and data analysis. Finally, the process of integrating the qualitative and quantitative data is considered (4.6) before the chapter is summarised (4.7).

4.2 Methodological approach

4.2.1 Mixed methods research

A mixed methods approach was adopted for the current thesis. Broadly, mixed methods research incorporates both quantitative and qualitative methods in data collection, analysis and interpretation (Shorten & Smith, 2017). One key aspect of this approach is the integration of both methods of data collection to provide a coherent and well-rounded evaluation of the phenomena under investigation

(Saraswati et al., 2021). Dunning et al. (2008) outline two key objectives of mixed methods research in QoL research: confirmation and comprehension. Confirmation refers to the convergence of findings from multiple data sets (in this case, qualitative and quantitative). Traditionally, confirmation often involves the quantification of qualitative data during the analysis stage to streamline comparisons between data sets (e.g., Roberts et al., 2002; Sandelowski et al., 2007). However, in researching complex and dynamic experiences, as qualitative work most often aims to do, the richness and complexity of the data gleaned from qualitative methods may be lost in the process of quantification, and the qualitative method itself may be undermined (Monrouxe & Rees, 2020). Furthermore, there are issues with the process of quantification itself, for example how to classify codes appropriately, particularly when there are outliers present (Shorten & Smith, 2017). Additionally, the quantification of qualitative data implies a positivist epistemology, in which an objective truth can be gained from qualitative data. This is at odds with several qualitative methodologies, including the chosen method for the qualitative element of the current thesis, reflexive thematic analysis (Braun & Clarke, 2006). Mitchell (1986) attempted to circumvent these issues by suggesting “conceptual validation” as an alternate approach to achieving confirmation in mixed methods research. This approach aims to identify “logical patterns of relationships and meanings” between the data sets (Mitchell, 1986, p.25). It is the latter approach that is taken by the current thesis. The second goal of mixed methods research, comprehension, combines the data from both research approaches to provide a thorough, broad understanding of the topic under investigation. This process is closely linked to confirmation, and Mitchell (1986) suggests that the two are mutually exclusive.

Mixed methods research is increasingly utilised in health-related research, most likely due to the complexity of the topic area and the benefits derived from combining two separate but complementary approaches to the study of health-related topics. For example, the integration of qualitative and quantitative methods may offer a more comprehensive understanding of health-related topics and greater opportunity for suggesting future research directions, particularly for topics that are traditionally under-researched (Dawadi et al., 2021), such as endometriosis. Furthermore, a mixed methods approach allows for lived experience to be considered from a patient perspective, to ensure that findings from quantitative data and subsequent recommendations for future practice are considered in line with patient needs and voices (Regnault et al., 2018). This is of particular importance in the current study, given that many individuals experiencing endometriosis have felt silenced and unheard in both research and medical settings (Rowe et al., 2019). The merits of adopting a mixed methods paradigm have been recognised by several organisations including the International Society for Quality of Life Research, who have advocated for the use of mixed methods research in QoL research (Regnault et al., 2018). However, mixed methods research can be difficult to implement due to the demands it places on researcher skillsets. For example, researchers must have a strong knowledge of qualitative, quantitative, and mixed method paradigms to effectively conduct this type of research (Halcomb, 2018). Furthermore, there are issues in the conceptualisation of widely used terms associated with mixed methods research, such as triangulation, which has led to wide disparities in the ways in which qualitative and quantitative data have been integrated.

Triangulation most often refers to the cross-validation of study results by examining points of convergence across the data collected from qualitative and quantitative data (Gibson, 2017). Triangulation is often used to test the reliability of one method by validating the results against those acquired using a second method (Morgan, 2019). However, it has been suggested that corroborating results in this way is not possible due to disparities in the nature of the data collected from quantitative and qualitative methods (Maxwell, 2022), and instead points of convergence, divergence, and complementarity between the results collected from each method should be emphasised (Sale et al., 2002; Maxwell, 2022). The present thesis therefore examines points of complementarity, convergence, and divergence within both data sets and does not necessarily consider divergence as evidence of unreliable and invalid methodology, but as points necessitating further exploration and/or explanation. Adopting a more complementary approach to integrating mixed-methods data also addresses problems arising from the ‘paradigm wars’ (Denzin, 2010), in which some researchers have argued that qualitative and quantitative paradigms are incompatible due to the contradictory research philosophies that underpin both types of research. Some philosophies allow for the blending of qualitative and quantitative approaches in a mixed methods paradigm including critical realism and pragmatism (Schoonenboom, 2019; Shan, 2021). It is the latter that underpins the present thesis, and this is discussed in further detail within section 4.2.2 of the current chapter.

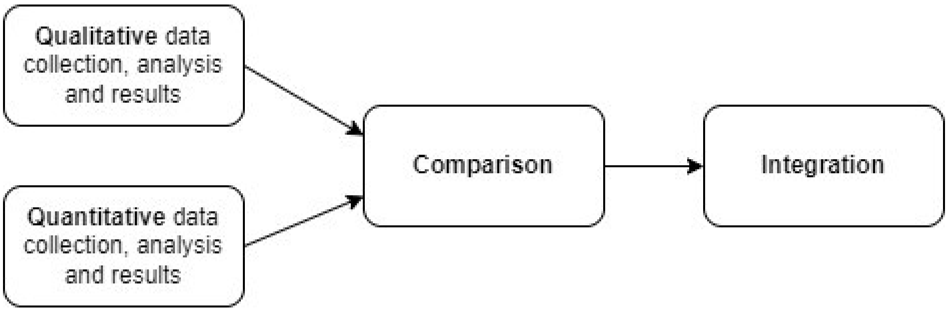
The current thesis adopted a convergent parallel design (see figure 4.1), in which qualitative and quantitative data were collected concurrently, analysed separately and subsequently integrated. A mixed methods design was adopted for two key reasons:

i) To allow the voices of individuals with endometriosis to be heard. Research suggests that individuals experiencing endometriosis often feel unheard and invalidated in their thoughts and experiences (Young et al., 2015). Therefore, it was deemed important to position the voices of those living with endometriosis at the forefront of the current thesis.

ii) There is currently no research examining the role of IPs in endometriosis-related QoL. By its nature, mixed-methods research allows for an in-depth, complementary approach which combines the expertise of the patient group with generalisable data relating to the pervasiveness of IPs within the wider endometriosis community.

Figure 4.1

Convergent parallel design



Adapted from Creswell & Plano-Clark (2011)

4.2.2 Pragmatism

The current thesis is grounded in a pragmatic epistemology. Pragmatism is underpinned by the ideology that the philosophical and/or methodological approach to research should be driven by what works best for addressing the issue under investigation, rather than by notions of the nature of truth and reality (Kaushik & Walsh, 2019). From a philosophical standpoint, the role of action and human agency is emphasised in pragmatism, which holds that human actions are driven by their anticipated consequences, which in turn are modelled upon past experiences and the belief systems subsequently built upon these experiences (Shan, 2021). Therefore, rather than external factors shaping behaviours, thoughts and actions, the individual themself is viewed as a key driving force of their own experience (Kaushik & Walsh, 2019). However, pragmatic researchers recognise that actions and behaviours cannot be separated from the context in which they arise (Morgan, 2014). Epistemologically, knowledge is based on past experience and beliefs are modelled upon experiences occurring in the social world. Human actions in turn have the potential to shape individual realities and the wider environment, which is seen as dynamic and unfixed (Kaushik & Walsh, 2019). In this vein, pragmatists maintain that, as reality is based on personal experience and actions, there can be no identical worldview between people, but varying degrees of shared beliefs between individuals based on their experiences and knowledge (Morgan, 2014). Rather than constituting reality, knowledge is a means to achieving goals and enhancing the human experience (Allemang et al., 2022).

Some pragmatic researchers have outlined their belief that there is a separate, objective reality that can be accessed only through human experience (Kaushik & Walsh, 2019). However, there is a general consensus amongst pragmatists that the nature of reality will never be determined as meaning is contingent on individual human experience and context (Morgan, 2014). Reality and truth are viewed as unfixed and changeable, dependent on what affords the ‘best results’ in specific contexts (Elder-Vass, 2022). Therefore, the focus in pragmatic research is on inquiry rather than addressing epistemological and ontological questions, as, to the pragmatist, it is doubtful that an agreement on the nature of knowledge and reality will ever be determined (Kaushik & Walsh, 2019). In this vein, pragmatism positions itself as a proactive method for problem-solving, in which inquiry is a means of supporting action in real-world contexts. In its objective to adopt the best tools for specific topics, pragmatism is dynamic, embracing research methods and tools across the spectrum. Thus, this approach is often associated with mixed methods paradigms (e.g., Mitchell, 2018). However, many philosophical approaches have been adopted for mixed methods projects, including critical realism and post-positivist stances (e.g., Mukumbang, 2023), so the use of mixed methods research does not automatically imply a pragmatist viewpoint and it is important therefore that researchers state their stance within their research. Additionally, pragmatists have used tools across the spectrum to answer their research questions, and it should not be assumed that mixed methods approaches offer the best means of answering all research questions. Nonetheless, as discussed in section 4.2.1, mixed methods research is beneficial for health research in particular, in that the information collected reflects the complexity of the subject area.

Some critics of pragmatism suggest that this philosophical stance can be used as justification for adopting any method in research without thorough exploration of the implications of utilising these tools, particularly with regards to epistemology and ontology (e.g., Biddle & Schafft, 2015; Hampson & McKinley, 2023). However, in side-lining epistemological and ontological arguments, pragmatists argue that the research question takes precedence over what is often viewed as arbitrary dialogue surrounding the nature of truth and reality (Maarouf, 2019). Therefore, this approach focusses on problem-solving and enacting real-world change.

To exemplify pragmatism in the case of the current research, it was noted that there was a dearth of research associated with endometriosis. Upon further investigation, QoL outcomes had been researched extensively, but no research pertaining to IPs and wellbeing was identified. Subsequently, research questions and study protocols were developed based on the identified gaps in knowledge. A mixed methods approach was deemed most appropriate to address the research questions, to allow for both exploratory and structured investigation into this complex research area. It was recognised that mixing qualitative and quantitative methods offered the best opportunity to drive understanding of endometriosis, as both paradigms yield important and relevant information that may be used to address the central research questions. Therefore, significance was placed upon the research question and how best to address this in order to drive change, in line with a pragmatic research stance.

4.3 Ethics

Ethical approval for the current thesis was gained from the University of Strathclyde and the NHS ethics board. In line with the British Psychological Society's Code of Ethics and Conduct (2021), the principles of respect, competence, responsibility, and integrity were upheld throughout the research process. Ethical considerations pertinent to the current investigation are discussed in further detail below.

4.3.1 Informed consent

Due to the sensitive and highly personal nature of the subject matter, informed consent is vitally important in the context of the current study. The survey element of the current project was often circulated by gatekeepers such as the organisers of online support groups and charity representatives, so the extent to which participants were able to offer informed consent in this context must first be considered. There is a risk that some participants, for example those with strong ties to the charities or groups where the survey link was posted, may have felt pressured or obliged to complete the survey. To mitigate against this risk, gatekeepers distributed the survey alongside a description of the survey contents and a note stating that taking the survey was optional (appendix A), before a detailed information sheet (appendix C) was presented to participants upon accessing the survey link. It was further emphasised within the information sheet that participants were not obliged to complete the survey upon accessing the link and could leave at any time as per their right to withdraw. Similarly, prior to the interviews, participants were provided with a detailed information sheet (Appendix I) before indicating their consent to participate via email. As an additional safeguard, time was allocated at the start of the interview for interviewees to ask any questions or to request information relating to the study before they were asked to again indicate their consent to participate in the interview. Participants were also made aware of their right to withdraw at any time during the interview. Furthermore, the inclusion criteria of the current thesis (section 4.4.1.2) stipulates that participants must have a good understanding of English to ensure that all participants could understand the information sheet and therefore consider their participation carefully.

4.3.2 Confidentiality

Personal details (i.e., names and e-mail addresses) were collected within the current project to: i) allow researchers to re-contact participants for the 1-year follow-up survey; ii) identify and contact participants interested in participating in the interview; and, iii) match responses from the baseline survey to the follow-up survey. Therefore, it was important to preserve participant confidentiality and anonymity.

Within the survey element of the current project, participant details were entered into the survey platform Qualtrics, which was password protected and accessible only by the lead researcher. Contact details were transferred to a password-protected Excel sheet on secure University servers where they were stored prior to follow-up. Participant details were deleted after baseline and follow-up responses were matched. Similarly, the details of potential participants for interviews were stored in a separate password-protected Excel sheet which was deleted upon completion of the one-to-one interviews. All potentially identifying information including names and locations were removed from interview transcripts. Audio recordings of interviews were deleted upon the completion of transcription, within 2 weeks of the conclusion of each interview.

4.3.3 Risks and burden associated with participation

As described in chapters 1 and 2, endometriosis is associated with adverse mental health outcomes. Therefore, there is a risk of distress amongst participants when asked to disclose information pertaining to their condition and associated experiences. To mitigate against this, participants were provided with a list of support organisations within the information sheets (appendices C, F, and I) and debrief documents (appendices E, H, and K) for both the surveys and interview. It was also made clear throughout the process that participants could leave (either the survey or interview) at any time. If, during the interview, participants appeared to experience distress, the interviewer ceased the interview and gave the participant time to process their emotions. The interviewer explicitly asked participants if they would like to continue or disengage from the interview. Regardless of their answer, support options were explicitly discussed with the participant and, if they opted to continue, participants were given as much time as they felt necessary before the interview was resumed. Although several participants became visibly upset during the interview process, all opted to continue. At debrief, participants often advised that they were glad to have taken part.

Aside from the potential for emotional distress, it was recognised that participation in the interview involved a significant time commitment. With this in mind, interviews were arranged at a time and date convenient to each participant. Participants were also offered compensation for their time in the form of a £20 Amazon gift voucher.

4.4 Longitudinal survey

The first element of the current thesis comprised a two-wave longitudinal survey designed to assess a range of psychosocial factors and their relation to HRQoL and wellbeing outcomes in endometriosis. This survey aimed to address the following research aims:

i) Investigate the longitudinal predictors of HRQoL and wellbeing outcomes in endometriosis;
ii) Determine if IPs predict HRQoL and wellbeing outcomes over and above demographic and clinical factors;
iii) Determine the stability of IPs in the context of endometriosis;
iv) Investigate coping as a potential mechanism explaining the link between IPs and outcomes, as theorised by the CSM-SR.

Longitudinal research allows for psychological models to be tested over time to detect any changes in variables over the course of the chosen timescale (Caruana et al., 2015). This type of research offers several advantages over cross-sectional studies, which provide a snapshot of a single moment in time (Wang & Cheng, 2020). Firstly, they allow a sequence of events to be established, so a more detailed picture of the interaction between the variables of interest is provided (Neale, 2020). Additionally, the predictive validity of a range of factors can be determined though longitudinal study. Furthermore, longitudinal designs mitigate against some potential biases such as recall bias, in providing a baseline measurement of the variables under investigation to compare with follow-up results (Caruana et al., 2015). This can equate to higher validity and confidence in the acquired results compared to cross-sectional designs, to such an extent that, within many cross-sectional studies, the design of the research is stated as a limitation with recommendations to include the variables in a longitudinal research design in the future (Spector, 2019). Although there are clear benefits to employing a longitudinal design in research, there are also risks associated with longitudinal designs, most notably the threat of participant attrition over time (Caruana et al., 2015). No recent estimates of attrition across longitudinal studies were identified, however estimated attrition rates range from 30-70% according to previous literature (Gustavson et al., 2012). The risk of attrition rises with each wave of a longitudinal study, so the more points of data collection involved in a study, the higher the risk of participant drop-out (Gustavson et al., 2012). High rates of participant withdrawal can lead to attrition bias, in which the final sample of participants significantly differs from the initial baseline sample, leading to concerns around the validity of comparing results from different study time-points (Jacobsen et al., 2022). Taken together, longitudinal studies with multiple waves of data collection, occurring over several years, are at the highest risk of problematic attrition rates and attrition bias. As the current study involves only two waves of data collection spaced 12-months apart, the risk of achieving the highest estimates of attrition was deemed low. Nonetheless, to mitigate against potential attrition, participants were over-recruited during the baseline data collection stage (see section 4.4.1.4).

An online survey was utilised as the most appropriate means of obtaining large quantities of data across a substantial geographical area in this time constrained project. It must be noted that data collection occurred during the COVID-19 pandemic, when lockdowns were in place across the UK and Ireland, forcing the survey into an online environment. However, it is likely that an online survey would have been utilised regardless of COVID-19 due to the convenience and reach associated with employing this technique.

4.4.1 Participants

4.4.1.1 Sampling strategy

Participants were recruited by convenience sampling, with elements of snowball sampling. Convenience sampling is beneficial in time constrained situations as it allows for responses to be collected without monitoring and re-visiting the sampling strategy to ensure a wholly representative sample. Allowing anyone who fits the inclusion criteria to participate also increases the reach of the survey, potentially leading to an increased number of participants which is particularly beneficial for novel areas of investigation. However, in prioritising the reach of the survey the representativeness of the survey data may be lost through convenience sampling, and therefore it is uncertain whether a representative picture of the target population may be derived from the study sample (Etikan et al., 2016). Demographic disparities in the individuals most likely to respond to surveys have previously been noted. For example, White individuals from higher socioeconomic backgrounds are reportedly most likely to respond to surveys distributed through convenience sampling (e.g., Jang & Vorderstrasse, 2019). This is indeed the case in endometriosis research, where some have argued that endometriosis was traditionally treated as a condition of ‘White, middle-class women’ (Jones, 2016). However, according to one study, around 6 out of 10 cases of endometriosis may be undiagnosed (Morassutto et al., 2016) and therefore it may not be possible to build an accurate demographic profile of the individuals experiencing endometriosis as many individuals may not yet have a diagnosis. Nonetheless, based on the demographics of the UK and existing estimates of the demographical spread of individuals living with endometriosis, a sampling matrix was devised to target individuals who were likely to be under-represented in the survey data through the qualitative element of the current research project (see section 4.5.3.2).

4.4.1.2 Inclusion and exclusion criteria

Table 4.1 summarises the criteria that potential participants were required to meet before they could be considered for inclusion in the study. Originally, the survey was open to residents of the UK only, however during the initial stages of data collection this criterion was expanded to include individuals residing in the Republic of Ireland. This decision was taken to expand the reach of the project and the target number of participants, particularly after one large charity that had previously agreed to distribute the survey became uncontactable, leading to concerns around reaching the target number of participants. Ireland was deemed an acceptable location for recruitment due to its proximity to the UK, a comparable healthcare model, and similarities in the culture around endometriosis and menstruation.

Please note that these criteria were applied to all elements of the overarching project (i.e., baseline survey, follow-up, qualitative research).

Table 4.1

Inclusion criteria

Criterion	Rationale
Aged over 18	Adults were recruited for the current study to conform to ethical standards and to ensure that informed consent could be given. Adolescents and children may also have different needs and experiences with endometriosis and menstruation and are less likely to be diagnosed with endometriosis.
Medically confirmed diagnosis of endometriosis	There are similarities in the symptoms of endometriosis and several other conditions such as adenomyosis and chronic pelvic pain. An individual therefore cannot be diagnosed with endometriosis until they have undergone medical investigation to identify endometrial tissue (see chapter 1).
Resident of UK or Republic of Ireland	Similar societal attitudes surround menstruation across the UK and Ireland. It was important to ensure that the culture around endometriosis was streamlined to prevent potentially confounding sociological variables. The UK and Ireland also have similar healthcare systems – although there are often charges related to healthcare in the Republic of Ireland, these are often subsidised through the public healthcare system. Including countries with a vastly different healthcare system may skew results and add another variable to be controlled for within the current study.

It should be noted that individuals were required to have a medical diagnosis, rather than a surgical diagnosis of endometriosis. A medical diagnosis refers to a confirmation of endometriosis from a medical professional, and therefore does not necessarily have a surgical element. However, as outlined in chapter 1 (section 1.3.3), surgical inspection through laparoscopy is the gold standard for detecting endometriosis (Mak et al., 2022). It is therefore possible that individuals without a surgically-derived diagnosis of endometriosis participated in the current research, raising questions around the authenticity of their endometriosis diagnosis. However, it was deemed important to capture as many perspectives from individuals with endometriosis as possible, and some participants may have been diagnosed through unconventional channels, such as MRI or transvaginal ultrasound. Indeed, research has suggested that cases of DIE and ovarian endometriosis (or chocolate cysts) can be accurately diagnosed through methods such as transvaginal ultrasound (Goncalves et al., 2021). Therefore, the decision was taken to include participants with medically confirmed cases of endometriosis, rather than just surgically confirmed cases. As is the case with all data deriving from self-report measures, there is an element of risk that participants may not conform to the inclusion criteria. This should be kept in mind when considering the findings of the current research.

4.4.1.3 Recruitment

Recruitment for the baseline survey occurred between April 2021 and August 2022. A multipronged approach to recruitment was taken. Participants were recruited for the survey through social media channels including Facebook, Instagram, and Twitter. On Facebook, support groups for people experiencing endometriosis were targeted and a post explaining the remit of the study (appendix A) was posted where appropriate. Group administrators were also asked if they could distribute the survey amongst their group members. Online forums were targeted including Reddit, Mumsnet and Endometriosis.net, where the same social media blurb was posted where permitted and appropriate. Charities were also contacted. The World Endometriosis Research Foundation posted a link to the survey on their website. One large endometriosis charity expressed interest in distributing the survey however ceased contact during the recruitment period and subsequently became uncontactable. The loss of a potentially major contributor to participant numbers through this charity meant that alternate routes to recruitment were explored. The inclusion criteria were expanded to include individuals living in the Republic of Ireland as well as the UK (see table 4.1) and NHS ethical approval was sought to allow for the distribution of the survey in hospitals across Scotland’s central belt. Upon receiving NHS ethical approval, posters for the survey (appendix B) were placed in two endometriosis clinics in the Lothian area. Participants could enter the survey by clicking a hyperlink or by scanning a QR code with their phone.

The majority of participants (403; 98.8%) accessed the baseline survey through social media channels and charities, whilst 5 participants (1.2%) were recruited through the NHS. Three hundred and sixty-eight participants disclosed where they had first encountered the survey. Of those recruited through non-NHS channels (N = 363), 137 individuals were recruited through support groups (37.2%), 136 found the survey on social media (36.9%), including Facebook, Twitter, Instagram and LinkedIn, 68 were recruited through forums (18.4%) such as Reddit and MumsNet, 13 discovered the survey through word of mouth (3.5%) and 4 learned about the project through charity websites (1.1%). The remainder came across the baseline survey through web searches.

Within the baseline survey, participants were asked to provide their contact details and were subsequently re-contacted for follow-up. Participants’ personal details were transferred to a secure spreadsheet upon completion of the baseline survey, where they were organised according to the date of recruitment. Participants were re-contacted in groups around one year after completing the baseline survey (M = 1.03 years). Recruitment for the follow-up survey occurred between April 2022 and June 2023.

4.4.1.4 Sample size

G*Power was used to calculate the appropriate sample size for the current study. An a priori linear multiple regression model with 32 predictor variables at 95% power indicated a target sample of 270 participants for a medium effect size. It was estimated that up to 40% of participants would be lost at follow-up. This figure was based on previous research estimates and through discussion amongst all researchers based on their experience with longitudinal data. Accounting for potential attrition, a new target sample size of 432 participants was calculated for the baseline survey, so that at least 270 were retained at the follow-up stage.

Following data collection, univariate analysis was conducted to ascertain the suitability of each factor for multivariate analyses. Resultantly, the number of predictor variables was reduced from 32 to 22 (see chapter 5, section 5.5.7). Based on the revised number of predictor variables, calculations on G*Power indicated a new target sample of 230 participants for the follow-up assessment. Power was set at 95%, alpha at .05 for a medium effect size.

4.4.1.5 Participant demographics

Baseline survey

Four hundred and forty-three participants responded to the baseline survey, however 11 incomplete responses and 20 duplicates were removed from the study, leaving 412 participants. A further 4 participants were removed from the dataset due to residing outside the UK or Ireland. Therefore, 408 participants were included in the final dataset. Those who had completed the B-IPQ and all wellbeing measures were included in this sample. 373 (91.4%) participants completed the full survey. For all completed scales, 0.17% of data was missing and 99.83% was complete. Missing data cells were populated with the serial mean for each variable so that sub-scales could be calculated.

Participants resided in the UK and Ireland. They were aged between 19 and 56 with a mean age of 33.92 years (SD = 7.99). Details regarding gender were not recorded, although it is important to note that not everyone who experiences endometriosis identifies as female. Additional demographic information can be found in table 4.2. Participants had experienced endometriosis for approximately 15.5 years (SD = 8.44) and had been diagnosed for around 5.07 years (SD = 5.61), indicating a mean diagnostic delay in this sample of 10.4 years. Participants first approached their GP an average of 12.62 years prior to their participation in the study (SD = 8.11), indicating that, of the 10.4 years diagnostic delay, there was a help seeking delay of 2.87 years and a delay within medical settings of 7.55 years. This corresponds with recent estimates of diagnostic delay in the UK of 7.5 years for endometriosis (Endometriosis UK, 2023). However, when the additional help seeking delay is considered, the delay associated with obtaining support and treatment for endometriosis far surpasses this estimate.

Two hundred and forty (58.8%) participants experienced at least one co-morbid condition. Of these participants, 122 were diagnosed with a psychological condition, 102 disclosed a gastrointestinal condition, and 59 had respiratory problems. Several experienced adenomyosis (52) and polycystic ovary syndrome (46). Other co-morbid conditions commonly reported by participants included bladder conditions (40), fibromyalgia (34), autoimmune conditions (25) and thyroid problems (13). Further details relating to participants’ endometriosis are detailed in table 4.3.

Table 4.2

Participant demographics for baseline survey

	N	%
Ethnicity (*n = 408*)		
English	159	39%
Scottish	122	29.9%
Another White Background	34	8.3%
Welsh	34	8.3%
Irish	21	5.1%
Northern Irish	15	3.7%
Asian and White	5	1.2%
Indian	4	1.0%
African	4	1.0%
Another Mixed Background	4	1.0%
Pakistani	2	0.5%
Other	1	0.2%
Another Asian Background	1	0.2%
Another Ethnic Background	1	0.2%
Caribbean	1	0.2%
Relationship Status (*n = 407*)		
Married	152	37.3%
Cohabiting with partner	138	33.9%
Single	93	22.9%
Divorced or separated	6	1.5%
In a civil partnership	5	1.2%
Widowed	2	0.5%
Prefer not to say	11	2.7%
Educational attainment (*n = 407*)		
Undergraduate / Bachelors degree	118	29%
Postgraduate degree	113	27.8%
Certification of Higher Education (CertHE)/Higher Apprenticeship/Higher National Certificate (HNC)/NVQ Level 4/Level 4 Diploma or equivalent	41	10.1%
Secondary education to Highers/A-level/Leaving certificate level or equivalent	40	9.8%
Diploma of Higher Education (DipHE)/Foundation degree/Higher National Diploma (HND)/NVQ level 5/Level 5 diploma or equivalent	28	6.9%
Secondary education to GSCE/CSE/O-levels/National 5/Junior certificate level or equivalent	21	5.2%
Doctoral degree	20	4.9%
Completed secondary school education to National 3/4 or standard grade	10	2.5%
Left school with no qualifications	8	2%
Prefer not to say	8	2%
Employment status (*n = 408*)		
Employed full-time	217	53.2%
Employed part-time	64	15.7%
Full-time student	31	7.6%
Disabled or unable to work	28	6.9%
Self-employed	25	6.1%

Homemaker/Full-time parent	15	3.7%
Unemployed, looking for work	9	2.2%
Employed on a zero hours/casual contract	6	1.5%
Unemployed, not looking for work	6	1.5%
Part-time student	5	1.2%
Other	1	0.2%
Prefer not to say	1	0.2%
Country of residence (*n = 408*)		
England	187	45.8%
Scotland	147	36%
Wales	43	10.5%
Northern Ireland	16	3.9%
Ireland	15	3.7%

Table 4.3

Participant clinical information at baseline

	N	%
Treatment (*n = 408*)		
NHS	248	60.8%
Some private, some NHS	124	30.4%
Completely private	32	7.8%
Prefer not to say	4	1.0%
Co-morbid condition (*n = 408*)		
Yes	240	58.8%
No	161	39.5%
Prefer not to say	7	1.7%
Surgery (*n = 408*)		
Had surgery	343	84.1%
Not had surgery	64	15.7%
Prefer not to say	1	0.2%
Number of surgeries (*n = 343*)		
1	175	51.0%
2	77	22.4%
3	45	13.1%
4	25	7.3%
5	10	2.9%
6	3	0.9%
10	4	1.2%
More than 12	4	1.2%
Trying for baby (*n = 407*)		
Yes	174	42.8%
No	227	55.8%
Prefer not to say	6	1.5%
How long did it take you to conceive / how long have you been trying to conceive? (*n = 176*)		
Less than 6 months	33	19.1%
6-12 months	27	15.6%
1-2 years	24	13.9%
Longer than 2 years	82	47.4%
Prefer not to say	7	4%

The majority of participants used painkillers or hormonal treatment such as the contraceptive pill to treat their endometriosis. As indicated in table 4.3, several participants had undergone surgery as a treatment, whilst some had tried herbal or alternate medicines as a means of managing their condition. Some participants (n = 5) disclosed that they used cannabis as a self-treatment for endometriosis.

Follow-up survey

Two hundred and eighty-three participants completed the follow-up survey. All responses were complete and no cases were removed. Participant retention rate was 69.36%. Ten participants provided erroneous or incomplete contact information within the baseline survey and therefore could not be contacted.

Participants were aged between 20 and 57 with a mean age of 35.27 years (SD = 8.14). 93.6% of participants were White, compared to 94.3% of respondents to the baseline survey. Mirroring the demographics of baseline respondents, 71.2% of participants who completed the follow-up survey were married or cohabiting with a partner. Participants tended to be in full or part time employment (72.1%) and were likely to hold a university-level degree (60.3%), similar to the baseline cohort. The majority of participants resided in England (47%) followed by Scotland (34.3%). Ultimately, there was little difference observed in the demographics between participants within the baseline group and respondents to the follow-up survey.

Clinical information relating to participants' endometriosis can be found in table 4.4. As indicated by this table, there is little difference between the endometriosis information provided by follow-up participants and baseline respondents.

Table 4.4

Clinical endometriosis information at follow-up

	N	%
Treatment (*n = 283*)		
NHS	165	58.3%
Some private, some NHS	95	33.6%
Completely private	21	7.4%
Prefer not to say	2	0.7%
Co-morbid condition (*n = 283*)		
Yes	163	57.6%
No	114	40.3%
Prefer not to say	6	2.1%
Surgery (*n = 283*)		
Had surgery	245	86.6%
Not had surgery	38	13.4%
Number of surgeries (*n = 245*)		
1	122	49.8%
2	56	22.9%
3	36	14.7%
4	19	7.8%
5	7	2.9%
6	2	0.8%
10	1	0.4%
More than 12	2	0.8%
Trying for baby (*n = 283*)		
Yes	119	42.2%
No	161	57.1%
Prefer not to say	2	0.7%
How long did it take you to conceive / how long have you been trying to conceive? (*n = 118*)		
Less than 6 months	21	17.8%
6-12 months	17	14.4%
1-2 years	19	16.1%
Longer than 2 years	58	49.2%
Prefer not to say	3	2.5%

Two hundred and forty-five participants indicated that they had undergone surgery for their endometriosis in the 12 months preceding completion of the follow-up survey. Like respondents to the baseline survey, the majority of participants used painkillers and hormonal treatments to manage their endometriosis. Seven participants had become pregnant in the 12 months preceding completion of the follow-up survey.

4.4.2 Design

A longitudinal design was adopted for the current study. A hierarchical regression model was used. The predictor and outcome variables measured in the current study are described below.

4.4.2.1 Predictor variables

Thirty-two predictor variables were outlined for potential inclusion in the regression model. These variables are outlined below.

First, demographical variables were measured. Specifically, age and household income were measured on a continuous scale, whilst other demographical factors including ethnicity (with two levels: White, Non-White background), marital status (with two levels: in a relationship, single), educational background (with two levels: university education, not attended university), and employment status (with three levels: full-time employed, unemployed, part-time employed) were measured categorically.

These demographical factors were selected based on previous research suggesting that age, marital status and socio-economic background are associated with higher QoL (Han et al., 2014; Lövkvist et al., 2016; Nutakor et al., 2023). Ethnicity was included as a predictor because people from Non-White backgrounds often face unique barriers to support in healthcare settings, as well as at social, cultural, and medical levels which may impact on HRQoL (Chauhan et al., 2020; Lu et al., 2021; Scheppers et al., 2006). Ethnicity was categorised according to the list of ethnic groups outlined by the UK Government (2021). Due to a lack of diversity in participant's ethnic backgrounds, responses were combined into two categories for analysis: White and Non-White.

Several clinical factors were also outlined as potential predictor variables. Namely, symptom duration, time since diagnosis, diagnostic delay, help-seeking delay, medical delay, healthcare source (with three levels: NHS, private healthcare, both NHS and private), presence of co-morbid conditions (with two levels: yes or no), the number of surgeries, and fertility (with four levels: trying for baby for under 6 months; 6-12 months; 12 months to 2 years; over 2 years) were included as potential predictor variables. The existing literature is unclear on the impact of endometriosis-specific elements on QoL and wellbeing, however diagnostic delay and time since diagnosis have been implicated in adverse QoL outcomes (Nnoaham et al., 2011; Gallagher et al., 2018). Similarly, treatment type, quantity of surgeries and fertility have been linked to QoL and wellbeing both in and out-with the context of endometriosis (Luk & Loke, 2015; Barbara et al., 2021). Experiencing multiple health conditions is further associated with a risk of adverse wellbeing outcomes such as depression, which may impact HRQoL (Brettschneider et al., 2013). Symptom duration, time since diagnosis, diagnostic delay, help-seeking delay, medical delay, and number of surgeries were measured on a ratio scale. Healthcare source, co-morbid conditions, and fertility were measured categorically.

As a key focus of the current research, IPs were measured, with all 9 dimensions included as predictor variables: identity, timeline, personal control, treatment control, consequences, cause, emotional response, concern, and illness coherence. Each IP was measured on an interval scale.

Research has suggested that coping is implicated in endometriosis-related QoL (Zarbo et al., 2018). Therefore, 6 health-directed coping strategies were included as predictor variables: 1) acting, problem-orientating coping; 2) information seeking and exchange of experiences; 3) depressive processing; 4) willingness to accept help; 5) active search for social integration; and 6) trust in medical care. Each dimension was measured on an interval scale.

Finally, self-efficacy and perceived social support were included as potential predictor variables based on previous research suggesting that these factors are implicated in QoL and mental wellbeing outcomes across a range of chronic conditions (Peters et al., 2019; De Maria et al., 2020; Yuan et al., 2021). Both psychosocial predictors were measured on an interval scale.

A series of univariate exploratory analyses were subsequently employed to determine which predictors would be entered into each regression model. Ultimately, 22 predictors remain in the final analysis (see chapter 5 section 5.5.7 for further details).

4.4.2.2 Outcome variables

Six outcome variables were included in the present research: HRQoL, anxiety, depression, stress, self-reported disability and pain intensity.

These variables were selected based on research establishing a connection between endometriosis and adverse outcomes in each of these factors (e.g., Gao et al., 2020; Pope et al., 2015; Vitale et al., 2017). Pain has traditionally been measured as a predictor variable, however it is posited that pain has a cyclical relationship with wellbeing outcomes (Facchin et al., 2015). Therefore, the current study aims to ascertain the impact, if any, of psychosocial factors on pain perception. Each variable was measured on an interval scale.

4.4.2.3 Mediating variables

The CSM-SR (Leventhal, 2016) theorises that IPs directly inform coping strategies (see chapter 3 section 3.2 for an overview of the CSM-SR). Coping strategies then inform behavioural and emotional outcomes. It was deemed appropriate therefore to ascertain whether a mediating effect of coping exists in the relationship between IPs and wellbeing outcomes in the context of endometriosis. Six health-specific coping dimensions were included in the current research as potential mediating variables: 1) acting, problem-orientating coping; 2) information seeking and exchange of experiences; 3) depressive processing; 4) willingness to accept help; 5) active search for social integration; and 6) trust in medical care. Each dimension was measured on an interval scale.

4.4.3 Data collection

The following section of the current chapter details the materials incorporated in the baseline questionnaire, along with a description of the pilot study distributed to a small group of participants ahead of the full-scale survey launch.

4.4.3.1 Materials

The Brief Illness Perceptions Questionnaire

The Brief Illness Perceptions Questionnaire (B-IPQ; Broadbent et al., 2006) is a shortened, 9-item version of the Revised Illness Perceptions Questionnaire (IPQ-R; Moss-Morris et al., 2002), which itself is a modified version of the original Illness Perceptions Questionnaire (IPQ; Weinman et al., 1996). Influenced by qualitative interviews conducted by Leventhal and colleagues (e.g., Meyer et al., 1985) and the explanatory models of illness devised by Kleinman (1978), the IPQ provides a theoretically-driven assessment of the 5 key components of cognitive IPs as described by the CSM-SR – identity, timeline, control/cure, consequences, and cause. Due to the multitude of conditions the questionnaire could – and indeed, has – been used to assess, the IPQ is designed to be flexible, allowing the researcher scope to alter the constitution of the questions and response options to correspond with the specific condition under investigation. In 2002, The IPQ-R (Moss-Morris et al., 2002) was devised. It was noted that the original IPQ overlooked the emotional representations associated with a health threat or condition which, according to the CSM-SR, work in parallel with cognitive IPs to shape coping responses. Furthermore, based on a review of the literature, the authors of the IPQ-R identified two additional dimensions of IPs: cyclical timeline beliefs and illness coherence. Finally, following factor analysis, the authors observed that the control/cure dimension of IPs loaded onto two factors, indicating that it was necessary to split this element into two distinct categories. Therefore, the IPQ-R measures 9 dimensions of IPs: identity, timeline, personal control, treatment control, consequences, cause, emotional response, concern, and illness coherence. The measure has high validity and reliability (Moss-Morris et al., 2002); however, it was recognised that the length of the questionnaire, which includes over 80 items, may be prohibitive in some scenarios. Therefore, the B-IPQ was devised, comprising one question for each of the 9 dimensions of IPs. The B-IPQ yields good psychometric properties including test-retest reliability and predictive validity (Broadbent et al., 2006). A meta-analysis prepared in 2013 (Broadbent et al., 2015) reported that the B-IPQ had, in the 7 years since its conception, been utilised at least 188 times in published articles. A fresh meta-analysis or review could provide updated estimates, however this is beyond the scope of the current thesis.

In the context of the current research, the B-IPQ was selected to measure IPs based on: i) the length of the measure, ii) its psychometric properties and iii) the inbuilt flexibility of the measure. Using a brief measure of IPs allowed for the exploration of several factors within the project, which may run concurrent with IPs. Furthermore, using a brief measure such as the B-IPQ reduces the risk of participant fatigue and incomplete survey responses. Despite a significantly reduced number of items in the questionnaire, the B-IPQ has sound psychometric qualities including good predictive validity, test-retest reliability, and discriminant validity (Broadbent et al., 2006), further cementing the decision to adopt this measure.

Capitalising on the flexibility afforded by the B-IPQ, within the present research the term “illness” was replaced with “endometriosis” on all items in the questionnaire. For example, the question “How much control do you think you have over your illness?” was modified to “How much control do you think you have over your endometriosis?”. All questions, aside from the ‘cause’ item, were scored on a 11-point Likert scale (e.g., 0: “absolutely no control” – 10: “extreme amount of control”). For the ‘cause’ item, participants were asked to list, in rank order, up to three factors they believed to have caused their endometriosis. Participants could write freely in this section, but it was also made clear that, given that there is currently no known cause for endometriosis, participants could also skip this question. The BIPQ was used in both the baseline and follow-up surveys.

The Endometriosis Health Profile Questionnaire-5

The Endometriosis Health Profile Questionnaire-5 (EHP-5; Jones et al., 2004) is a shortened, 11-item version of the 53-item Endometriosis Health Profile Questionnaire-30 (EHP-30; Jones et al., 2001), which aims to capture endometriosis-specific HRQoL. Prior to the conception of the EHP-30, HRQoL amongst endometriosis patients was assessed using a plethora of measures, most commonly the World Health Organisation Quality of Life assessment (WHOQOL; The WHOQOL group, 1998), and the Short Form-36 (SF-36; Jenkinson et al., 1993). Jia et al. (2012) report that 9 different measures have been used to measure HRQoL amongst individuals living with endometriosis. The utilisation of a varied array of measures is problematic, due to disparities in the constitution of scales, response items and scoring. Furthermore, generic measures of QoL such as the WHOQOL and SF-36 do not allow for the measurement of condition-specific predictors of QoL, such as dyspareunia and treatment effectiveness in endometriosis. Additionally, the psychometric qualities and internal consistency of non-specific QoL measures are not well established for endometriosis (Jia et al., 2012). Therefore, it is widely recommended that the EHP-30, or it’s shortened version, the EHP-5, are utilised in research on endometriosis-related QoL (Culley et al., 2013). Both versions of the EHP were devised following exploratory interviews with individuals living with endometriosis. Both the EHP-30 and the EHP-5 are comprised of two sections: the core questionnaire, including 30 and 5 items respectively, and the modular questionnaire, including 23 and 6 items respectively. The core questionnaire measures 5 distinct HRQoL categories, thought to affect the majority of individuals with endometriosis: pain, control and powerlessness, emotional wellbeing, social support and self-image. The modular questionnaire measures 6 dimensions of HRQoL which are not necessarily applicable to all individuals with endometriosis: sexual intercourse, work, relationship with children, feelings relating to medical professionals, treatment, and infertility. The EHP-5 is comprised of one question for each core and modular category. For the core questionnaire, each question is scored on a 5-point Likert scale (0: ‘Never’; 4: ‘Always’). The modular questionnaire is scored on the same Likert scale, but with the addition of a ‘Not relevant’ option. Scores from each item are summed and expressed as a percentage, with 0% indicating the best possible health status and 100% indicating the worst. A composite scale of overall HRQoL can also be formulated and expressed as a percentage. Since its inception, the EHP-30 and EHP-5 collectively have been utilised in at least 139 research papers, including in clinical intervention research (Jones et al., 2023). The EHP-5 yields good psychometric properties, including discriminant validity (Jones et al., 2004; Jones et al., 2023), responsiveness (Aubry et al., 2017) and test-retest reliability (Selcuk et al., 2015). When compared to the EuroQoL-5D, another brief HRQoL measure, the EHP-5 was significantly more sensitive to the impact of pain and medical treatment for endometriosis specifically (Aubry et al., 2017). Furthermore, a meta-analysis on HRQoL instruments recommends the utilisation of condition-specific tools for endometriosis (Bourdel, 2019). Therefore, the decision was taken within the present research to adopt the EHP-5. As with the B-IPQ, this measure was adopted for use within the current study based on the reliability and validity of the questionnaire, as well as the opportunity afforded by the EHP-5 to reduce the likelihood of participant fatigue. To create the overall HRQoL variable, participant responses were summed and divided by the highest possible score, then multiplied by 100 to create a HRQoL score ranging from 0 (representing the worst possible HRQoL) to 100 (representing the best possible HRQoL). The EHP-5 demonstrated good reliability (α = .791) and was used in both the baseline and follow-up surveys.

The Patient Health Questionnaire-4

The Patient Health Questionnaire-4 (PHQ-4; Kroenke et al., 2009) is a rapid assessment of the symptoms of anxiety and depression. The questionnaire combines the Patient Health Questionnaire-2 (PHQ-2; Kroenke et al., 2003), a 2-item assessment of depression, and the General Anxiety Disorder-2 scale (GAD-2; Kroenke et al., 2007), a 2-item measure of anxiety. The PHQ-4 was developed in response to concerns that lengthier measures of depression and anxiety are not accessible to all individuals presenting with comorbid anxiety and depression, due to lapses in concentration and fatigue associated with both conditions (Kroene et al., 2009). Although not a diagnostic tool, the PHQ-4 is a reliable indicator of depression and/or anxiety susceptibility in the general population (Löwe et al., 2010). The PHQ-2 yields strong specificity (90%) and sensitivity (83%) for major depressive disorder (Kroenke et al., 2003). Additionally, the GAD-2 demonstrates good sensitivity for generalised anxiety disorder (88%), panic disorder (76%) and social anxiety disorder (70%) (Kroenke et al., 2007). Since its conception, the PHQ-4 has been translated into numerous languages including Persian (Ahmadi et al., 2019), Spanish (Kocalevent et al., 2014) and Arabic (Kliem et al., 2016). The measure possesses good construct validity and internal reliability (Löwe et al., 2010; Khubchandani et al., 2016), however reliability is decreased when using the tool with clinical populations (Kerper et al., 2014). Nonetheless, ultra-short assessments of anxious and depressive symptoms have been recommended to screen for potential cases of depression and anxiety prior to formal diagnosis due to their simplicity and time-saving properties (Kroene et al., 2007).

In the context of the current project, this measure was included amongst a variety of wellbeing assessments to provide a gauge of the overall wellbeing and QoL of the study population. In this vein, the PHQ-4 does not intend to measure clinically significant anxiety or depression, but to provide an indicator of the extent of low and anxious mood amongst the study population. Each of the four items are scored on a 4-point Likert scale (0: 'Not at all' – 3: 'Nearly every day'). Anxiety is calculated by combining the scores of questions 1 and 2, whilst depression is determined by combining the scores of questions 3 and 4. A score of 3 or greater for the first two items indicates anxious mood, whilst a score of 3 or above for questions 3 and 4 suggests depressive symptoms. Both the anxiety ($\alpha = .866$) and depression ($\alpha = .856$) subscales demonstrated good reliability. This measure was used in both the baseline and follow-up surveys.

The Perceived Stress Scale-4

The Perceived Stress Scale-4 (PSS-4; Cohen et al., 1983) is a brief, 4-item version of the 14-item Perceived Stress Scale (PSS-14; Cohen et al., 1983). The PSS-4 was developed alongside the PSS-14 as a means of gauging stress levels and stress management in time-constrained situations (e.g., during a brief medical consultation). Both scales have been hugely influential, with over 26,000 citations at the time of writing. Cohen et al. (1983) describe the PSS-4 as a valid, reliable measure of stress, however the PSS-14 and its revised version, the PSS-10, have been prioritised in tests of psychometric quality (Barbosa-Leiker et al., 2013; Smith et al., 2014; Maroufizadeh et al., 2018; Bastianon et al., 2020). Research that does examine the psychometric properties of the PSS-4 is often contradictory. Ingram et al. (2014) reported that the PSS-4 lacks internal consistency due to a problematic structure, and the PSS-10 should therefore be used in lieu of the PSS-4. Similarly, Lee (2012) advocated for the use of the PSS-10 due to superior psychometric properties, however this report also described the PSS-4 as ‘useful and feasible’ in time-constrained situations. Additionally, a large-scale study of 37,451 British, French and Spanish citizens reported that the PSS-4 yields adequate internal consistency and reliability, making it a useful tool to measure stress in a general population sample (Vallejo et al., 2018). Correspondingly, several researchers claim that the PSS-4 is an adequate gauge of stress and is an appropriate tool in situations where time is limited and where the PSS-10 cannot be utilised (Karam et al., 2012; Lesage et al., 2012; Demkowicz et al., 2020).

The PSS-4 was utilised in the current research to gain an insight into the stress experienced by the study population. Stress was measured as part of a package of wellbeing outcomes, as such it was considered advantageous to adopt an ultra-brief indication of stress to reduce the likelihood of participant fatigue. Items on the PSS-4 are measured on a 5-point Likert scale (0: ‘Never’ – 4: ‘Very often’). Questions 1 and 4 are summed, whilst questions 2 and 3 are reverse scored to determine the final overall stress score. Total stress score can range from 0 – 16, with 0 indicating no stress and 16 indicating the most stress possible. The PSS-4 demonstrated good reliability (α = .792) and was used in both the baseline and follow-up surveys.

Essen Coping Questionnaire (Franke et al., 2016)

The Essen Coping Questionnaire (ECQ; Franke & Jagla, 2016) is a 45-item scale designed to gauge 9 coping styles specific to experiencing ill-health/disease: 1) acting, problem-oriented coping; 2) distance and self-promotion; 3) information seeking and exchange of experiences; 4) trivialisation, wishful-thinking and defence; 5) depressive processing; 6) willingness to accept help; 7) active search for social integration; 8) trust in medical care; 9) finding inner stability. This measure has been used primarily amongst German speaking populations since its conception in 2000 and was translated to English in 2016 (Franke & Jagla, 2016). The ECQ has been used to assess coping strategies in various clinical areas, including with transplant patients (Kumnig et al., 2012), individuals with chronic obstructive pulmonary disease (Vaske et al., 2017), people living with Parkinson’s disease (Liebermann et al., 2020), and those experiencing polycystic ovary syndrome (Jauca et al., 2010).

The ECQ was selected for use in the current study due to its specificity to chronic illness, and the large number of coping strategies it encapsulates. It was felt important to reflect coping strategies specific to ill-health rather than general coping mechanisms, particularly in the context of COVID-19 and related lockdowns that have led to increased stress and alterations in coping strategies for many (Brown et al., 2020; Kar et al., 2021; McPherson et al., 2021). Therefore, that the ECQ frames its questions in the context of the experienced health condition was a major factor in selecting this measure. According to Fanke and Jagla (2016), all items on this questionnaire demonstrate acceptable-good reliability (α >.6) with the exception of trivialisation, wishful thinking, and defence (α = .51). However, the validity of the measure is unclear, with a factor analysis mapping the 45 items onto 5 separate overarching factors rather than 9 (Fanke et al., 2016). Nonetheless, the ECQ continues to be utilised in clinical-based research to gauge coping style (Chatoo & Lee, 2022) and was deemed appropriate for use in the current study due to its specificity to managing chronic conditions such as endometriosis.

The measure includes 5 questions relating to each of the 9 categories of coping. Each question is ranked on a 5-point Likert scale (0 = 'not at all' – 5 = 'extremely'). Scores for each category of coping were derived by summing up the responses to the corresponding questions and dividing them by the number of questions to gain an average for each coping style. The reliability for each subscale is presented in table 4.5 below. Acting, problem-oriented coping, information seeking and exchange of experiences, depressive processing, and trust in medical care all demonstrated good reliability, whilst active search for social integration demonstrated acceptable reliability. All other subscales fell short of the acceptable threshold. It should be noted that there is much debate surrounding what constitutes an 'acceptable' reliability score. A Cronbach's alpha value of >0.7 is often considered acceptable (Taber, 2018), however scores of >0.6 (Churchill, 1979) and even >0.5 (Ryu et al., 2010) are often cited as demonstrating acceptable reliability. Before discarding or retaining the sub-scales that fell short of the acceptable range for the current study of 0.6, correlations between each of the items on these sub-scales were examined. All items on the distance and self-promotion sub-scale and all items on the trivialisation, wishful thinking and defence sub-scale were very weakly correlated, implying a lack of commonality between the items on these scales.

Therefore, distance and self-promotion and trivialisation, wishful thinking and defence were discarded from further analysis. This aligns with Tavakol & Dennick's (2011) guidelines that if low alpha is caused by poor correlation between scale items, then items should be discarded or revised. Moderate correlations between 3 items on the willingness to accept help sub-scale were evident, however the remaining items in this scale showed weak correlations. After removing these 2 items, Cronbach's alpha increased to .712, demonstrating good reliability (see table 4.6). Therefore, willingness to accept help was retained with the omission of questions 9 and 45. Items on the finding inner stability sub-scale were generally poorly correlated. One item demonstrated a very weak correlation to the other items in the subscale and was subsequently removed, however alpha increased only modestly to .571, demonstrating a lack of commonality between the remaining items on this scale. In line with Tavakol & Dennick's (2011) guidelines, finding inner stability was discarded from analysis.

The ECQ was used in the baseline survey only.

Table 4.5
Reliability scores for each subscale of the Essen Coping Questionnaire

Coping style	*Cronbach's alpha (α)*
Action, problem orientated coping	.742
Distance and self-promotion	.455
Information seeking and exchange of experiences	.723
Trivialisation, wishful thinking and defence	.300
Depressive processing	.713
Willingness to accept help	.577
Active search for social integration	.690
Trust in medical care	.700
Finding inner stability	.535

Table 4.6
Revised reliability scores for WAH and FIS

Coping style	*Item(s) removed*	*Revised Cronbach's alpha (α)*	*Included in analysis*
Willingness to accept help	9, 45	.712	Y
Finding inner stability	37	.571	N

Chronic Pain Grade

The Chronic Pain Grade (CPG; Von Korff et al., 1992) is a 7-item measure of chronic pain intensity and disability. The CPG has been used widely in research on musculoskeletal pain (Generaal et al., 2017), inflammatory bowel disease (Morrison et al., 2013), and as a broader gauge of chronic pain prevalence within the general population (Häuser et al., 2014). Although the CPG was published prior to the WHO International Classification of Functioning, Disability and Health, all outcomes (i.e. impairment, activity limitation and participation restriction) are measured by the questionnaire (Dixon et al., 2007). The questionnaire consistently yields good psychometric properties across the literature, with all seven items demonstrating good re-test reliability and moderate to good internal consistency (0.74 – 0.91; Smith et al., 1997). Translated versions of the scale have also shown good reliability and validity (Klasen et al., 2004; Salaffi et al., 2006).

The CPG was utilised in the current study to measure endometriosis-related pain intensity and disability. The measure includes 3 subscales: i) characteristic pain intensity; ii) disability score; iii) disability points. Disability points are derived by combining the number of 'disability days' indicated by participants with the disability score derived from the scale. Each item on the CPG is scored on a 11-point Likert scale (e.g., 0 = no pain, 10 = pain as bad as it could be) with the exception of question 4 which asks participants, 'about how many days in the past 6 months have you been kept from your usual activities because of your pain?'. This question gauges 'disability days', and asks participants to indicate the approximate number of days in which they've been unable to function as a result of their condition. Participants' disability points were used to represent self-reported disability, whilst characteristic pain intensity was used to represent self-reported pain. This measure was used in both the baseline and follow-up surveys.

Self-efficacy for managing chronic diseases 6-item scale

The self-efficacy for managing chronic diseases 6-item scale (SE-MCD-6; Lorig et al., 2001) is designed to measure self-efficacy specific to chronic ill-health (Ritter & Lorig, 2014). Higher self-efficacy is consistently linked to improved QoL for patients living with chronic conditions (e.g., Banik et al., 2018), so it was deemed important to measure this factor for the current study. The SE-MCD-6 has been used to measure self-efficacy in several chronic conditions including heart disease (Barham et al., 2019), kidney disease (McAuley et al., 2022) and type 2 diabetes (Zhao et al., 2018). The scale has been translated into several languages and consistently demonstrates high reliability and validity across several studies in various languages (Ritter & Lorig, 2014). This measure was chosen for the current study due to its specificity to chronic conditions and good psychometric properties.

The SE-MCD-6 measures factors common to several chronic conditions including symptom control, functioning, emotional distress and treatment. Responses are given on a 10-point Likert scale (1: 'not at all confident'; 10: 'totally confident'). The mean of the combined six items is calculated to produce an overall 'self-efficacy' score. This scale demonstrated good reliability (α = .835) and was used in the baseline survey only.

Brief Perceived Social Support Questionnaire

The Brief Perceived Social Support Questionnaire (B-PSSQ; Kleim et al., 2015) is an ultra-brief measure of perceived support from others. Social support is a protective factor for QoL (Wang et al., 2018) and mental health (Sheikh et al., 2016), therefore it was felt necessary to incorporate a measure of this within the current investigation. The B-PSSQ has been translated into several languages, including Chinese, English and German, and demonstrates strong psychometric properties across countries (Lin et al., 2019). The questionnaire has been used to measure social support in a variety of settings, such as amongst university students (Yıldırım & Tanrıverdi, 2021), in relation to gambling-related harm (Browne et al., 2019) and recently in the context of COVID-19 (Sommerlad et al., 2021).

The B-PSSQ is considered a reliable and valid measure (Kleim et al., 2015). To reduce the risk of participant fatigue within the current project, it was deemed important to utilise an ultra-brief measure of social support. The B-PSSQ contains 6 items, each measured on a 5-point Likert scale (1: ‘not true at all’; 2: ‘very true’). Responses are summed and the mean taken to provide an overall ‘perceived social support’ score. This scale demonstrated good internal reliability (α = .823). The B-PSSQ was used in the baseline survey only.

Free text box

At the end of the baseline survey, a free text box was presented to participants, with text reading “please feel free to use this box to provide any further details which have **not** already been covered in the questionnaire about the ways in which your endometriosis symptoms and diagnosis have affected your life, and about how you think and feel about your endometriosis.”. In this box, participants could write their thoughts and feelings freely. A free text box was not included within the follow-up survey.

4.4.3.2 Pilot study

To ensure that relevant data was collected by the baseline survey, a pilot study was conducted with members of an endometriosis support group based in Scotland. Prior to this, clinical researchers from the EXPPECT team based in Edinburgh were consulted regarding the variables to include in the survey, before an expert group of endometriosis patients were approached to offer feedback on the baseline survey. Fourteen participants completed an early iteration of the baseline survey and provided feedback on the content. Based on this feedback, some minor changes were made to the survey. Some spelling mistakes in the treatment section on the survey were rectified, and questions relating to the provision of care and treatment (i.e., whether care was provided by the NHS or privately) were added into the survey on the recommendation of the expert group. A free text box for participants to expand on their answers and/or experiences was also added to the questionnaire following feedback from the pilot group (see appendix D for the full baseline survey).

4.4.3.3 Procedure

Both the baseline and follow-up surveys were hosted online on Qualtrics. Upon accessing each survey, participants were presented with an information sheet detailing the aims and scope of the study and a consent form (appendices C and F). After indicating their consent within the baseline survey, participants were asked to state whether they had received a medical diagnosis of endometriosis. If they answered no to this question, they were thanked for their time and directed to the end of the survey. Participants who met the inclusion criteria were then asked to supply their email address and name so that their baseline and follow-up responses could be matched. Participants could opt not to share their personal details in the baseline survey. Participants were also asked to indicate if they would be interested in participating in a related interview to discuss their experiences of endometriosis in further detail during the baseline survey. Subsequently, participants were presented with the full survey to complete, including questions relating to IPs, QoL, pain and general wellbeing (see appendix D for the full baseline survey, and appendix G for the full follow-up survey). A free text box was included at the end of the baseline survey to allow participants to write freely about their experiences and perceptions of endometriosis. Upon completion of each survey, a debrief was presented to participants (appendices E and H) and they were given the contact details of the research team should they have any questions or concerns. The follow-up survey was distributed to participants 12 months after their baseline response was recorded. Participants could withdraw their responses to the point of anonymisation of the data, when responses across the two time points were matched and personal data was erased from the data file.

4.4.4 Data Analysis

An exploratory approach to analysis was adopted in the current study. SPSS was used to analyse data. For the baseline data, a correlation matrix was devised to investigate the potential links between all variables. Next, the differences in IPs between baseline (T1) and follow-up (T2) were determined using a series of t-tests to ascertain whether IPs are dynamic or stable in this population. Univariate analysis was performed to establish which of the potential predictor variables would be incorporated into the subsequent regression analysis. Specifically, a series of correlations were performed between the predictor variables at T1 and outcome variables at T2. The results of this analysis determined the predictor variables included in each regression model. Ultimately, 22 predictor variables were retained for the regression analyses as a result of this process (see chapter 5.5.7 for further detail). Six hierarchical regression analyses were performed to ascertain the relationship between the remaining predictor variables and the outcome variables. Within each regression model, demographic variables were entered first, followed by clinical factors, IPs, coping strategies, and psychosocial variables. The results of these analyses can be found in chapter 5 (see section 5.5.8).

Additionally, conventional content analysis (Hsieh & Shannon, 2006) was used to categorise participants' responses within the free text box. Primarily, responses were read and coded according to their content by the researcher. These codes were then revisited and organised into meaningful categories and sub-categories. Definitions for each category were outlined, and example quotes were identified (see chapter 5, section 5.5.4).

Finally, several multiple mediation analyses were conducted to ascertain the role of coping in the relationship between IPs and outcomes. Several coping styles were input as potential mediators in the relationship between each category of IP (e.g., consequences) and each outcome variable (e.g., HRQoL). Forty-one multiple mediation analyses were conducted (see chapter 5 section 5.5.9 for further detail).

4.5 Qualitative interviews

To aid understanding of the perceptions and experiences of those diagnosed with endometriosis, it was deemed appropriate to include a qualitative element within the current project. As discussed in chapter 1, the experience of endometriosis is unique to each individual, despite some common shared experiences between many of those affected. It is expected that the survey will detect broad commonalities in IPs between individuals experiencing endometriosis, however the nuanced and complex nature of endometriosis-related cognitions may not be fully reflected through quantitative data alone. Qualitative research, on the other hand, can offer a window into the unique opinions, thoughts, and feelings of participants, providing rich, in-depth data pertaining to the experiences of the target population (Jain, 2021). Qualitative research is particularly beneficial for exploring intricate or somewhat unexplored topics (Clarke & Jack, 1998; Thorogood & Green, 2018), insofar as it simplifies complex data into meaningful, understandable ideas without relinquishing the richness of participant accounts (Thorogood & Green, 2018). Conversely, participant experience and nuance may be lost in quantitative approaches where inferences are made from numerical data, making a qualitative investigation particularly beneficial when investigating participant experiences within under-researched topics. Influential organisations such as the National Institute for Health and Care Excellence have increasingly employed qualitative research to drive recommendations on clinical practice (Carmona et al., 2022). However, there remains a reliance on numerical figures and statistics to drive policy change within the UK. With this in mind, qualitative approaches can support the design of such research by offering potential areas for quantitative investigation based on participant's experiences and ideas. Additionally, adopting a qualitative approach offers a platform for participants who feel rarely heard (Sofaer, 1999). As described in chapter 1, this is a particularly pertinent issue for individuals experiencing endometriosis (Young et al., 2015).

This element of the research aims to gain an in-depth understanding of participants' perceptions and beliefs surrounding their endometriosis, and the relation of these factors to their overall QoL. In line with a pragmatic approach (see section 4.2), reflexive thematic analysis was utilised for the current study.

4.5.1 Thematic analysis

Broadly, thematic analysis (TA) offers a comprehensive overview of participant experiences by organising data into codes and themes that encapsulate the main crux of participant accounts. This is particularly beneficial for novel and/or complex areas of study, as is the case in the present research, in that the generated themes can offer an in-depth understanding of participant experiences that goes beyond the inherent boundaries of quantitative approaches. Historically, there has been a lack of qualitative research on endometriosis, however TA is increasingly utilised to explore endometriosis-related QoL outcomes (Roomaney & Kagee, 2018; Rush & Misajon, 2018; Fernley, 2021). TA is a popular approach in this type of research due to its ability to distil complex ideas related to endometriosis into comprehensive, digestible themes to aid understanding of how the condition is experienced.

Furthermore, TA offers flexibility above and beyond that offered by many other qualitative approaches. Primarily, this flexibility stems from the nature of TA as independent of a fixed theoretical basis. That is, TA is a method, offering a range of tools for analysing qualitative data, rather than a methodology, which dictates a philosophical stance in approaching research (Terry et al., 2017). This is not to say however that TA exists out-with a theoretical framework, but that the researcher has flexibility in applying distinct philosophies to their analysis. Therefore, TA can be used by researchers with a range of epistemological and ontological stances, perhaps accounting, in part, for the growing popularity of this method. It is important, however, that the philosophical stance of the researcher is outlined within TA research as this has implications for the ways in which this method is applied (Braun & Clarke, 2012). This theoretical freedom is rare, in that qualitative data is often analysed using distinct methodologies that are intrinsically tied to a theoretical stance (e.g., interpretative phenomenological analysis and phenomenology (Smith & Nizza, 2022). In terms of the current project, adopting a pragmatic approach (see section 4.2) means making decisions based on what works best in terms of addressing the research question, rather than following fixed philosophical ideologies (Kaushik & Walsh, 2019). By offering theoretical flexibility, TA lends itself to a pragmatic epistemology, where the focus is on developing a practical understanding of the issues under investigation rather than on the nature of truth and reality (Patton, 2014). This was deemed particularly important for the topic under investigation, as endometriosis has been little researched historically and subsequently there is a need for a deeper understanding of this condition and the way in which it impacts the lives of those who experience it.

Additionally, along with its theoretical flexibility, TA allows researchers to adopt an inductive or deductive approach to organising data. In line with a pragmatic approach, it was deemed appropriate within the current project to use both inductive and deductive elements to develop a coherent account of the impact of endometriosis-related perceptions and experiences on participants' HRQoL. An inductive approach was necessary to establish broad, overarching themes stemming from the interviews, whilst a deductive approach was adopted to compare the themes and ideas arising from the transcripts against the pre-existing IP categories. The flexibility associated with TA allowed for both approaches to be taken and was a further determining factor in adopting this approach.

Although TA is widely and increasingly used within a variety of research settings, there is a lack of consensus on what exactly TA is, with many authors neglecting to define their perspective on TA within their work (Terry et al., 2017). It is likely due to the flexibility and the broad settings in which TA has been applied that there is debate regarding the nature of this method. Historically, TA has been used in many research settings, for example to aid the quantification of qualitative data in a process resembling content analysis (e.g., Christ, 1970) and to interpret and distil significant quantities of data into broad codes and themes that tell the story of participant experiences (e.g., Rush & Misajon, 2018). It is the latter that the current study aims to achieve within a TA framework. However, some have argued that many qualitative approaches organise data into themes, at least in some capacity (Gibson & Brown, 2009), leading to further debate surrounding the nature of TA – specifically, whether TA is merely a tool for organising data used in several different qualitative approaches (Willig, 2013), or if it can be considered a standalone method (Terry et al., 2017).

The current research positions TA as a standalone method. Braun & Clarke's (2006; 2018) reflexive TA has been adopted. One of the key cornerstones of this method is a 'Big Q' approach to qualitative research (Kidder & Fine, 1987). In contrast to a 'small q' approach, in which qualitative research is facilitated by quantitative language and concepts (e.g., data saturation; inter-rater reliability), the 'Big Q' approach situates qualitative concepts and tools at the forefront of research. In this approach, qualitative research tells stories about the data collected rather than speaking to a 'scientific truth' about the concepts under investigation (Varpio et al., 2017). The role of reflexivity is emphasised in Braun & Clarke's approach to TA – it is seen as an inevitability that the researcher's own assumptions and thoughts will shape the research, and rather than this constituting a hinderance it is instead viewed as a valuable tool in relaying participants' stories. The current study endeavours to take this approach, although there is a level of complexity in adopting a purely 'Big Q' approach to the present study due to the mixed methods nature of the overarching project, which stipulates a blend of quantitative and qualitative approaches. In designing the qualitative element of the project, the likely sample size and representativeness of the quantitative survey sample was considered and guided recruitment, and therefore the qualitative portion of the current project cannot be fully detached from the context of the wider project. Nonetheless, the principles of reflexive TA were adopted for this element of the research - in particular the focus on the research process as fluid, immersive and heavily reliant on the interpretation of the researcher.

4.5.2 The Researcher

In line with a reflexive approach, it is important to explicitly state the researcher's beliefs and experience in relation to the present study.

The researcher has a background in using both qualitative and quantitative research methods, although has tended to use quantitative methods in previous projects. This is not to say that the researcher has a preference for quantitative methods, but that quantitative methods have been deemed best suited to the questions posed within their previous research projects. As stated above and in line with a pragmatic approach (see section 4.2.2), the researcher does not view one method of data collection and analysis as 'superior' to another, but endeavours to select the tools best suited to answering the research question.

The researcher believes that qualitative methods are vital in conveying the experiences and perceptions of any target population, but particularly in complex and novel areas of study such as endometriosis. It is felt extremely important to give a voice to individuals who have felt silenced in research historically. The researcher views themselves as a feminist with a keen interest in systemic and institutionalised misogyny within society, which may have prompted interest in the research topic, in that endometriosis affects women and those assigned female at birth and has been historically under-researched (as is the case with most 'women's diseases'). The researcher believes that this lack of research is borne out of pervasive stigma surrounding menstruation. Although the researcher is encouraged by recent shifts in the discourse surrounding menstruation, which has enabled open conversations and reduced stigma around this topic, it is thought that menstruation is still considered a taboo subject and therefore increased understanding is required.

Additionally, the researcher has personal experience of living with chronic menstrual-related pain. The researcher is therefore cognisant of the issues and barriers faced by individuals living with similar conditions, particularly surrounding diagnosis and the stigmatised nature of menstrual-related conditions. This has fuelled a strong resolve to support individuals experiencing such conditions through research and advocacy.

It is anticipated that these experiences will influence the way in which participant's accounts of their own experiences are relayed by the researcher, and this should therefore be kept in mind by the reader.

4.5.3 Participants

4.5.3.1 Sampling strategy

Participants were selected purposively. Purposive sampling is often used within qualitative research as a means to select the participants 'most likely to yield appropriate and useful information' (Kelly, 2010, p.317). In the context of the current research, a purposive approach to sampling was deemed appropriate, as it allows for the recruitment of a diverse sample of participants. This sampling technique is also conducive to a pragmatic approach, in that it allows for the selection of the participants best suited to providing useful, in-depth knowledge relevant to the research question. Due to a convenience sampling approach, it was expected that the quantitative element of the current project would likely yield an unrepresentative sample of individuals experiencing endometriosis. Specifically, it was anticipated that White individuals from higher socioeconomic brackets would be most likely to complete the survey based on previous research on the representativeness of survey populations (e.g., Jang & Vorderstrasse, 2019). Unrepresentative samples are a commonly cited limitation in survey-based research. Generalising conclusions from a sample unreflective of the target population can result in the circulation of inaccurate information which, in some cases, may have implications for wider practice and policy. For example, during the first year of the COVID-19 outbreak, several research organisations sought to estimate vaccine uptake rates across the population, to prepare for demand and drive health strategies. However, when generalised to the full US population, large-scale surveys incorporating upwards of 75,000–250,000 participants significantly overestimated the uptake of these vaccines due to unrepresentative samples (Bradley et al., 2021), demonstrating the importance of mitigating against the impact of unreflective samples even in large-scale studies. Therefore, incorporating purposive sampling within this distinct but complementary study allows for the selection of a diverse sample of individuals to ensure that the views of individuals from a range of demographic backgrounds are reflected in the study results.

4.5.3.2 Sampling Matrix

Prior to recruitment for the interviews, a sampling matrix was devised to ensure that a diverse sample was recruited from the survey population (see table 4.7). Primarily, survey demographics were compared against the characteristics of the general UK population to ascertain the representativeness of the sample. It is important to note that there is no published demographic profile associated with individuals living with endometriosis, so the UK population was used as a benchmark with the expectation that endometriosis does not discriminate and can affect individuals of all backgrounds. As expected, the survey sample consisted largely of individuals from White backgrounds in higher socioeconomic brackets. The majority of respondents were in full-time work, held university-level degrees and were around 34 years of age. Due to the low number of survey participants from Non-White backgrounds, recruiting individuals from a range of ethnic backgrounds was a priority for the interviews. According to the 2011 census data (the most recent account of demographics in the UK at the time of producing the matrix), 86% of individuals residing in England and Wales, 96% in Scotland, and 98% in Northern Ireland were from White backgrounds. Combined, 87% of individuals residing in the UK identified as White in 2011 (Office for National Statistics, 2011). In the time since conducting the interviews, the 2021 census for England and Wales revealed a 4% decrease in the number of people from White backgrounds residing in the UK, now at 82% (Office for National Statistics, 2021). In the survey sample at the time of producing the matrix, 94% of respondents were from White backgrounds, indicating an unrepresentative sample of the full UK population. Therefore, it was deemed appropriate to over-recruit people from ethnically diverse backgrounds to ensure a balance between both elements of the research. Also prioritised for recruitment were people from lower income brackets, as those from higher income brackets may have access to additional services and treatments (e.g., through private healthcare), and were over-represented in the survey data. Similarly, both younger participants and individuals approaching or at menopause (aged >45 years) were sought to gain an understanding of their experiences with endometriosis. People who stated they were unable to work due to their symptoms were also sought, as research shows a detrimental impact on work functioning related to endometriosis (Missmer et al., 2022) but the majority of individuals recruited for the survey were in full-time work. Furthermore, individuals with a university-level degree were vastly over-recruited within the survey, and therefore people without university degrees were sought for this portion of the research. According to the 2011 census, 27% of residents in England and Wales and 26% of residents in Scotland held a degree or similar qualification (Office for National Statistics, 2011; Scotland's Census, 2011), yet 61.5% of the survey sample held a degree at undergraduate, master's, or doctorate level.

Table 4.7

Sampling Matrix

Target demographic	Rationale	Number to be recruited
Non-white ethnicity	Endometriosis has been studied predominantly from the perspective of White individuals due to under-recruitment of people from Non-White backgrounds. Over-recruiting individuals from a diverse range of backgrounds will allow for the experiences of people from different ethnic backgrounds to be heard.	8-10
Single relationship status	Social support, including intimate relationships, may have a protective effect against some of the QoL-related impact of living with a chronic condition (e.g., Lopez-Martinez, 2008). It is important to consider the experiences of single individuals as well as those in long-term relationships.	5-8
Not completed University education	Those with University-level degrees tend to be over-recruited in endometriosis research. It is important to consider the views of individuals with a wide range of educational backgrounds.	5-8
Not in full-time employment	As above, it is important to reflect the views of people in a range of employment situations. In the survey element of the present research, it was noted that most participants were in full-time employment so people in other types of work were under-represented. This is particularly important in this context because people with endometriosis are often unable to work, or work to reduced hours.	5-8
Over the age of 48	There is little research around how endometriosis impacts menopausal and peri-menopausal individuals, although recent literature suggests that these individuals may still experience symptoms of endometriosis. It was felt necessary to reflect their views.	3-5

4.5.3.3 Recruitment

Individuals were eligible to participate if they met the criteria as listed in table 4.1 (section 4.4.1.2). Potential participants indicated their interest in participating in the interview within the survey element of the current research project (see section 4.4.3.3), and were selected in line with the sampling matrix (table 4.7). Potential participants were contacted individually via email in groups of 5-8. If they did not reply to the interview invitation on the second attempt, the next group of 5-8 were contacted. This was to ensure that the sampling matrix was adhered to, and that all of those contacted had an opportunity to respond. Potential participants were provided with an information sheet providing details about the interview (appendix I) and, if interested in participating, were asked to give written consent to participate via email. Interviews were arranged at a time that suited each participant, and prior to the commencement of the interview, participants were asked to reiterate their consent verbally after another opportunity to ask questions relating to the research.

The recruitment period occurred between August 2021 and February 2022, during the COVID-19 pandemic. At this time, face-to-face contact was limited by COVID-19 related lockdowns across the UK, dictating that recruitment and interviews must occur online. However, it is likely that, in the absence of COVID-19 lockdown measures, individuals would have been recruited for an online interview due to the geographical limitations associated with face-to-face interviews. By hosting interviews online, participants could be recruited from across the country, whereas face-to-face interviews would have limited recruitment to those residing in the central belt of Scotland. As this is a UK-wide project, it was deemed important to ensure a geographical spread of participants.

4.5.3.4 Sample size

Data saturation

There is significant variation in the sample sizes used across qualitative research, with debate surrounding the ways in which participant sample sizes should be determined. There is no one way to calculate sample size either in advance or during recruitment, however researchers are frequently asked to provide an a priori sample size by funders and institutions. Therefore, determining a sample size in advance of recruitment has become a necessity in many disciplines. The concept of data saturation is positioned by several authors as the ‘gold standard’ in determining sample size in TA research (Hancock et al., 2016; Braun & Clarke, 2021). For example, the American Psychological Association’s journal reporting standards for qualitative research (2020) suggests data saturation as a rationale for the cessation of data collection. However, data saturation is generally poorly conceptualised, and subsequently this term is associated with numerous definitions. Perhaps the most widely used definition of data saturation is that saturation occurs when no new codes or themes are identified within the dataset (e.g., Francis et al., 2006). There have been attempts to operationalise the concept of data saturation to provide an ‘optimum’ sample size for TA, at which point data saturation is achieved (e.g., Guest et al., 2006). Suggested sample sizes for achieving data saturation range from around 6 to 16 interviews, but tend to sit at around 12 transcripts (Braun & Clarke, 2021). However, the disparity in suggested sample size estimates means that researchers can ‘cherry-pick’ the figure that best suits their available resources. For example, researchers with limited time may select a lower recommended sample size if there are tight deadlines associated with their project, still citing ‘data saturation' as the rationale for this rather than time constraints (Braun & Clarke, 2019). Similarly, projected sample sizes based on estimates of when data saturation *should* occur are quoted across the spectrum of TA-based research (Braun & Clarke, 2021), often with little explanation of the author's own definition of data saturation, or consideration of why it is important to achieve saturation. Furthermore, data saturation is intrinsically grounded in a positivist epistemology, implying that there is an objective, scientific truth to be uncovered within participant accounts, and that a certain quantity of transcripts can uncover this truth regardless of the topic of investigation (Varpio et al., 2017). Additionally, data saturation is often concerned with the number of occurrences of a theme, which poses 2 potential issues: 1) there is no agreed number of occurrences that constitutes data saturation (Braun & Clarke, 2021); and 2) in prioritising the number of occurrences of each code and theme, the meaning behind these themes is often neglected, leading to under-developed themes (Hennick et al., 2017).

The concept of data saturation is at odds with many iterations of TA, including Braun and Clarke's (2019) reflexive TA. In a far-reaching critique of the implementation of data saturation in qualitative research, Braun and Clarke (2021) suggest that using data saturation as a rationale for the cessation of data collection implies that the themes generated from TA are immovable and representative of a scientific truth, untouched by the interpretation of the researcher. Thus, this implies a 'small q' approach to qualitative data and is at odds with reflexive TA as a fluid and dynamic process in which the researcher plays a key role in generating the story told by their data.

Determination of sample size

Braun and Clarke (2021) suggest that “data saturation is not a universally useful or meaningful concept for all types of TA research”. Specifically, this concept appears to be incompatible with reflexive TA (Braun & Clarke, 2019). For studies in which a sample size must be established ahead of data collection, such as this one, Braun and Clarke (2021) suggest determining a provisional range of acceptable sample sizes based on ‘interpretative, situated and pragmatic judgement’. For the current research, the novelty of the research area, coupled with the complexity of endometriosis, time constraints, and the expectations of relevant publications were considered to produce a provisional sample of 15-20 interviews. This was thought sufficient to present a compelling account of participants’ experiences that incorporates the nuanced and dynamic nature of endometriosis and its subsequent impact on QoL. Pragmatically, at the time of data collection, it was judged appropriate to expand the range of interviews to 25-30. The current study constitutes a novel area of investigation into a complex, dynamic condition, and collating the accounts of a large, diverse sample of participants was thought to provide the best opportunity to provide a reflective and meaningful account of how individuals with endometriosis perceive and navigate their condition. Furthermore, due to the heterogeneity associated with endometriosis, conducting an increased number of interviews was thought to constitute a more reflective account of experiencing the condition, with more opportunity for nuance and diversity to be recognised within the constructed themes. A further consideration in increasing the sample size was the opportunity for publication. In an increasing number of journals, a higher number of participants in qualitative research equates to an increased chance of publication, and publication of the current study would increase the reach of the acquired results.

It was considered important to publish the present research to support understanding of the ways in which endometriosis is experienced, potentially leading to further research in the area and advancements in psychological care for affected individuals.

4.5.3.5 Participant demographics

Thirty participants residing in the UK attended individual semi-structured interviews. The use of the sampling matrix (see table 4.7) ensured that a diverse range of participants were recruited for the present study. Participants were aged between 20 and 55 years (M= 35.6, SD= 9.49). Additional participant demographics can be found in table 4.8. Participants had experienced symptoms of endometriosis for between 4 and 40 years (M= 14.83 years, SD= 9.18), and had been diagnosed for an average of 5 years (SD= 6.97). Further information on the nature of participants' endometriosis can be found in table 4.9.

The inclusion criteria as described in section 4.4.1.2 was utilised in participant selection, although as they had each previously completed the survey, it was expected that all participants met these criteria.

Table 4.8

Interview participant demographics

	N	%
Ethnicity		
White British	20	66.7%
Indian	2	6.7%
African	2	6.7%
Another Mixed Background	2	6.7%
Pakistani	1	3.3%
Asian and White	1	3.3%
Another Ethnic Background	1	3.3%
Another White Background	1	3.3%
Relationship Status		
Married	10	33.3%
Cohabiting with partner	10	33.3%
Single	9	30%
Widowed	1	3.3%
Educational attainment		
Undergraduate / Bachelors degree	10	33.3%
Postgraduate degree	6	20%
Secondary education to GSCE/O-levels/National 5 or equivalent	4	13.3%
Secondary education to Highers/A-level or equivalent	3	10%
Diploma of Higher Education/Foundation Degree/Higher National Diploma/NVQ level 5/level 5 diploma or equivalent	3	105
Left school with no qualifications	2	6.7%
Completed secondary school to National 3/4 or standard grade	1	3.3%
Prefer not to say	1	3.3%
Employment status		
Employed full-time	11	36.7%
Disabled or unable to work	6	20%
Employed part-time	5	16.7%
Self-employed	3	10%
Unemployed, looking for work	2	6.7%
Employed on a zero hours or casual contract	1	3.3%
Full-time student	1	3.3%
Part time student	1	3.3%
Country of residence		
England	17	56.7%
Scotland	12	40%
Wales	1	3.3%

Table 4.9

Interview participant clinical information

	N	%
Treatment		
NHS	16	53.3%
Some private, some NHS	13	43.3%
Completely private	1	3.3%
Co-morbid condition		
Yes	18	60%
No	12	40%
Surgery		
Had surgery	24	80%
Not had surgery	6	20%
Number of surgeries		
1	10	33.3%
2	8	26.7%
3	3	10%
4	2	6.7%
5	1	3.3%
Trying for baby		
Yes	12	40%
No	17	56.7%
Prefer not to say	1	3.3%

4.5.4 Data collection

4.5.4.1 Semi-structured interviews

Semi-structured interviews were used to capture the perspectives and experiences of participants. Interviews are the most common method of data collection in TA research and constitute an effective means of gauging participants' thoughts, feelings, perspectives and experiences (Gill et al., 2008). Semi-structured interviews use broad, open-ended questions and prompts to elicit data from participants. These interviews allow the interviewer to request elaboration on some of the ideas presented by participants, and to ask questions based on participant responses, unlike structured interviews in which all questions are pre-set. It was thought appropriate to use semi-structured interviews in the current project rather than structured interviews as this method of data collection offers flexibility and for participants to expand upon their own individual experiences. Similarly, unstructured interviews, in which interviews occur without any pre-set questions, were not utilised due to the complexity of the topic matter and to ensure a common thread ran through interviews.

4.5.4.2 Materials

A topic guide was created to facilitate the semi-structured interviews (see appendix J). The topic guide included broad, open-ended questions relating to the perceived impact of endometriosis and participants' feelings toward their condition, before a series of prompts alluding to the IPs as described in the CSM-SR were given. The topic guide ends with prompts for coping style and social support, two factors thought to guide the behavioural responses of individuals experiencing a health threat or condition (Von Ah et al., 2004; Leventhal 2016; Labrague, 2021). The topic guide was created prior to two pilot interviews and developed following these interviews in which the usefulness of the guide was assessed. At this point, many of the prompts on the topic guide were written out as open-ended questions, however it became clear that much of the information elicited by these questions was likely to be covered by participants during the first general questions. Therefore, the topic guide was updated to alter many of the open-ended questions to prompts. Each prompt is presented next to the corresponding IP category within the topic guide.

4.5.4.3 Procedure

After stating their intention to take part in the interview, an information sheet was sent to participants through email (appendix I) before a suitable date and time for interview was determined. Interviews took place online and were audio-recorded. Interviews lasted between 42 and 90 minutes (M= 62 minutes). Participants were first asked broad, general questions about the impact of endometriosis on their lives and their feelings towards endometriosis. This gave the interviewee the opportunity to discuss their experiences in as much detail as they wished, whilst giving the interviewer an idea of the most salient aspects of living with endometriosis for the participant. Depending on participant responses, a series of prompts were then used to elicit information regarding their IPs, coping styles and social support (see appendix J). Following the interview, participants were debriefed (see appendix K) and provided with a £20 Amazon e-voucher as compensation for their time. An incentive was deemed appropriate due to the duration of the interviews and the sensitive nature of the topic. After each interview, the researcher noted their immediate thoughts and feelings around the ideas expressed by each participant, and lightly interpreted some of the perspectives and experiences stipulated within the interview.

4.5.5 Data Analysis

Braun & Clarke’s reflexive TA (2006) was used to analyse the data. The first step of this technique, familiarisation, began prior to transcription of the interviews, when the researcher took notes on the ideas and perspectives expressed within each interview. Following data collection, interviews were transcribed verbatim from the audio recordings, with any potentially identifying information removed from each transcript (e.g., names, location information). This was a time-consuming process in which transcription took on average one full working day per participant. The time-consuming nature of this process however ensured immersion in the data, facilitating familiarity with the ideas and experiences reflected within each interview. Audio recordings were generally clear, subsequently there were no issues in transcribing the audio into text and no redacted data (aside from any identifying information) within the transcripts. Once satisfied with the accuracy of the transcription, the corresponding audio recording was deleted to ensure participant confidentiality. Following the transcription of all interviews, the researcher re-read all transcripts whilst noting prominent ideas deriving from the dataset and documenting these reflections in reflexive notes.

Next, codes were constructed from the transcripts using NVivo. This involved re-reading the transcripts and assigning codes to the data. Codes were assigned to ideas relevant to the research question throughout each transcript. One hundred and fifty-six codes were primarily identified. Similar and duplicate codes were merged, and others were re-examined and redefined leaving 124 codes. It must be noted that the 6 steps of reflexive TA as described by Braun and Clarke (2006) are dynamic rather than linear, so this process again facilitated familiarisation with the data. During this phase, the researcher’s reflexive notes were instrumental in refining codes and ensuring that personal biases were acknowledged and addressed where possible.

Codes were compared to the research question and the pre-existing IP categories to determine their relevance before complementary codes were combined to create distinct and meaningful preliminary themes. At various points, several codes could be placed into multiple overarching categories so time was taken to consider how best to convey participant accounts through the production of the themes. Reflexive notes provided insight into these decisions, supporting the construction of themes through recognition of the researcher’s own preconceptions and the essence of the narratives given by participants during interview. Therefore, themes must be viewed as a construction facilitated by the researcher’s own perspective of the data. Nine preliminary themes were assembled before these were again reviewed. At this stage several themes were merged after overarching meanings and similarities between some themes were established. Two themes were dropped as they were deemed to be only loosely linked to the research aims. Remaining themes were again compared to the pre-existing IP categories to determine points of overlap with this model within participant accounts. Five themes remained following this process. These themes were then defined and named. This process occurred alongside the stage of writing-up and interpretating themes. Preliminary titles were assigned to themes, however as the themes were constructed and interpretation unfolded during the write-up of each theme, it became clear that the original theme titles did not completely capture the sentiment of participant accounts. Therefore, theme definitions were re-worked until the researcher was satisfied that the theme names captured the crux of participant’s experiences and perceptions. The write-up of the final report was informed by Braun and Clarke’s (2023) recommendations for reflexive TA. Whilst some recommendations could not be actioned due to the nature of this thesis (i.e., merging the results and discussion sections), care was taken to abide by these recommendations where possible.

4.6 Integration of mixed-methods data

The integration of the acquired data occurs in the discussion chapter of the current thesis (see chapter 7). Quantitative and qualitative data were kept separate prior to this process so as not to lose sight of the unique and meaningful data that can be derived from each technique, and to reduce the risk of the interpretation of one data type being influenced by the simultaneous interpretation of another. Thus, a narrative approach to comparison was adopted, whereby the results of both the qualitative and quantitative phases of the current research were merged together following analysis. Ultimately, Morgan's (2018) approach to integration was adopted. This approach examines points of divergence, convergence and complementarity across mixed methods results to provide a balanced and nuanced account of the phenomena under investigation. Chapter 7 provides a full overview of the techniques used to integrate the data collected within the present thesis.

4.7 Chapter summary

The current chapter detailed the design and methods adopted to address the research questions posed by the current project. The methodological approach was primarily outlined, with a discussion on mixed methods research and the appropriateness of utilising this approach for the current research, followed by consideration of the philosophical underpinnings of the current project. An overview of pertinent ethical considerations relevant to the current research was then given. Details of each element of the project, namely, the longitudinal survey and qualitative interviews, were provided, including details of the participants who took part in each stage of the project, data collection techniques, and details of the analytical strategies employed. The researcher’s positionality and previous experience was also outlined within this section.

The following chapter details the results stemming from the quantitative component of the current thesis.

CHAPTER 5

Study 1: A longitudinal investigation into the role of illness perceptions and coping in endometriosis-related quality of life and wellbeing outcomes

5.1 Abstract

Endometriosis is associated with adverse health-related quality of life (HRQoL) consequences. The common-sense model of self-regulation (CSM-SR) theorises that IPs shape an individual's response to a health threat or condition, including their coping strategies. However, IPs have yet to be comprehensively explored in relation to endometriosis. The current study aimed to establish the longitudinal predictors of several wellbeing outcomes in the context of endometriosis. Four hundred and eight participants with a medically confirmed diagnosis of endometriosis completed the baseline survey, whilst 283 individuals completed the follow-up survey 12 months' later. Both surveys obtained details on participants' demographics, clinical factors, IPs, coping strategies, self-efficacy, and social support. A regression model was employed to ascertain the predictors of HRQoL, anxiety, depression, stress, pain, and disability. Collectively, IPs predicted all outcomes one year later. However, singularly, only perceptions surrounding the identity and timeline of endometriosis longitudinally influenced HRQoL, pain, and disability. Anxiety, depression, and stress were strongly predicted by coping, namely the use of withdrawal and rumination as a coping mechanism in response to

endometriosis. Several multiple mediation analyses revealed coping as a mediator in the relationship between all IPs and outcomes. Maladaptive coping strategies had the most prominent negative impact on this relationship. Adaptive coping styles had a protective effect on the relationship between IPs and outcomes, although this effect was not as prominent. These findings suggest that interventions based on minimising the use of maladaptive coping mechanisms and supporting more positive IPs in the context of endometriosis may support the HRQoL of individuals living with endometriosis.

5.2 Introduction

The current chapter outlines the quantitative component of the current thesis. First, the study background and aims are outlined (5.3), followed by a brief description of the methods employed in the current study (5.4). Next, the results are outlined (5.5), including descriptive statistics, several hierarchical multiple regressions, and multiple mediation models. The results are then contextualised within the discussion section (5.6), with strengths, limitations, and future research directions also highlighted. Finally, the chapter is summarised (5.7).

5.3 Study background and aims

As outlined in chapter 2, endometriosis is associated with adverse QoL and wellbeing outcomes (Gao et al., 2006; Gete et al., 2023; Jia et al., 2012; Kalfas et al., 2022). Several factors are theorised to underpin this relationship, including pain (McPeak et al., 2018), functioning (Jones et al., 2004), body image (Van Niekerk et al., 2022), and coping styles (Zarbo et al., 2018). However, several factors which may influence HRQoL and wellbeing have yet to be comprehensively considered, including IPs. IPs predict QoL and mental distress in several chronic conditions such as irritable bowel disease (Rochelle & Fidler, 2013), fibromyalgia (Homma et al., 2018), and chronic pain (Siemonsma et al., 2013), as discussed in chapter 3. Many of these conditions share similarities with endometriosis in terms of their chronicity and symptoms. Therefore, it is reasonable to suggest that IPs may impact HRQoL and wellbeing outcomes in the context of endometriosis. Early evidence of IPs as a mediator between trait emotional intelligence and HRQoL has emerged (Barberis et al., 2023). However, this research measures IPs as a single construct rather than breaking it down into its constituent dimensions, and, in treating IPs as a single mediator, the research does not fully explore the links between IPs and HRQoL. As evidenced in chapter 3, IP-based interventions have been designed and utilised to support the QoL and wellbeing of individuals with a variety of health conditions (e.g., Sararoudi et al., 2016). Therefore, determining the impact of IPs in the context of endometriosis has the clear potential to support individuals experiencing this condition.

Additionally, according to the CSM-SR, coping mediates the relationship between IPs and health-related outcomes (Leventhal et al., 2016). IPs are theorised to mould coping responses to a health threat, with coping strategies driving cognitive and behavioural outcomes. However, previous research on IPs in the context of chronic health conditions has often neglected to test coping as a mediator in this relationship. It is essential to test the mediating role of coping to determine the direct and indirect effects of IPs on health-related outcomes.

The current study aimed to investigate the longitudinal predictors of HRQoL and wellbeing outcomes in the context of endometriosis. Furthermore, the present research aimed to investigate whether IPs can predict endometriosis-specific HRQoL and wellbeing outcomes over and above demographic and clinical factors. A longitudinal approach with two time-points was adopted to address these aims, and a regression model was employed to establish the predictive power of each of the psychosocial variables measured. Additionally, a mediation model was utilised to establish the role of coping in the relationship between endometriosis and HRQoL, and the dynamic nature of IPs in the context of endometriosis was assessed.

5.4 Methods

This section of the current chapter provides a brief outline of the methods used within the current study. For a full overview of the study method, including the methodological approach, details pertaining to the measures used, and further information relating to participant demographics, see chapter 4 (section 4.4).

5.4.1 Participants

Participants were recruited through a combination of convenience and snowball sampling. Individuals accessed the survey predominantly through endometriosis support groups (37.2%) and social media platforms (36.9%). Individuals aged over 18, residing in the UK or Ireland, and who self-reported a medically confirmed diagnosis of endometriosis were eligible to participate. See chapter 4 (section 4.4.1.3) for further details regarding the recruitment process.

Four hundred and forty-four participants were recruited for the baseline survey. Thirty-five participants were removed from the dataset due to incomplete responses, duplicate entries, or not meeting the inclusion criteria (e.g., residing out-with the UK). Therefore, 408 baseline responses were retained. Two hundred and eighty-three participants completed the follow-up survey 12 months' later, indicating an attrition rate of 30.84%. All follow-up responses were complete. G*Power was used to calculate the appropriate sample size for the current study. An a priori linear multiple regression model with 22 predictor variables at 95% power indicated a target sample of 230 participants for a medium effect size.

At the time of the follow-up survey, participants were aged between 20 and 57 with a mean age of 35.27 years (SD = 8.14). The majority of participants were from

White backgrounds (93.6%), were married or cohabiting with a partner (71.2%) and were in full or part time employment (72.1%). Participants had experienced endometriosis for approximately 15.5 years (SD = 8.44) and had been diagnosed for around 5.07 years (SD = 5.6), indicating a mean diagnostic delay of 10.4 years. There was a help-seeking delay of 2.87 years. Most participants disclosed at least one co-morbid condition (57.6%) and had undergone surgery for endometriosis (86.6%).

To check for response bias between the baseline and follow-up surveys, a series of independent samples t-tests and chi-square analyses were run. These analyses demonstrated no significant differences between those who completed the follow-up survey and those who did not in demographic background or health status.

For further information on participant demographics, see chapter 4 (section 4.4.1.5).

5.4.2 Design

A longitudinal design incorporating two surveys distributed 12 months apart was adopted for the current study. Following exploratory correlation analyses (see section 5.5.7), 22 predictor variables and 6 outcome variables were incorporated into the final regression model. Details of these variables can be found in chapter 4 (section 4.4.2.1).

5.4.3 Materials

The baseline and follow-up surveys incorporated several validated measures of the phenomena under investigation. Each measure is described in greater detail within chapter 4 (section 4.4.3.1). The measures adopted include the Brief Illness Perceptions Questionnaire (B-IPQ; Broadbent et al., 2006), the Endometriosis Health Profile Questionnaire-5 (EHP-5 Jones et al, 2004), the Patient Health Questionnaire-4 (PHQ4; Kroenke et al., 2009), the Perceived Stress Scale-4 (PSS-4; Cohen et al., 1983), the Essen Coping Questionnaire (ECQ; Franke et al., 2016), the Chronic Pain Grade (CPG; Von Korff et al., 1992), the Self-Efficacy for Managing Chronic Disease Scale (SE-MCD-6; Lorig et al., 2001), and the Brief Perceived Social Support Questionnaire (B-PSSQ; Kleim et al., 2015). Additionally, at the end of the baseline survey, a free text box was presented to participants, with text reading “please feel free to use this box to provide any further details which have **not** already been covered in the questionnaire about the ways in which your endometriosis symptoms and diagnosis have affected your life, and about how you think and feel about your endometriosis.”. In this box, participants were able to write their thoughts and feelings freely. Table 5.1 outlines the measures incorporated within each survey phase.

Table 5.1

Measures included in baseline and follow-up surveys

Measure	*Baseline*	*Follow-up*
B-IPQ	✓	✓
EHP-5	✓	✓
PHQ-4	✓	✓
PSS-4	✓	✓
ECQ	✓	
CPG	✓	✓
SE-MCD-6	✓	
B-PSSQ	✓	
Free text box	✓	

For further detail on the measures used within the current research, see chapter 4 (section 4.4.3.1).

5.4.4 Data collection

After gaining ethical approval from both the University of Strathclyde's ethics committee and the NHS research ethics committee, the full baseline survey was piloted with 14 members of an endometriosis support group. These participants provided feedback on the content of the survey, which, where appropriate, was modified according to their responses (see chapter 4, section 4.4.3.2 for further details).

Both baseline and follow-up surveys were hosted online through Qualtrics. For both phases of the survey, participants were first presented with an information sheet detailing the aims and scope of the study (appendices C and F). They were then asked to indicate their consent to participate. During the baseline survey, participants were asked to confirm that they had received a diagnosis of endometriosis – if they indicated that they were not medically diagnosed, they were directed to the end of the survey. Following this, they were invited to provide their contact details for future follow-up surveys and data matching. Participants could choose not to share their details. Subsequently, participants completed the full baseline survey (appendix D) before receiving a debrief (appendix E).

Twelve months after participating in the baseline survey, the follow-up survey was distributed via email (appendix F) to participants using the contact details provided in the baseline survey. Participants were required to read another information sheet and reiterate their consent to participate (appendix G). Following completion of the survey, participants were debriefed (appendix H). Participants had the option to withdraw their responses until the point of anonymisation, when data from both time points were matched, and personal details were deleted.

5.4.5 Analysis

Chapter 4 (section 4.5) gives a full overview of the analytical approach utilised within the current study. First, baseline data was entered into a correlation matrix to examine the relationships between the IPs and the outcome variables. A second correlation matrix was devised to assess the relationships between all other psychosocial predictor variables and outcomes. Additionally, the relationships between IPs and coping were determined through further correlational analysis. Content analysis was performed to analyse responses to the open-ended question presented during the baseline survey. Paired samples t-tests were also used to determine any differences in IPs between baseline (T1) and follow-up (T2) to establish whether IPs are dynamic in this population. Next, exploratory univariate analyses using ANOVAs, t-tests and correlational tests were performed between the predictors measured at baseline and outcome variables measured 12 months later to determine the predictors to be input into the final regression models. A series of hierarchical regressions were subsequently conducted to determine the factors underlying wellbeing outcomes in individuals experiencing endometriosis. Finally, several multiple mediation analyses were performed to determine whether coping mediated the relationships between IPs at baseline and outcomes at the follow-up stage.

5.5 Results

5.5.1 Baseline descriptive results

The current section outlines the descriptive results stemming from the baseline questionnaire only. The descriptive results from the follow-up questionnaire are presented in section 5.5.5.

5.5.1.1 Wellbeing variables

Table 5.2 displays the mean values and standard deviations for all measured wellbeing variables at baseline.

Table 5.2

Descriptive statistics for all measured wellbeing variables at baseline

Variable	*Mean*	*SD*	*Range of scale*
Depression	2.83	1.84	0-6
Anxiety	3.1	1.88	0-6
Stress	8.76	3.02	0-16
HRQoL	63.9	19.73	0-100
Pain	67.21	18.16	0-100
Disability	3.96	1.92	0-6

According to the PHQ-4, a score of 3 or more indicates mild depression, whilst a score of 2 or less indicates no depression (Kroenke et al., 2009). With a mean depression score of 2.83, participants sit between these values, indicating no to mild depression in this group. Nonetheless, this score was far higher than that of the general population at 1.0 (Kroenke et al., 2009). The PHQ-4 uses the same cut-off points for calculating anxious mood, indicating that this group of participants experienced mild anxiety. As above, anxiety was substantially higher in this group than in the general population at 1.4 (Kroenke et al., 2009).

Participants indicated moderate levels of stress. Stress was higher in the study population compared to a general UK population sample which placed the average stress score at 6.11 (Warttig et al., 2013). Furthermore, participants within the current study demonstrated relatively poor HRQoL, although there was some variation in scores as indicated by the standard deviation in table 5.2. Higher scores on the EHP-5 indicate lower HRQoL. Table 5.3 provides additional information pertaining to the HRQoL of those who participated in the present study. As indicated by the figures within this table, HRQoL was particularly impacted by a perceived lack of social support, the impact of endometriosis on sexual intercourse, poor self-image, and perceptions of treatment ineffectiveness. Note that a higher score on each item in table 5.3 equates to more negative responses.

Table 5.3

Participant scores on specific HRQoL dimensions at baseline

HRQoL dimension	*Mean*	*SD*	*Range of scale*
Social support	2.94	1.049	0-4
Intercourse	2.92	1.159	0-4
Self-image	2.84	1.126	0-4
Treatment	2.84	1.131	0-4
Control and powerlessness	2.70	1.084	0-4
Infertility	2.69	1.356	0-4
Emotional wellbeing	2.59	1.023	0-4
Relationship with medical professionals	2.14	1.430	0-4
Work	2.11	1.193	0-4
Pain	2.07	1.089	0-4
Relationship with children	2.04	1.162	0-4

Additionally, a negative impact of pain on HRQoL was reported by participants, as indicated within table 5.3. There was a high degree of variation in participant scores, corresponding with the heterogeneous experience of endometriosis. Interestingly, participants’ HRQoL appeared to be impacted more severely by clinical and social aspects than pain itself.

5.5.1.2 Illness perceptions

Mean values and standard deviations were calculated for each IP dimension (see table 5.4). Higher scores indicate more negative IPs, with the exception of the personal control, treatment control, and coherence dimensions, in which lower scores indicate more negative IPs.

Table 5.4

Descriptive statistics for illness perceptions at baseline

IP	*Mean*	*SD*	*Range of scale*
Consequences	7.79	1.92	0-10
Timeline	8.96	1.95	0-10
Identity	7.56	2.094	0-10
Concern	7.9	2.17	0-10
Emotional representation	8.11	2.12	0-10
Personal control	2.46	2.32	0-10
Treatment control	4.98	2.43	0-10
Coherence	7.37	2.46	0-10

As illustrated by table 5.4, participants held largely negative perceptions of their endometriosis. Participants envisioned adverse consequences associated with endometriosis, identified with many symptoms of the condition, perceived that endometriosis would endure throughout their lifespan, and held negative emotional representations of their condition. Additionally, participants felt a lack of personal control over the condition, although they held neither positive nor negative perceptions over the control of their treatment, perhaps reflecting the heterogeneity in treatment effectiveness for endometriosis as discussed in chapter 1. Participants generally reported a strong understanding of their condition.

As part of the B-IPQ, participants were asked whether they perceived a cause associated with their condition. Two hundred and one participants (49.3%) suggested potential causes for their endometriosis. Of these respondents, 137 (68.2%) believed that their condition was primarily caused by genetic and hereditary factors including genes and a family history of endometriosis. Other potential causes suggested by participants included trauma (5.5%), hormones (4.5%), birth control (4.5%), early onset of menstruation (3%), surgery (2.5%), giving birth (2.5%), diet/lifestyle (2%) and immune response (2%). However, the ‘cause’ dimension of the

B-IPQ was ultimately dropped from further analysis due to: i) limited heterogeneity in participant responses; and ii) the lack of participants who responded to this item. Taken together, meaningful results could not be gained from the inclusion of cause in the final regression model, and therefore this dimension was discarded.

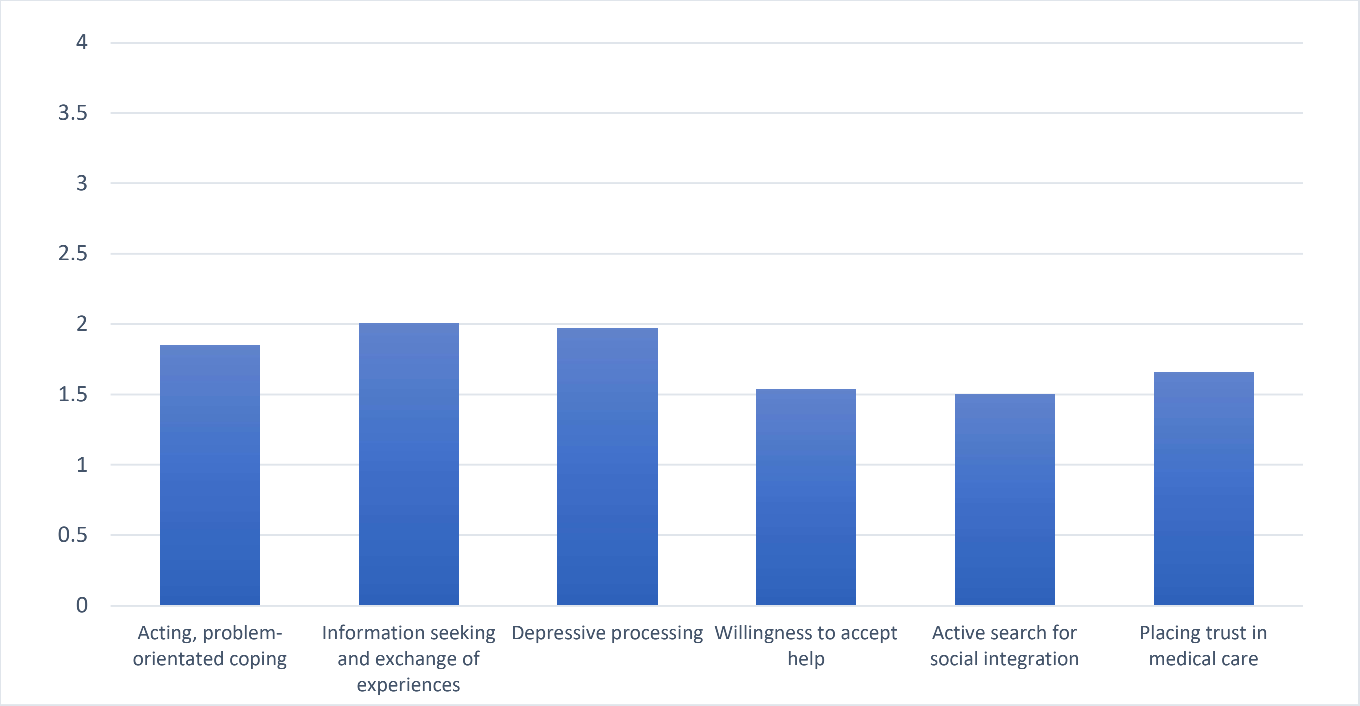
Scatterplots were created to visualise the relationships between each of the 8 remaining IP dimensions and the wellbeing variables. Several IPs appear to relate to each outcome variable, with the strongest relationships between IPs and HRQoL, pain and disability. The scatterplots indicate that HRQoL, pain and disability worsen as IPs become more negative. However, against this general trend, coherence does not appear to be related to any of the measured wellbeing variables from a visual inspection of the scatterplots.

5.5.1.3 Coping

Participants employed various strategies to cope with the impact of endometriosis. The mean scores for each coping subscale are displayed in figure 5.1 below.

Figure 5.1

Coping strategies used by participants



As illustrated by figure 5.1, information seeking and exchanging of experiences was the most used coping strategy employed by participants, followed by depressive processing, and acting, problem-orientated coping. Participants were least likely to employ strategies for social integration, for example by meeting new acquaintances, going out with friends, and visiting others, which may be reflective of the social functioning detriments associated with endometriosis (Moradi et al., 2014). Willingness to accept help and placing trust in medical care were used by participants, but not to a great extent. In fact, no single coping strategy was predominantly employed by participants, indicating considerable disparity in the way that participants coped with their experiences of endometriosis.

5.5.1.4 Social support and self-efficacy

Table 5.5 displays the mean values and standard deviations for self-efficacy and social support in this group.

Table 5.5

Descriptive statistics for self-efficacy and social support at baseline

Variable	*Mean*	*SD*	*Range of scale*
Self-efficacy	3.71	2.07	0-10
Social support	18.9	6.84	0-30

Self-efficacy was measured specifically for managing chronic disease - in this case, endometriosis. A higher score indicates higher self-efficacy. As illustrated in table 5.5, participants' self-efficacy for managing their condition was fairly low. In terms of social support, there was much variation in participant scores as indicated by the standard deviation in table 5.5. However, generally, participants reported good levels of social support, as indicated by the mean value. This is perhaps a consequence of the recruitment process, where many participants were drawn from endometriosis support groups.

5.5.2 Correlation matrices exploring psychosocial variables and outcome variables at T1

Two correlation matrices were created to: i) assess the relationship(s) between IPs and wellbeing outcomes at baseline (T1) and ii) establish the associations between additional psychosocial variables and outcomes at T1.

5.5.2.1 Correlation matrix exploring IPs and outcomes at T1

Firstly, the correlation matrix exploring IPs and outcomes at T1 will be outlined. As stated previously, the ‘cause’ dimension was dropped from analysis due to the lack of responses to this question and the homogeneity of the available participant responses. A series of scatterplots indicated that each of the IPs had a linear relationship with each outcome variable. There were no obvious outliers identified from a visual inspection of each scatterplot. Z scores however revealed 21 potential outliers (3 for consequences, 7 for timeline, 1 for identity, 2 for concern, 6 for emotional response, and 2 for pain) from 13 participants. Each case was checked to ensure that the data had been input correctly, and there were no obvious errors. Removal of the outliers resulted in no change to the data distribution or the observed findings. Ultimately, the identified outliers remain in the data set, as in large samples it is reasonable to anticipate some extreme observations (Field, 2013) and these scores were not over-represented in the data. Furthermore, in health conditions such as endometriosis, there is substantial heterogeneity in the experiences of those living with the condition. Therefore, some extreme data points are expected. Each variable included in the correlation matrix followed a non-normal distribution with the exception of stress and HRQoL. A series of Pearson’s correlations were conducted due to the robustness of this technique when analysing non-normal data distributions (Field, 2013). Comparison of the Pearson’s correlation coefficients with those yielded by a Spearman's rank-order test revealed no substantial differences in the associations amongst the variables included within the matrix below (table 5.6).

Table 5.6

Pearson's correlation matrix for IPs and wellbeing outcomes at baseline

	Consequences	*Timeline*	*Personal control*	*Treatment control*	*Identity*	*Concern*	*Coherence*	*Emotional response*	*Anxiety*	*Depression*	*Stress*	*HRQoL*	*Pain intensity*	*Disability*
Consequences	----	.299**	-.306**	-.206**	.682**	.624**	.081	.597**	.336**	.389**	.402**	.674**	.631**	.595**
Timeline		----	-.096	-.263**	.224**	.225**	.009	.251**	.154**	.174**	.179**	.334**	.319**	.206**
Personal control			----	.295**	-.277**	-.349**	.136**	-.286**	-.256**	-.275**	-.246**	-.321**	-.256**	-.189**
Treatment control				----	-.155**	-.150**	.043	-.194**	-.139**	-.134**	-.204**	-.253**	-.182**	-.058
Identity					----	.518**	.087	.451**	.271**	.417**	.345**	.683**	.683**	.589**
Concern						----	.002	.590**	.304**	.352**	.324**	.577**	.448*	.395**
Coherence							----	.062	-.039	-.020	.015	-.016	.052	.119*
Emotional representation								----	.375**	.415**	.444**	.583**	.456**	.438**
Anxiety									----	.623**	.630**	.471**	.325**	.296**
Depression										----	.645**	.555**	.418**	.398**
Stress											----	.523**	.374**	.404**
HRQoL												----	.704**	.667**
Pain intensity													----	.638**
Disability														----

** Correlation is significant at the <.01 level
* Correlation is significant at the <.05 level

The correlation matrix reveals a set of statistically significant correlations between IPs, emotional and psychological states, and aspects of QoL amongst the participants included in the present study.

All IPs, with the exception of coherence, were related to each outcome variable. Perceptions of the consequences, identity, concern, and the emotional representation of endometriosis demonstrated the strongest relationships with HRQoL, anxiety, depression, stress, pain intensity, and disability. Each of these correlations demonstrated a medium to large effect size. The direction of each of the relationships between IPs and outcomes indicates that, as IPs worsen, so too do health and wellbeing outcomes.

Coherence was weakly correlated with disability but no other outcome variable, indicating that this IP has little effect on wellbeing outcomes in this population. The correlation between coherence and disability represents a small effect size, demonstrating that, as disability increases, there is a slight increase in understanding of the condition (see table 5.6).

5.5.2.2 Correlation matrix exploring psychosocial predictors and outcomes at T1

A second correlation matrix was devised to explore the relationships between each of the remaining psychosocial factors (i.e., coping, self-efficacy, and social support) and each outcome variable (i.e. HRQoL, anxiety, depression, stress, pain, and disability) at T1. Visual inspection of scatterplots indicated that each psychosocial variable had a linear relationship with each outcome variable, and there were no obvious outliers identified. Using a cut-off point of 3 or -3, Z scores indicated

7 potential outliers amongst the psychosocial variables (1 potential outlier for acting, problem-oriented coping, 2 for willingness to accept help, 1 for active search for social integration, 3 for self-efficacy). Removal of the outliers had no effect on the data distribution or the analytical output. Therefore, these points remain in the dataset. All coping variables and social support followed a normal distribution. Self-efficacy was positively skewed to the right. A Pearson’s correlation matrix was produced (Table 5.7) due to the robustness of this technique when analysing non-normal data distributions (Field, 2013).

Table 5.7

Pearson's correlation matrix for psychosocial variables and wellbeing outcomes at baseline

	APC	*ISE*	*DP*	*WAH*	*ASI*	*TMC*	*Self-efficacy*	*Social support*	*HRQoL*	*Anxiety*	*Depression*	*Stress*	*Pain intensity*	*Disability*
APC	----	.195**	-.274**	.352**	.449**	.239**	.354**	.319**	-.229**	-.227**	-.276**	-.349**	-.147**	-.160**
ISE		----	.224**	.368**	.255**	-.189**	-.159**	.017	.281**	.155**	.077	.097	.244**	.324**
DP			----	-.054	-.174**	-.293**	-.498**	-.289**	.542**	.497**	.552**	.585**	.338**	.424**
WAH				----	.517**	.066	.165**	.352**	-.065	-.097	-.109*	-.130*	-.048	.029
ASI					----	.080	.259**	.395**	-.118*	-.187**	-.241**	-.265**	-.093	-.090
TMC						----	.393**	.274**	-.417**	-.184**	-.189**	-.267**	-.271**	-.209**
Self-efficacy							----	.212**	-.557**	-.351**	-.455	-.468**	-.425**	-.421**
Social support								----	-.285**	-.250**	-.303**	-.301**	-.200**	-.095
HRQoL									----	.471**	.555**	.523**	.704**	.677**
Anxiety										----	.623**	.630**	.325**	.296**
Depression											----	.645**	.418**	.398**
Stress												----	.374**	.404**
Pain intensity													----	.638**
Disability														----

** Correlation is significant at the <.01 level
* Correlation is significant at the <.05 level

Table 5.7 outlines a series of statistically significant correlations between coping, self-efficacy, social support and wellbeing outcomes.

In terms of coping styles, acting, problem-oriented coping, depressive processing, and trust in medical care were related to all outcome variables, with depressive processing exhibiting the strongest relationship with wellbeing and HRQoL factors. The positive correlations indicate that, as the use of depressive processing increases, as too does anxiety, depression, stress, pain, and disability. An increase in HRQoL score along with depressive processing also indicates that the use of this coping strategy is associated with a decline in HRQoL, as lower scores on this scale indicate better overall HRQoL (Jones et al., 2001). Conversely, the negative relationships between acting, problem-oriented coping and outcome variables indicate that, as the use of acting, problem-oriented coping increases, the risk of anxiety, depression, stress, adverse HRQoL effects, pain, and disability declines. Similarly, higher trust in medical care is also associated with lessened risk of adverse health and wellbeing outcomes. Meanwhile, willingness to accept help was only weakly correlated with anxiety and stress, indicating a minimal impact on wellbeing outcomes associated with the use of this coping strategy.

Self-efficacy and social support were also related to wellbeing outcomes. Specifically, higher self-efficacy was associated with lessened anxiety, depression, stress, pain, and disability, as well as increased HRQoL. The same effect was found for social support, where higher perceived support led to more positive wellbeing outcomes. However, there was no relationship between social support and self-reported disability.

5.5.3 Relationships between IPs and coping

A further correlation matrix was developed to assess the relationships between the IP dimensions and the 6 coping styles included in analysis: 1) acting, problem-orientating coping; 2) information seeking and exchange of experiences; 3) depressive processing; 4) willingness to accept help; 5) active search for social integration; and 6) trust in medical care. Scatterplots indicated a linear relationship between each IP and coping style. From a visual inspection of the scatterplots, there were no obvious outliers. However, Z scores indicated 1 potential outlier for active search for social integration. This case was checked to ensure that the data was input correctly. There were no obvious errors, and removal of the outlier made no difference to the data distribution. Subsequently, this case remains in the dataset. Additionally, 21 potential outliers were identified within IP scores – these outliers and the subsequent actions taken are described above in section 5.5.2.1. Each coping style followed an approximately normal distribution as established by a visual inspection of histograms and P-P plots. Details on the distribution of the IP dimensions can be found in section 5.5.2.2. A Pearson’s correlation matrix was devised to analyse the relationships between IPs and coping. The results of this analysis are outlined below, in table 5.8.

Table 5.8

Pearson's correlation matrix for IPs and coping styles at baseline

	Consequences	*Timeline*	*Personal control*	*Treatment control*	*Identity*	*Concern*	*Coherence*	*Emotional rep*	*APC*	*ISE*	*DP*	*WAH*	*ASI*	*TMC*
Consequences	----	.299**	-.306**	-.206**	.682**	.624**	.081	.597**	-.137**	.272**	.429**	.011	-.056	-.323**
Timeline		----	-.096	-.263**	.224**	.225**	.009	.251**	-.061	.099	.225**	-.005	-.054	-.279**
Personal control			----	.295**	-.277**	-.349**	.136**	-.286**	.132**	.027	-.278**	.121*	.062	.181**
Treatment control				----	-.155**	-.150**	.043	-.194**	.089	.004	-.158**	.107*	.122*	.252**
Identity					----	.518**	.087	.451**	-.122*	.183**	.388**	.031	-.091	-.269**
Concern						----	.002	.590**	-.171**	.209**	.414**	-.038	-.144**	-.268**
Coherence							----	.062	.110*	.284**	-.001	.149**	.064	.072
Emotional representation								----	-.251**	.231**	.523**	-.086	-.169*	-.295**
APC									----	.195**	-.274**	.352**	.449**	.239**
ISE										----	.224**	.368**	.255**	-.189**
DP											----	-.054	-.174**	-.293**
WAH												----	.517**	.066
ASI													----	.080
TMC														----

** Correlation is significant at the <.01 level
* Correlation is significant at the <.05 level

The correlation matrix reveals several statistically significant relationships between IPs and coping styles. Depressive processing was related to all IPs, with the exception of coherence. The direction of these relationships indicate that, as depressive processing increases, perceptions surrounding the consequences, timeline, illness identity, emotional representation, concern and controllability over endometriosis worsen. Trust in medical care was also associated with all IPs except for coherence, indicating more positive perceptions around endometriosis as trust in medical care increases.

Acting, problem-oriented coping was related to all IPs with the exception of the anticipated timeline and perceptions around treatment control. The direction of these relationships indicates that, as acting, problem-oriented coping increases, IPs become more positive. Additionally, information seeking and exchange of experiences was related to the perceived consequences of endometriosis, and the direction of this relationship indicates that the more information sought by individuals experiencing endometriosis in relation to their condition, the higher the anticipated negative consequences of endometriosis. A higher degree of information seeking and exchange of experiences was further associated with a more negative illness identity, greater concern relating to endometriosis, increased understanding of endometriosis and a more adverse emotional representation of endometriosis.

Willingness to accept help was related to only three IPs – personal control, treatment control, and coherence. The direction of these relationships indicates that a greater willingness to accept help was associated with higher perceptions of control around endometriosis as well as greater understanding of the condition. Finally, active search for social integration was related to higher perceptions of treatment control, lessened concern around the symptoms and impact of endometriosis, and a less negative emotional representation of endometriosis.

5.5.4 Content analysis

A content analysis was performed on the responses to the open-ended question presented to participants at the end of the baseline survey. This analysis aimed to ascertain the factors impacting wellbeing beyond those examined within the survey. Collectively, 166 participants (40.69%) entered a response into the free text box. From participant responses, 45 codes were first derived. Codes were then distilled into overarching meaningful categories, which may themselves be distilled into two broader groupings: healthcare experiences, and social aspects. These categories are presented in table 5.9 along with the number and percentage of participants referencing each aspect. A sample quote has also been included for each category.

Table 5.9

Meaningful categories derived from content analysis

Category	*N*	*%*	*Quote*
Healthcare experiences			
Lack of effective treatment options	68	40.97%	"*The benefits of current medical treatments are short-lived*"
Dismissal and normalisation of symptoms in medical environment	45	27.1%	"*I haven't been listened to. I have been dismissed*"
Diagnostic delay	40	24.1%	"*It took so long to get a diagnosis*"
Delayed treatment	34	20.48%	"*Surgery could be 2 years away. This is a really demoralising and disheartening position to be in*"
Lack of endometriosis knowledge and expertise in healthcare settings	34	20.48%	"*A lot of the time I feel frustrated at the lack of expertise*"
Inadequate healthcare and psychological support after diagnosis	27	16.27%	"*Support following diagnosis is completely non-existent*"
Feeling forced to source private healthcare	18	10.84%	"*The fact that most women seem to be having to turn to private healthcare is ridiculous*"
Adverse health impact of available treatment	18	10.84%	"*After a hysterectomy for endometriosis, I have ongoing chronic pain*"
Anticipated and/or actual recurrence of endometriosis following treatment	15	9.04%	"*Endo could grow back and I am worried about that happening.*"
Effective treatment for symptom minimisation	8	4.82%	"*Since my operation I have been taking the Cerazette pill which manages my pain very well.*"
Social aspects			
Experiencing and/or anticipation of fertility problems	42	25.3%	"*The infertility caused by this illness is more detrimental to my overall health than the condition itself.*"
Issues with daily functioning	27	16.27%	"*Endometriosis severely affects every aspect of my daily life.*"
Anticipated and/or experienced impact on relationships	24	14.46%	"*Getting diagnosed affected my relationships a lot.*"

Detrimental impact on work and career trajectory	20	12.05%	*“I have had to leave work because the frequent and unpredictable absences was having an impact on my ability to carry out my job”*
Reduced sexual functioning	18	10.84%	“*Sex has never been pleasant and always painful. I now hate the idea of having sex which has progressed to hating any type of intimacy*”
Reduced social functioning	16	9.64%	“*I was unable to physically socialise due to the extreme fatigue and pain*”
Societal lack of awareness and understanding of endometriosis	12	7.23%	“*I believe endometriosis is further exacerbated by the lack of public awareness on endometriosis which significantly reduces the quality of life of those affected*”
Negative body image and/or confidence	11	6.63%	“*I am unable to fit into my clothes and don’t feel human when things are bad.*”
Adverse impact on education	5	3.01%	“*I’m uncertain if I’ll be able to do my Master’s degree with the pain I experience*”

As illustrated in table 5.9, participants expressed a detrimental impact on their wellbeing arising from several factors, most frequently surrounding the ineffectiveness of available endometriosis treatments, including painkillers, hormonal medications, and surgical therapies. The dismissal and normalisation of endometriosis symptoms within healthcare settings was experienced by several participants, who often described a marked impact on their wellbeing as a direct result of these experiences. Concerns surrounding fertility was a major driver of wellbeing for many participants, many of whom were at different points in their fertility journey. For example, some participants expressed fear surrounding their future ability to conceive and carry a child due to endometriosis, whilst others had experienced miscarriage and ongoing fertility problems. Some were undergoing or had completed IVF treatment, whilst others described themselves as infertile. Many attributed fertility problems to reduced wellbeing and to impaired relationships with significant others.

Perhaps unsurprisingly, delays within healthcare settings were frequently described, including diagnostic delay and treatment delay. For several participants, treatment delays were exacerbated by COVID-19, which fuelled anxiety relating to the progression of their symptoms. Diagnostic delay was often connected to the minimisation of endometriosis symptomology, in that after approaching healthcare professionals, participants' symptoms were described as normal and further investigation was delayed. Furthermore, participants frequently described a lack of knowledge and expertise related to endometriosis within the healthcare system, which fuelled diagnostic and treatment delays. Many described a sense of abandonment within the healthcare system after receiving their diagnosis, with several drawing on the lack of emotional (e.g., counselling) and physical support (e.g., pain management) offered within these settings. Several individuals felt forced into private healthcare, and for some this led to financial strain.

Additionally, the effectiveness of treatment was often labelled as short-lived. Several participants described the recurrence of their symptoms following treatment such as surgery, with an undercurrent of fear that symptoms would return following additional surgical procedures. However, for a minority of participants, treatment had been effective and life-changing. Some used hormonal treatments, whilst for others surgical interventions or removal of the reproductive organs gave them relief from the symptoms of endometriosis, increasing their wellbeing and QoL.

Considering social factors, participants described multiple functioning detriments that impacted their wellbeing, including reduced daily functioning (e.g., housework, mobility), social functioning (e.g., accepting social invitations), and functioning at work. Participants described absenteeism and presenteeism at work, that for some led to negative impacts on their career progression. Additionally, many participants described a limited sex life, often caused by pain during intercourse. Many attributed the breakdown of previous intimate relationships to reductions in sexual functioning, whilst others described withdrawing from sex and romantic relationships entirely due to the pain they experienced. Reduced functioning was connected to negative impacts on the life trajectory, such as loss of work, strain on relationships including partners and friendships, a negative impact on education, and reduced life satisfaction. Several participants also felt that the lack of societal awareness of endometriosis led to isolation and frustration, as well as increased help-seeking delays. Finally, several participants described negative impacts on their body image prompted by the physical changes to their body as a result of endometriosis. This included symptoms such as bloating and functioning limitations, particularly sexual functioning, which often triggered a loss of self-confidence.

5.5.5 Follow-up descriptive results

5.5.5.1 Wellbeing variables

Means and SDs were calculated for each outcome variable at the follow-up (T2) stage. Results are displayed below in table 5.10.

Table 5.10

Descriptive statistics for all measured wellbeing variables at follow-up

Variable	*Mean*	*SD*	*Range of scale*
Depression	2.57	1.89	0-6
Anxiety	2.92	1.93	0-6
Stress	8.22	3.26	0-16
HRQoL	58.14	22.57	0-100
Pain	60.54	23.18	0-100
Disability	3.17	2.13	0-6

A depression score of 2.57 indicates no to mild depression (Kroenke et al., 2009), similar to the observed values at T1. This score was higher than that recorded for the general population (Kroenke et al., 2009), indicating a higher prevalence of depressed mood in individuals with endometriosis. Depression scores had decreased since T1, although the standard deviation (SD) had increased, indicating a lower overall average but increased variation in participant scores. Similarly, anxiety scores had declined modestly compared to the T1 data, whilst the SD had increased. The change in mean from 3.1 to 2.92 brought the average anxiety score below the cut-off point of 3 for mild anxiety, indicating no to mild anxiety at T2. As with depression, this score was higher than that of the general population (Kroenke et al., 2009).

Compared to the T1 descriptive data, stress had decreased at T2, but remained higher than the stress levels recorded by the general population (Warttig et al., 2013). As with depression and anxiety, there was greater deviation in stress scores at T2 compared to T1. An improvement in HRQoL at T2 was also demonstrated by a decrease in the mean HRQoL score compared to T1, although the observed values at T2 still indicated impaired HRQoL. There was a substantially higher SD at T2 compared to T1, again indicating wider variation in participant scores.

Pain and disability were also improved compared to T1; however, the recorded values indicate that participants still experienced high levels of pain and functioning detriments. As with the other outcome variables, there was higher variation in the scores recorded at T2 compared to T1.

5.5.5.2 Illness perceptions

Mean values and standard deviations were calculated for IPs at T2 (table 5.11). Higher scores indicate more negative IPs, with the exception of the personal control, treatment control, and coherence dimensions, in which lower scores indicate more negative IPs.

Table 5.11

Descriptive statistics for illness perceptions at follow-up

IP	*Mean*	*SD*	*Range of scale*
Consequences	6.98	2.34	0-10
Timeline	9.00	2.01	0-10
Identity	6.88	2.48	0-10
Concern	7.14	2.50	0-10
Emotional representation	7.49	2.40	0-10
Personal control	2.78	2.45	0-10
Treatment control	5.15	2.32	0-10
Coherence	7.42	2.26	0-10

Mirroring the descriptive results for the T1 data, participants held largely negative IPs related to their condition. Participants perceived adverse consequences associated with experiencing endometriosis, saw the condition as enduring and as carrying several symptoms. Participants were concerned about their condition, which also prompted a negative emotional response. They had a good understanding of their condition, however disclosed a lack of personal control surrounding endometriosis. Contrarily, participants were neutral regarding their control surrounding treatment, perceiving neither high nor low control. Nonetheless, compared to T1, participants demonstrated more positive IPs in all categories at T2. As stated within section 5.5.1.2, the ‘cause’ dimension of IPs was dropped from analysis due to the limited response rate and homogeneous causal attributions given by participants who offered a potential cause for their endometriosis.

5.5.6 Comparison of illness perceptions between T1 and T2

The CSM-SR posits IPs as dynamic and changeable (Leventhal et al., 2016). Therefore, a series of paired samples t-tests were conducted between the baseline (T1) and follow-up (T2) data to test the stability and trajectory of IPs over the course of the study duration. It must be noted that the distribution of each IP deviated from normality both at T1 and at T2. Nonetheless, it is important to emphasise that t-tests are recognised for their robustness in the presence of normality violations, particularly when dealing with large sample sizes (Laerd Statistics, n.d.). Table 5.12 details the results from the paired samples t-tests performed for IPs.

Table 5.12

Paired samples t-tests on IPs between baseline and follow-up

Pair	Mean change	SD	t	DF	p
T1 consequences + T2 consequences	-.81	2.059	6.641	282	<.001**
T1 timeline + T2 timeline	.03	1.78	-.335	282	.369
T1 personal control + T2 personal control	.25	2.57	-1.617	282	.053
T1 treatment control + T2 treatment control	.23	2.53	-1.504	282	.067
T1 identity + T2 identity	-.67	2.19	5.181	282	<.001**
T1 concern + T2 concern	-.77	2.25	5.748	282	<.001**
T1 coherence + T2 coherence	.07	2.20	-.503	282	.308
T1 emotional representation vs T2 emotional representation	-.60	1.98	5.128	282	<.001**

** Result is significant at the <.001 level

As illustrated in table 5.12, the paired samples t-tests revealed significant disparities in various IPs between T1 and T2. There was a statistically significant improvement in the perceived consequences of experiencing endometriosis at T2 (t = 6.641, df = 282, p <.001), along with an amelioration in symptoms, as evidenced by a significant decrease in scores on the identity dimension (t = 5.181, df = 282, p <.001). Further improvements were identified in concern related to endometriosis (t = 5.748, df = 282, p <.001), and participants exhibited a more positive emotional response towards experiencing the condition at T2 (t = 5.128, df = 282, p <.001). This lends early support to the CSM-SR's theory that IPs are dynamic and changeable (Leventhal et al., 2016).

5.5.7 Exploratory univariate analyses

A series of ANOVAs, t-tests, and correlations were conducted with the objective of exploring the relationships between potential predictor and outcome variables. This process was undertaken to determine the suitability of variables for inclusion in the subsequent multivariate regression models. Table 5.13 displays the correlations between the continuous predictor variables at T1 and outcome variables at T2.

Table 5.13

Correlation coefficients between predictor variables at T1 and outcome variables at T2

	HRQoL	*Anxiety*	*Depression*	*Stress*	*Pain intensity*	*Disability*
Age	-.189**	-.084	-.011	-.069	-.060	-.104
Income	-.250**	-.151*	-.165**	-.349**	-.193**	-.159**
Symptom duration	.030	.047	.103	.105	.074	.057
Time since diagnosis	-.039	-.053	.039	-.069	.030	-.077
Diagnostic delay	.070	.102	.095	.188**	.067	.134*
Help-seeking delay	-.118*	-.078	-.065	-.051	-.121*	-.061
Medical delay	.150*	.159**	.143*	.233**	.148*	.183**
Number of surgeries	.027	-.016	.114	.034	.057	-.028
Consequences	.511**	.288**	.330**	.376**	.419**	.442**
Timeline	.338**	.174**	.113	.179**	.330**	.238**
Personal control	-.260**	-.219**	-.251**	-.302**	-.188**	-.190**
Treatment control	-.151*	-.140*	-.167**	-.212**	-.170**	-.127*
Identity ¤	.523**	.216**	.297**	.326**	.460**	.455**
Concern	.453**	.243**	.314**	.300**	.333**	.335**
Coherence	-.003	-.059	-.027	-.045	-.007	.037
Emotional response	.481**	.335**	.365**	.404**	.355**	.367**
Action, problem-focussed coping	-.230**	-.236**	-.303**	-.334**	-.138*	-.173**
Information seeking	.249**	.105	.150*	.121*	.171**	.241**
Depressive processing	.453**	.394**	.454**	.454**	.195**	.282**
Willingness to accept help	.037	-.074	-.102	-.066	.017	.048
Search for social integration	-.028	-.143*	-.153*	-.217**	.007	-.044
Trust in medical care	-.408**	-.181**	-.243**	-.280**	-.346**	-.337**
Self-efficacy	-.435**	-.344**	-.448**	-.458**	-.314**	-.397**
Social support	-.255**	-.242**	-.328**	-.336**	-.154*	-.142*

** Result is significant at the <.01 level
 * Result is significant at the <.05 level

5.5.7.1 Demographic factors

Table 5.13 reveals several statistically significant relationships between participant demographics at T1 and outcome variables at T2. Age was significantly negatively correlated with HRQoL but showed no relation to any other outcome variable. As a lower score indicates higher overall HRQoL (Jones et al., 2001), this indicates that as age increases, HRQoL improves. Furthermore, combined household income was negatively correlated with all outcome variables, indicating that, as combined household income increases, there are improvements in HRQoL, wellbeing, pain, and self-reported disability.

A series of t-tests were conducted to determine any differences in outcomes between individuals who had attended university, and those who had not. The analysis indicated that those who had attended university had better HRQoL scores (M = 53.26, SD = 22.09) than those who had not (M = 67.2; SD = 20.95), *t*(274) = 5.07, p<.001. There was also a significant difference between those who had attended university (M = 2.71, SD = 1.87) and individuals who did not (M = 3.29, SD = 1.97) in anxiety scores, *t*(274) = 2.44, p = .008, and between those with a higher education degree (M = 2.24, SD = 1.80) and those without (M = 3.16, SD = 1.85) in depression scores, *t*(274) = 4.00, p<.001. Additionally, stress was higher in those with no university education (M = 9.22, SD = 3.27) compared to those who had attended university (M = 7.61 SD = 3.08), *t*(274) = 4.03, p<.001. Self-reported pain was higher in individuals with no university education (M = 69.40, SD = 19.39) than in those who went to university (M = 55.47, SD = 23.78), *t*(227.06) = 5.24, p<.001, and disability scores were also higher in those without a university education (M = 3.69, SD = 1.95) in comparison to those educated at university level (M = 2.86, SD = 2.18), *t*(210.31) = 3.23, p<.001. Collectively, this indicates that individuals who have attended university tend to exhibit more positive HRQoL, pain, and wellbeing outcomes than those who have not attended university.

A series of ANOVAs were next conducted to ascertain whether employment status was related to HRQoL and wellbeing outcomes. Significant differences in HRQoL scores were observed between those in full-time work (M = 55.87, SD = 21.53), part-time work (M = 57.59, SD = 26.32), and unemployed individuals (M = 64.98, SD = 20.73), *F*(2, 279) = 3.61, p = .028. Post-hoc tests using Tukey's HSD revealed that only the difference between unemployed individuals and those employed full-time was significant (p = .023) indicating that individuals experiencing unemployment have lower HRQoL than those in full-time employment. Similarly, there were significant differences between those in full-time employment (M = 2.77, SD = 1.93), part-time employment (M = 2.74, SD = 1.94), and unemployed individuals (M = 3.53, SD = 1.79) in anxiety scores, *F*(2, 279) = 3.67, p = .027. Post-hoc analysis using Tukey's HSD indicated that only the difference between those in full-time employment and those experiencing unemployment was significant (p = .025), indicating that anxiety is higher for unemployed individuals compared to individuals in full-time work. In terms of stress, a significant difference between individuals employed full-time (M = 7.93, SD = 3.15), part-time (M = 7.84, SD = 3.42), and unemployed individuals (M = 9.42, SD = 3.25) was observed, *F*(2, 279) = 5.04, p = .007. Post-hoc tests employing Tukey's HSD revealed significant differences between both individuals employed full-time and individuals experiencing unemployment (p = .007) and individuals in part-time jobs and unemployed individuals (p = .032), suggesting that employment is a protective factor against stress. Furthermore, pain scores differed significantly between those experiencing unemployment (M = 68.42, SD = 19.08), individuals in part-time work (M = 60.00, SD = 27.50), and those in full-time employment (M = 57.96, SD = 22.56), *F*(2, 279) = 4.51. p = .012. Tukey's HSD post-hoc analysis revealed significant differences between those employed full-time and unemployed individuals, indicating that unemployed individuals reported significantly higher levels of pain relative to those in full-time employment. Disability also significantly differed between those in full-time work, (M = 2.91, SD = 2.07), part-time employment (M = 3.04, SD = 2.23) and unemployed individuals (M = 4.02, SD = 2.00). Post-hoc tests using Tukey's HSD indicated significant differences in disability scores between those in full-time employment and unemployed individuals (p = .002) and those in part-time employment and unemployed individuals (p = .043), suggesting that individuals experiencing unemployment report significantly higher disability than those in employment. Finally, depression scores did not differ between those experiencing unemployment (M = 3.02, SD = 1.90), individuals employed part-time (M = 2.34, SD = 2.00), and participants in full-time employment (M = 2.47, SD = 1.80), *F*(2, 279) = 2.263, p = .106.

Next, t-tests were conducted to determine the impact of relationship status on wellbeing outcomes. There were no significant differences in HRQoL scores between people in a relationship (M = 56.9, SD = 23.30) and single individuals (M = 60.35, SD = 21.24), *t*(272) = -1.09, p = .139, or in the anxiety scores of those in a relationship (M = 2.88, SD = 1.87) and single individuals (M = 2.84, SD = 2.09), *t*(272) = .148, p = .441. Additionally, there were no significant differences in the depression scores of those in a relationship (M = 2.44, SD = 1.78) compared to single participants (M =

2.8, SD = 2.11), *t*(272) = -1.39, p = .083, or the stress scores between single individuals (M = 8.41, SD = 3.73) and those in a relationship (M = 8.04, SD = 3.09). Conversely, participants in a relationship reported lower levels of pain (M = 58.53, SD = 23.58) than single individuals (M = 64.71, SD = 22.14), *t*(272) = -1.92, p = .028, and lower disability (M = 2.98, SD = 2.11) than single participants (M = 3.50, SD = 2.14), *t*(272) = -1.79, p = .038.

There was too little variation in ethnicity to detect significant differences between individuals of different ethnic backgrounds, with all but 22 participants describing themselves as White. Therefore, ethnicity was discarded from further analysis.

5.5.7.2 Clinical endometriosis factors

As depicted in table 5.13, limited statistically significant relationships were identified between the endometriosis-related data collected from participants at T1, and the outcome variables gathered at T2. Specifically, variables such as the duration of endometriosis symptoms, the time elapsed since endometriosis diagnosis and the number of surgeries performed exhibited no statistically significant correlations with any of the measured outcome variables.

Conversely, overall diagnostic delay (i.e., incorporating both delays attributed to help-seeking, and delays within medical settings) was positively and significantly associated with both stress and self-reported disability. This implies that as diagnostic delay increases, so too do stress and disability. Furthermore, help-seeking delay was negatively associated with pain and HRQoL, indicating that postponing support-seeking for endometriosis symptoms is related to improved

HRQoL and lessened pain symptomology. Additionally, diagnostic delay at the medical level – that is, the delay in acquiring a diagnosis of endometriosis following help-seeking within healthcare settings – was positively associated with all outcome variables, implying that, as diagnostic delay increases within medical settings, emotional distress, pain, and disability also increase, whilst overall HRQoL worsens.

To analyse the categorical variables, a series of ANOVAs and t-tests were performed. The impact of the type of healthcare received (i.e., private, NHS, or a mixture of both) on wellbeing outcomes was examined using a series of ANOVAs. Healthcare source was unrelated to HRQoL, *F*(2, 278) = .957, p = .385, anxiety, *F*(2, 278) = .229, p = .795, depression, *F*(2, 278) = 2.054, p = .130, stress, *F*(2, 278) = .701, p = .497, pain, *F*(2, 278) = .700, p = .497, and disability, *F*(2, 278) = .921, p = .399. Therefore, this variable was dropped from subsequent analysis.

The impact of fertility and sub-fertility on wellbeing was also analysed by a series of ANOVAs. Analysis revealed that fertility was unrelated to HRQoL, *F*(3, 111) = 1.282, p = .284, anxiety, *F*(3, 111) = .446, p = .721, depression, *F*(3, 111) = .769, p = .514, stress, *F*(3, 111) = .741, p = .530, pain, *F*(3, 111) = 1.090, p = .357, and disability, *F*(3, 111) = .660, p = .578. Consequently, fertility was removed from further analysis.

A series of t-tests were next conducted to determine the impact of co-morbid conditions on wellbeing outcomes. Pain significantly differed between those with co-morbid conditions (M = 62.62, SD = 21.07) and those without a co-morbid condition (M = 57.55, SD = 25.91), *t*(207.69) = 1.724, p = .043, indicating that those with a co-morbid condition reported significantly higher endometriosis-related pain scores than those without. However, those with a co-morbid condition did not differ from those with no co-morbid condition in relation to HRQoL, *t*(214.18) = .98, p = .164, anxiety, *t*(275) = .509, p = .306, depression, *t*(275) = -.313, p = .377, stress, *t*(261.64) = .345, p = .365, or disability, *t*(275) = 1.422, p = .078.

5.5.7.3 Illness perceptions

Table 5.13 illustrates a series of significant and positive correlations between the 8 categories of IPs assessed at T1 and the 6 outcome variables measured at T2. Specifically, the perceived consequences associated with experiencing endometriosis, the anticipated timeline of symptom progression, the number of experienced symptoms, participants' concern about their condition and their emotional response to endometriosis all positively correlated with each of the outcome variables. This indicates that as IPs worsen, HRQoL, pain, disability and mental wellbeing outcomes also deteriorate. However, there was one notable exception to this pattern of significant correlations, illustrated by the non-significant relationship between the anticipated timeline of endometriosis symptoms and self-reported depression.

Additionally, perceptions of personal control and control around endometriosis treatment were negatively associated with all outcome variables, indicating that as perceptions of control around endometriosis decrease, HRQoL, pain, disability and wellbeing outcomes worsen.

Conversely, coherence, which measures the extent to which participants understand their diagnosis, was not related to any of the measured outcome variables and was subsequently dropped from further analysis.

5.5.7.4 Coping strategies

Several statistically significant correlations between coping styles and the measured outcome variables are illustrated in table 5.13. Specifically, acting problem-oriented coping and a high level of trust in medical care were negatively related to all outcome variables, indicating that greater trust in healthcare services and a propensity for problem-solving coping strategies are each associated with improved wellbeing and HRQoL. Conversely, depressive processing, which includes social withdrawal and rumination, was associated with worse health and wellbeing outcomes, as evidenced by positive correlations with all measured outcome variables.

Coping through information seeking and exchanging experiences was positively associated with all outcome variables except for anxiety. Therefore, participants who tended to exchange their experiences with others or seek additional information about their condition reported worsened HRQoL, higher emotional distress and increased pain and disability. This may suggest that individuals with more severe endometriosis tend to seek support from others and look for further information about their condition.

Furthermore, individuals who used acting, problem-oriented coping by connecting with friends, socialising, and using their experiences to support other people showed improvements in stress, depression, and anxiety, as evidenced by negative correlations between these variables in table 5.13. As above, it may be the case that individuals with less severe endometriosis are more likely to employ such coping strategies. Willingness to accept help was unrelated to any outcome variable and was discarded from further analysis.

5.5.7.5 Psychosocial factors

Finally, table 5.13 displays negative correlations between self-efficacy and all outcome variables, and social support and all outcome variables. This indicates that, as perceived social support and self-efficacy increase, there is a concurrent decrease in anxiety, depression, stress, pain, and disability scores. HRQoL scores also decrease with an increase in self-efficacy and social support, indicating that these variables are associated with improvements in HRQoL.

Based on the above observations, six regression models were devised to determine the impact of demographics, clinical factors, IPs, coping styles, and psychosocial factors on endometriosis-specific HRQoL, anxiety, depression, stress, pain, and disability. These models are displayed below, in table 5.14. In all, 10 potential predictor variables were dropped due to a lack of association with the measured outcome variables, with 22 retained for analysis.

Table 5.14

Hierarchical regression models

Dependent variable	Predictor variables for multiple regression
HRQoL	*Layer 1*
19 predictors	Age
	Educational attainment
	Employment status
	Combined income
	Layer 2
	Medical delay
	Help-seeking delay
	Layer 3
	Perceived consequences
	Perceived timeline
	Perceived personal control
	Perceived treatment control
	Illness identity
	Concern
	Emotional representation
	Layer 4
	Action, problem-oriented coping
	Information seeking and exchange of experiences
	Depressive processing
	Trust in medical care
	Layer 5
	Self-efficacy
	Social support
Anxiety	*Layer 1*
17 predictors	Educational attainment
	Employment status
	Combined income
	Layer 2
	Medical delay
	Layer 3
	Perceived consequences
	Perceived timeline
	Perceived personal control

	Perceived treatment control Illness identity Concern Emotional representation *Layer 4* Action, problem-oriented coping Depressive processing Active search for social integration Trust in medical care *Layer 5* Self-efficacy Social support
Depression **17 predictors**	*Layer 1* Educational attainment Combined income *Layer 2* Medical delay *Layer 3* Perceived consequences Perceived timeline Perceived personal control Perceived treatment control Illness identity Concern Emotional representation *Layer 4* Action, problem-oriented coping Information seeking and exchange of experiences Depressive processing Active search for social integration Trust in medical care *Layer 5* Self-efficacy Social support
Stress **19 predictors**	*Layer 1* Educational attainment Employment status Combined income

	Layer 2
	Diagnostic delay Medical delay
	Layer 3
	Perceived consequences Perceived timeline Perceived personal control Perceived treatment control Illness identity Concern Emotional representation
	Layer 4
	Action, problem-oriented coping Information seeking and exchange of experiences Depressive processing Active search for social integration Trust in medical care
	Layer 5
	Self-efficacy Social support
Pain	*Layer 1*
20 predictors	Educational attainment Employment status Combined income Relationship status
	Layer 2
	Medical delay Help-seeking delay Co-morbid condition
	Layer 3
	Perceived consequences Perceived timeline Perceived personal control Perceived treatment control Illness identity Concern Emotional representation
	Layer 4
	Action, problem-oriented coping Information seeking and exchange of experiences

	Depressive processing Trust in medical care *Layer 5* Self-efficacy Social support
Disability **19 predictors**	*Layer 1* Educational attainment Employment status Combined income Relationship status *Layer 2* Diagnostic delay Medical delay *Layer 3* Perceived consequences Perceived timeline Perceived personal control Perceived treatment control Illness identity Concern Emotional representation *Layer 4* Action, problem-oriented coping Information seeking and exchange of experiences Depressive processing Trust in medical care *Layer 5* Self-efficacy Social support

5.5.8 Hierarchical multiple regressions

A series of hierarchical multiple regression analyses were conducted to ascertain the demographic, clinical, and psychosocial predictors of each outcome variable. Predictor variables were recorded at T1 to ascertain the longitudinal predictive value of these factors, whilst outcome variables were recorded 12 months later at T2. The results of these analyses are detailed below. Please note that full regression tables can be found in tables L.1 – L.6 in appendix L.

5.5.8.1 Health Related Quality of Life

First, a hierarchical multiple regression was performed to establish the predictors of HRQoL at the follow-up stage. Nineteen potential predictors were incorporated into the regression analysis. Demographic data was entered at the first step, followed by clinical endometriosis information. Next, IPs were included in the model, followed by coping style and, lastly, psychosocial variables. Table L.1 in appendix L (page 487) presents full details on the regression model.

Partial regression plots revealed linear relationships between HRQoL and each of the continuous predictor variables. Furthermore, there was a linear relationship between HRQoL and the predictor variables collectively, as illustrated by a scatterplot of standardised residuals and predicted values. The same scatterplot confirmed homoscedasticity within the data. There was independence of observations, as evidenced by a Durbin-Watson statistic of 1.820. Additionally, there were no correlations between variables >.7, indicating no multicollinearity within the data. Examination of the studentized residuals revealed 3 potential outliers in the data, however the Cook's distance associated with these cases were all considerably below 1, indicating that the inclusion of this data does not have a strong influence on the model. Therefore, these data points remain in the dataset. Examination of the leverage values revealed 5 risky leverage points ranging from .212 - .241. Ultimately, these values have been retained, as they have little influence on the results and have not led to the violation of the model assumptions. No highly influential points were observed from the Cook's distance, using a cut-off point of 1. Residuals of the outcome variable, HRQoL, were approximately normally distributed, as evidenced by a visual inspection of a normal P-P plot and histogram.

The full regression model including demographics, clinical information, IPs, coping styles, and psychosocial factors significantly predicted HRQoL, *F*(19, 231) = 11.56, *p*<.001. As illustrated in table L.1 (see appendix L, page 487), the full regression model accounts for 48.7% of the variance in HRQoL scores (adjusted R^2 = .445). As indicated by the significant R^2 change in step 3, IPs explain an additional 26.1% of the variance in HRQoL, above and beyond the variance explained by demographic and clinical factors alone. In model 4, coping style explains an additional 3.1% of the variance in HRQoL scores. The inclusion of social support and self-efficacy in model 5 explains a further 0.2% of the variance in HRQoL scores, however this increase was non-significant.

Whilst IPs collectively accounted for a substantial portion of the variance in HRQoL scores, only illness identity (p <.001) and anticipated timeline (p = .002) emerged as independent predictors of HRQoL within the full regression model. This indicates that a higher number of perceived symptoms and a longer anticipated timeline associated with endometriosis are linked to lower HRQoL. Age also predicted HRQoL, with a higher age associated with better HRQoL outcomes.

5.5.8.2 Anxiety

A hierarchical multiple regression was next performed to establish the longitudinal predictors of anxiety amongst the study population. Seventeen potential predictor variables were input into the regression model. As with the HRQoL regression, demographic data was entered at the first step, followed by clinical endometriosis information. Next, IPs were included in the model, followed by coping style and, lastly, psychosocial variables. Table L.2 (see appendix L, page 489) presents the results of the regression analysis.

There was independence of observations, as evidenced by a Durbin-Watson statistic of 2.067. Partial regression plots demonstrated linearity between anxiety and each of the continuous predictor variables, whilst a plot of studentised residuals against unstandardised predicted values illustrated linearity between anxiety and all predictor variables combined. The same plot demonstrated homoscedasticity within the data. Correlations between each measured variable did not exceed .7, demonstrating no multicollinearity. No outliers or highly influential points were identified in the data set, determined by examining studentised residuals and the Cook’s distance. Three cases of ‘risky’ leverage values were identified (ranging from .201 - .211), however as these cases had no strong influence on the results and did not lead to the violation of model assumptions, these cases remain in the dataset. Residuals of the outcome variable, anxiety, were approximately normally distributed, as evidenced by a visual inspection of a P-P plot and histogram.

The full regression model, including demographics, clinical information, IPs, coping styles and psychosocial factors significantly predicted anxiety, $F(17, 233) = 4.516$, $p < .001$. As illustrated in table L.2 (see appendix L, page 489), the full model accounts for 24.8% of the variance in anxiety score (adjusted $R^2 = .193$). The addition of IPs results in the largest change to R^2, explaining an additional 9.4% of the variance in anxiety scores above and beyond demographic and clinical factors. Coping style explains a further 7.8% of the variance in anxiety scores, whilst the addition of psychosocial variables including self-efficacy and social support explained a further 0.4% of the variance, however this change was non-significant.

IPs collectively accounted for a modest proportion of the variance in anxiety scores amongst participants, however no single IP emerged as a predictor of anxiety alone. Within the full model, only depressive processing, a coping style characterised by social withdrawal and rumination, significantly predicted anxiety (p <.001). This finding implies that as depressive processing increases, as too does anxiety.

5.5.8.3 Depression

A third hierarchical multiple regression was performed to ascertain the predictors of depression amongst participants. Seventeen potential predictors of pain were input into the model. As with the previously performed regression analyses, demographic variables were first entered into model, followed by clinical variables, IPs, coping style and, finally, psychosocial variables. The results of the full regression analysis are presented in table format within the appendices of the current thesis (see appendix L, table L.3 on page 491).

Independence of observations was indicated by a Durbin-Watson statistic of 1.906. There was linearity between the outcome variable, depression, and all predictor variables combined, as evidenced by a scatterplot of studentised residuals against unstandardised predicted values. The same graph indicated homoscedasticity within the data. Partial regression plots indicated that each continuous predictor variable had a linear relationship with depression. There were no correlations >.7 between variables, indicating no multicollinearity within the data. There were no outliers or highly influential points within the dataset, as indicated by an examination of studentized residuals and the Cook's distance. Three 'risky' leverage values were identified, ranging from .2 – .211. It was determined that these cases do not exert a strong influence on the results, and were relatively low risk. Consequently, these cases remain in the dataset. Finally, the residuals of the outcome variable, depression, are approximately normally distributed, as determined by visual examination of a histogram and a P-P plot.

The full regression model significantly predicted depression *F*(17, 234) = 6.920, p <.001. The model accounts for 33.5% of the variance in depression scores between participants (adjusted R^2 = .286). The inclusion of IPs in the model resulted in a significant change to R^2 of 11.5%, indicating that IPs influence depression above and beyond demographic and clinical factors. The addition of coping style prompts explained an additional 9.8% of the variance in depression scores above and beyond demographics, clinical factors and IPs. The addition of psychosocial variables resulted in a modest but significant change to R^2 of 3.3%.

As demonstrated in table L (see appendix L.3, page 491), depressive processing independently and significantly predicted depression (p <.001), indicating that higher levels of depressive processing increase the risk of depression. Beyond this coping strategy, only self-efficacy (p = .03) and social support (p = .006) were independent predictors of depression. The results indicate that higher self-efficacy and perceived social support decrease the risk of depression.

5.5.8.4 Stress

A fourth hierarchical multiple regression was conducted to determine the predictors of stress. Eighteen potential predictors were included in the regression model, with demographics entered at the first step, followed by clinical factors, IPs, coping strategies and psychosocial variables. Table L.4 (see appendix L, page 492) presents the results of the full regression model.

Independence of observations was evidenced by a Durbin-Watson statistic of 2.103. There was a linear relationship between the outcome variable, stress, and each continuous predictor variable, as evidenced by a visual assessment of partial regression plots. A scatterplot of standardised residuals against unstandardised predicted values revealed linearity between anxiety and all predictor variables combined. The same plot indicated that there was no homoscedasticity within the data. The correlation coefficient indicating the relationship between medical-level delays and overall diagnostic delay exceeded the .7 threshold, suggesting multicollinearity between these variables. Consequently, overall diagnostic delay was dropped from analysis, and all assumption tests were re-run. There were no further correlation coefficients exceeding .7, indicating no multicollinearity within the revised dataset. There were no outliers in the data set, as indicated by a review of the studentized residuals, and no highly influential points were identified following a review of the Cook's distance. Three 'risky' leverage points were identified, ranging from .203 - .217. These cases remain in the dataset, as they had no strong influence on the results, and the risk was deemed fairly low due to the leverage values. Finally, the residuals of the outcome variable, anxiety, were approximately normally distributed, as indicated by a histogram and P-P plot.

The full regression model, including demographics, clinical factors, IPs, coping styles and psychosocial factors, significantly predicted stress within the study population, *F*(19, 231) = 8.376, p <.001. The model explained 40.8% of the total variance in stress scores (adjusted R^2 = .359). As illustrated in table L.4 (see appendix L, page 492), the addition of IPs in model 3 prompted the most significant change in R^2, explaining an additional 14.4% of the variance above and beyond that explained by demographic and clinical factors. The addition of coping styles explained a further 8.3% of the variance in participant stress scores. Including self-efficacy and social support in the model explained 1.2% of the variance in stress scores, however this change was not significant.

Although IPs collectively accounted for a significant proportion of the variance in participant stress scores, no singular IP significantly and independently predicted stress. However, in terms of coping styles, depressive processing was significantly predictive of stress in the final regression model ($p < .001$), indicating that the greater the extent of depressive processing used by participants, the higher the likelihood of stress. Additionally, increased use of action-orientated coping strategies significantly predicted lowered stress in this sample ($p = .025$). Combined household income was the only additional predictor of stress ($p = .025$) in this model, indicating that as household income rises, self-reported stress decreases.

5.5.8.5 Pain

A further hierarchical regression analysis was conducted to assess the predictors of pain. Twenty potential predictor variables were included in the analysis. Demographic variables were entered at the first step, followed by clinical factors, then IPs, coping styles, and psychosocial variables in the final step. Table L.5 in appendix L (page 494) outlines the results of the full regression analysis.

Independence of observations was indicated by a Durbin-Watson statistic of 1.858. Partial regression plots indicated linearity between each continuous predictor variable and the outcome variable, pain. A scatterplot of studentised residuals plotted against unstandardised predicted values indicated linearity between pain and all predictor variables combined. The same plot indicated homoscedasticity within the data. There were no correlations over .7 identified within the correlation matrix, therefore there was no evidence of multicollinearity within the dataset. Two potential outliers were identified by inspection of studentised deleted residuals, however the Cook's distance associated with these cases was well below 1, indicating that these cases exert no strong influence on the results. Therefore, these cases remain in the dataset. There were no highly influential points identified following inspection of the Cook's distance. Four 'risky' leverage points were identified, ranging from .207 - .231, however these cases remain in the dataset as they are not considered highly influential or highly risky. Visual inspection of a histogram and P-P plot indicated that the residuals of the outcome variable, pain, were approximately normally distributed.

The full regression model including demographics, clinical factors, IPs, coping strategies, and psychosocial factors significantly predicted pain in this participant sample, *F*(20, 218) = 6.226, p <.001. The regression model accounts for 36.4% of the variance in pain scores (adjusted R^2 = .305). The addition of IPs prompts the largest change in R^2, explaining an additional 21.5% of the variance in participant pain scores above and beyond demographic and clinical factors (see table L.5 in appendix L, page 494). The addition of coping styles and psychosocial variables did not significantly increase the amount of variance explained by the model.

In terms of independent predictors of pain, only two IPs, timeline and identity, significantly predicted self-reported pain scores. The results suggest that as the number of symptoms perceived to be linked to endometriosis increases, as too does the intensity of pain reported. Additionally, as the perceived duration of endometriosis increases, so too does the severity of pain. No other factor independently predicted pain.

5.5.8.6 Disability

A final hierarchical multiple regression was conducted to ascertain the predictors of disability. Eighteen potential predictor variables were included in the analysis. As with previous hierarchical regressions, demographic variables were input at step 1, followed by clinical information, then IPs, coping strategies, and finally, psychosocial factors. Table L.6 in appendix L (page 496) illustrates the results of the regression analysis.

Independence of observations was determined by a Durbin-Watson statistic of 1.833. Partial regression plots indicated a linear relationship between each continuous predictor variable and the outcome variable, disability. A scatterplot of studentised residuals against the unstandardised predicted values indicated a linear relationship between all predictor variables combined and disability. The same graph implied homoscedasticity within the data. An examination of the correlation matrix revealed no correlations >.7, indicating no multicollinearity between variables. No outliers or highly influential points were identified following inspection of the Cook's distance statistic and studentised deleted residuals. Three 'risky' leverage points were identified, ranging from .207 - .217, however as these cases exerted no strong influence on the results or assumptions of the regression, they remain in the dataset. Visual inspection of a histogram and P-P plots indicated that the residuals of the outcome variable, disability, were approximately normally distributed.

The full regression model including demographics, clinical factors, IPs, coping strategies, and psychosocial variables significantly predicted disability, $F(20, 222) = 6.343$, $p < .001$. The regression model explains 36.4% of the variance between participants' disability scores (adjusted $R^2 = .306$). The greatest change in R^2 is prompted by the inclusion of IPs at step 3, which explains 21.3% of the variance in disability scores above and beyond demographics and clinical factors (see table L.6 in appendix L, page 496). The inclusion of both coping strategies and psychosocial variables did not prompt significant increases in R^2.

In the final regression model, perceptions around the illness identity predicted disability ($p < .001$) along with perceptions associated with the timeline of endometriosis ($p = .037$). This indicates that a greater number of symptoms associated with endometriosis and a longer timeline associated with the condition predicts worsened disability scores. Employment status was also predictive of disability scores ($p = .011$), indicating that individuals experiencing unemployment are more likely to report higher disability scores.

5.5.9 Mediation analyses

The mediating role of coping styles in the relationship between IPs measured at baseline and each outcome variable at the time of follow-up was assessed using several multiple mediation models. Mediation analyses were conducted using PROCESS v4.2 (Hayes, 2017). The results of these analyses are detailed below, organised by outcomes.

The assumptions for the following mediation models are detailed earlier in the current chapter. See sections 5.5.2, 5.5.3, 5.5.7, and 5.5.8 for details of the data distributions, outliers, and linearity of each variable. It should be noted that several variables included in the following analysis followed a non-normal distribution, however the PROCESS method of mediation analysis enlists a robust bootstrapping procedure to ensure minimal impact of non-normal data distributions on the results.

Forty-one multiple mediation analyses were conducted. The results of each multiple mediation analysis are detailed in tables M.1 – M.6 in appendix M, organised by wellbeing outcome. A fuller account of the mediating effect also accompanies each table within the appendices, along with illustrations of each mediation (see figures M.1 – M.41). Please note that a partial mediation indicates the presence of a significant direct effect of the IP on the outcome variable, as well as a significant indirect of coping in this relationship, signifying that the relationship between the IP and outcome variable exists even without the influence of the mediators, which too exert a significant effect on this relationship. Contrarily, a full mediation indicates that the total effect of the IP on the outcome variable is lost in the presence of the mediators, suggesting that the mediator(s) entirely underpins the relationship between the IP and outcome variable.

In each mediation model negative IPs were generally associated with increased use of information seeking and exchanging of experiences and depressive processing, as well as decreased trust in medical care and a lower likelihood of adopting action, problem-oriented coping styles. However, negative perceptions of the consequences of experiencing endometriosis were associated with decreased depressive processing.

5.5.9.1 HRQoL

As indicated by table M.1 (see appendix M, page 499), the relationships between each IP and HRQoL were mediated by the coping strategies adopted by participants. The relationships between each IP and HRQoL were all partially mediated by depressive processing (DP) and trust in medical care (TMC), with the exception of the relationship between treatment control and HRQoL, which was fully mediated by these coping strategies. Information seeking and exchange of experiences (ISE) mediated the relationship between identity and HRQoL, and concern and HRQoL. The higher the use of ISE and DP, the worse the HRQoL reported by participants. Conversely, increased TMC was related to better HRQoL.

5.5.9.2 Anxiety

Table M.2 (see appendix M, page 507) indicates that the relationship between each IP and anxiety was mediated by the coping mechanisms used by participants. Acting, problem-oriented coping (APC) and depressive processing (DP) fully mediated the relationships between concern and anxiety, and treatment control and anxiety. DP fully mediated all relationships between IPs and anxiety, with the exception of the relationship between perceived consequences and anxiety, which DP partially mediated. Higher use of APC had a protective effect on anxiety, whereas increased use of DP as a coping tool predicted increased anxiety.

5.5.9.3 Depression

As displayed in table M.3 (see appendix M, page 515), the relationship between each IP and depression was mediated by coping style. Specifically, acting problem-oriented coping (APC) and depressive processing (DP) either fully or partially mediated the relationships between all IPs and depression, with the exception of the relationship between identity and depression, in which only DP partially mediated this association. Higher use of DP led to worsened depression, whilst adopting APC reduced depression. Importantly, there was no direct relationship between timeline and depression, so a mediation analysis was not performed for this association.

5.5.9.4 Stress

As illustrated in table M.4 in appendix M (page 523), the relationship between each IP and stress was mediated by the coping strategies adopted by participants. Acting, problem-oriented coping (APC) and depressive processing (DP) partially mediated the relationships between emotional representation and stress, personal control and stress, and consequences and stress, whilst these coping styles fully mediated the relationships between concern and stress and treatment control and stress. DP alone fully mediated the association between identity and stress, and partially mediated the relationship between timeline and stress. APC had a protective effect on stress, whilst DP led to increased stress.

5.5.9.5 Pain

As outlined in table M.5 in appendix M (page 531), the relationship between each IP and pain was mediated by trust in medical care (TMC). Specifically, TMC had a partial mediating effect on each relationship, with the exception of the association between perceptions around treatment control and pain, for which it exerted a full mediating effect. Higher TMC related to lower pain.

5.5.9.6 Disability

Finally, as indicated by table M.6 (see appendix M, page 538), the relationship between each IP and disability was mediated by the coping styles adopted by participants. Specifically, trust in medical care (TMC) and information seeking and exchange of experiences (ISE) partially mediated the relationships between disability and anticipated consequences, identity, concern, and emotional representation. TMC fully mediated the relationships between disability and perceptions surrounding control, and partially mediated the relationship between the anticipated timeline of endometriosis and disability. As TMC increased, perceived disability decreased, whilst as ISE increased, participant disability scores increased.

5.6 Discussion

The current study aimed to ascertain the longitudinal predictors of HRQoL and wellbeing outcomes in individuals diagnosed with endometriosis. Using the CSM-SR as a framework, the current research sought to determine the role of IPs in health-related outcomes in this population, and to establish whether coping mediated these relationships.

Broadly, demographic variables such as age, combined income, and educational status, as well as clinical variables and combined IPs accounted for a significant proportion of the variance in each outcome variable. Combined coping styles significantly predicted HRQoL, anxiety, depression, and stress, whilst the remaining psychosocial variables, self-efficacy and social support, accounted for a significant proportion of the variance only in depression scores. Additionally, participants expressed concerns around the lack of available treatment options, fears around fertility, and frustration relating to the dismissal of their symptoms. Participants indicated that these factors were instrumental in shaping their QoL and perceptions of their condition.

Furthermore, several multiple mediation analyses revealed that coping influenced the relationships between each IP and outcome variable, at least partially. This indicates that, even where there is a direct relationship between IPs and outcomes, coping has some intervening effect on this association.

The following section of the current chapter aims to contextualise these findings.

5.6.1 Relationships between psychosocial factors and outcome variables

IPs measured at baseline were related to wellbeing outcomes measured at both the baseline stage and follow-up phase of the present research. Specifically, the anticipated consequences, perceived timeline, beliefs around personal control, perceived identity of endometriosis, concern surrounding the condition, and emotional representation of endometriosis were related to each outcome variable at both stages of data collection. More negative IPs predicted adverse wellbeing outcomes.

Several changes were observed in IPs between the baseline and follow-up stage of the present study. Specifically, perceptions around the consequences of endometriosis, the number of symptoms associated with the condition, concern around endometriosis, and the emotional representation of the condition became more positive between the baseline and follow-up surveys. Initially, this finding may appear counterintuitive, as endometriosis is a progressive condition that worsens over time (Zanelotti & DeCherney, 2017), with the severity of symptoms directly related to wellbeing (Gao et al., 2020). Additionally, several studies have observed stability in IPs over time across a range of chronic conditions, including IBS and arthritis (Dempster et al., 2015; Rutter & Rutter, 2007, see chapter 3). However, the current study's findings corroborate the CSM-SR's central tenet of dynamic and changeable IPs that alter in line with external factors, such as changes in treatment, and internal factors, such as positive appraisals of the actions taken in response to a health threat (Leventhal et al., 2016). This finding also converges with the results of additional research that has observed variable IPs in chronic conditions such as COPD (Fischer et al., 2010).

In this context, the positive shift in IPs may be reflective of successful treatment or increased support in the time between the baseline and follow-up survey. The timing of the distribution of the survey may also play a role. To exemplify, the baseline survey was distributed during UK-wide lockdowns in response to the COVID-19 pandemic. During this time, endometriosis was classified as a non-urgent medical complaint, leaving many unable to access treatment (Leonardi et al., 2020). A year later, COVID-19 induced lockdowns had been lifted, and 'non-essential' medical treatment had recommenced, potentially leading to effective treatment and more positive perceptions around endometriosis at the follow-up stage.

Additionally, many IPs including the anticipated consequences, timeline, and control surrounding endometriosis were associated with health and wellbeing outcomes. However, no relationship was observed between coherence and any outcome variable, with the exception of disability with which coherence was weakly correlated. Individuals with high levels of self-reported disability may hold more knowledge about their condition through increased information seeking, which was also related to disability (see section 5.5.2), potentially explaining the relationship between coherence and self-reported disability observed in the current study. Nonetheless, coherence was generally high amongst the study population, indicating a strong awareness and understanding of endometriosis amongst participants. The lack of an association between coherence and outcomes implies that, no matter the degree of understanding around endometriosis, HRQoL, anxiety, depression, stress, and pain are not affected. Therefore, contrary to research that has observed decreases in psychological distress in response to increased health literacy (e.g., Petrie et al., 2002), interventions aimed at increasing understanding and knowledge around endometriosis may be unlikely to support wellbeing in this population.

Considering factors out-with IPs, higher income and reduced diagnostic delays within healthcare settings were related to increased HRQoL, decreased psychological distress, and improved clinical outcomes including pain and disability. Within the current study, overall diagnostic delay was split into two variables: help-seeking delay, and delayed diagnosis in medical settings. There was a help-seeking delay associated with endometriosis of 2.87 years, substantially reduced from Cox et al.'s (2003) previously estimated help-seeking delay of 3.8 years. This decrease may be reflective of increased awareness and understanding of endometriosis over the past two decades, which has led individuals to source support earlier. Interestingly, within the study sample, as the help-seeking delay increased, HRQoL and stress improved. It is possible that individuals who delay help-seeking for longer periods have less severe endometriosis symptoms, which may be reflected in the negative relationship between help-seeking delays and pain and disability scores. Contrarily, the longer an individual awaits medical support and intervention following help-seeking, the worse their health and wellbeing outcomes. This is likely connected to an erosion of control surrounding health outcomes, fuelled by lengthy diagnostic and treatment delays within medical settings. The detrimental effect of diagnostic and treatment delays on QoL outcomes has been previously acknowledged within existing literature (Nnoham et al., 2011). Additionally, the findings from the content analysis performed on the open-ended question completed by participants at the baseline stage add further weight to this observation, as treatment delays and a lack of options for medical intervention were regularly cited by participants as negatively affecting their wellbeing.

In terms of future research directions, further longitudinal studies to ascertain the trajectory of IPs over a longer period would be beneficial to aid understanding of the dynamic nature of IPs in endometriosis, particularly out-with the challenges posed by COVID-19. Additionally, comparative studies across several chronic conditions, particularly menstrual-related conditions such as adenomyosis and chronic pelvic pain, would be beneficial to explore similarities and differences in the role of IPs and the coping strategies employed by individuals with endometriosis. Such research could contribute to a broader understanding of the generalisability of current research’s findings.

5.6.2 Regression models

When input into a regression model including demographic and clinical factors, coping styles, and psychosocial factors, IPs collectively exerted a strong and enduring impact on each outcome variable measured at the follow-up stage. However, when considering the effect of each IP singularly, only perceptions around the clinical elements of the condition predicted HRQoL, pain, and disability at follow-up, including beliefs surrounding the timeline and identity of the condition. Additionally, the predictive effect of singular IPs on mental health outcomes measured one year later (i.e., anxiety, depression, and stress) often disappeared with the inclusion of coping styles, most prominently depressive processing (DP), a coping style associated with rumination and social withdrawal. This implies that the use of maladaptive coping strategies leads to increased psychological distress, an observation that falls in line with previous research on coping in a range of chronic conditions (Kantidakis et al., 2021; Knowles et al., 2017). The impact of maladaptive coping mechanisms on mental health supersedes the effect of any singular IP.

Interestingly, the addition of IPs to each regression model accounted for the highest proportion of the observed variance in each outcome variable. So, whilst combined IPs had the strongest collective impact on all health and wellbeing outcomes, singular IP dimensions did not significantly predict mental health outcomes at the follow-up phase. This is in line with Rochelle & Fidler's (2012) findings that singular IPs were not predictive of mental distress in irritable bowel disease. Therefore, across several conditions, it appears that the combined effects of IPs exert a far more powerful effect on mental health than singular IPs alone.

The presence of a collective effect but absence of singular IP effects on mental health in this context may also reflect the complexity and heterogeneity of endometriosis. For example, a single IP may not be uniformly predictive of mental health outcomes, but combined, a strong effect of IPs may emerge across this diverse population. Some individuals may, for example, experience psychological distress in response to the anticipated consequences of endometriosis, whilst others may experience greater distress in response to the emotional representation of the condition. Therefore, combined IPs incorporate both experiences as a single factor, whereas singular IPs break down this effect, resulting in the significance of these connections becoming lost. Additionally, IPs are not isolated, often interacting and influencing one another (Leventhal et al., 2016). For example, high levels of concern around endometriosis may be linked to perceptions surrounding its consequences, and the culminative effect of these IPs may contribute to mental health outcomes, explaining the presence of a strong combined effect of IPs on each outcome.

Nonetheless, singular IPs, namely identity and timeline, predicted HRQoL, pain, and disability scores recorded at the follow-up stage above and beyond clinical and demographic factors. As perceptions of the symptoms associated with endometriosis and the anticipated timeline associated with the condition worsened, as too did HRQoL, pain, and disability scores. Reflective of the symptoms associated with endometriosis, a heightened sense of identity is likely indicative of more severe symptoms, leading to poorer outcomes. Furthermore, stronger identification with the symptoms of endometriosis may lead to a greater impact on HRQoL, as this may shape the self-concept and influence daily functioning (Carroll et al., 2020). Additionally, expectations about the timeline of endometriosis may impact the individual’s overall wellbeing, pain perception and functioning, contributing to reduced HRQoL and increased disability. Moreover, individuals with more severe symptoms, as indicated by strong identification with several endometriosis-specific symptoms, are potentially more likely to source medical support for their symptoms. In the case of endometriosis, the lack of effective treatment may therefore contribute to poorer HRQoL, increased pain, and higher self-reported disability. This theory is supported by the results of the content analysis derived from the open-ended question presented to participants at the end of the baseline survey. When asked to specifically give details of any factors impacting their wellbeing, several participants drew upon the lack of effective endometriosis treatment options, inadequate understanding of endometriosis, and dismissal in medical settings (see section 5.5.4).

Previous research has focussed on pain as a predictor of wellbeing, however assessing pain as an outcome in the current study reveals greater detail about the nature of the relationship between pain and wellbeing. That pain is predicted by psychosocial variables such as IPs, coping, and social support indicates a cyclical relationship – that pain influences these psychosocial variables, which in turn influence pain perception. This corroborates research suggesting that pain is a cyclical process in endometriosis (Facchin et al., 2015) by positioning pain as both an outcome and a predictor of wellbeing in this population.

Considering the impact of singular demographic variables on outcomes, age exerted a significant impact on endometriosis-specific QoL. Specifically, as age increased, so too did HRQoL. This corroborates research suggesting that increased age mitigates the negative impact of endometriosis on HRQoL (Lövkvist et al., 2016; Soliman et al., 2017). The association between age and HRQoL may be influenced by several factors. Firstly, older individuals may have developed more successful coping mechanisms over time, leading to a more positive impact on HRQoL. Additionally, with age, individuals may have adjusted their expectations in relation to endometriosis treatment and support. Furthermore, over time, individuals may have established stronger social support networks. With increased time in the medical system, participants may have accumulated more health-related knowledge and awareness, allowing them to better manage their condition. However, the current study's finding that coherence is unrelated to any outcome variable suggests that increased health literacy may play little role in the relationship between age and HRQoL in endometriosis.

After accounting for demographics, clinical factors, IPs, and coping styles, social support and self-efficacy did not exert a strong influence on any outcome variable, with the exception of depression. The link between increased social support and low mood is well-established in the literature (Alsubaie et al., 2019), which this finding conforms to. Considering the remaining outcome variables, the strong impact of coping and IPs appears to reduce the influence of self-efficacy and social support. However, due to the order in which the variables were input into the regression model, it is possible that some of the variance in social support and self-efficacy scores was already accounted for by IPs and coping in the regression model, lessening the impact of these variables. For example, some aspects of coping and social support indicate some overlap. To exemplify, the Essen Coping Questionnaire (ECQ, Franke & Jagla, 2016), which was used to measure coping in the current research, enquires about the likelihood of sourcing support through the 'active search for social integration' (ASI) and 'information seeking and exchange of experiences' (ISE) sub-scales. Furthermore, when gauging DP, it measures social withdrawal, whilst the brief social support scale (Kleim et al., 2015), which was used to measure social support within the current study, also considers the extent to which individuals seek out support when experiencing mental distress. Therefore, the impact of social support may have already been largely accounted for within the regression model prior to inputting the social support variable, raising the possibility of tautology and suppression effects.

Similarly, the effect of the emotional representation of endometriosis (i.e., how much endometriosis impacts the individual emotionally) loses significance when coping styles, particularly DP, are included in the regression model. This is particularly evident when considering the measured mental health variables (i.e., anxiety, depression, stress). One interpretation could be that DP mediates the relationship between the emotional representation IP and various mental health outcomes, contributing to this observed effect. This theory is upheld by the finding that DP does indeed influence the relationship between emotional representations and mental distress within the present study. Alternatively, it could be argued that the inclusion of DP diminishes the significance of the emotional representation because they measure similar constructs. However, it's crucial to note that DP assesses how individuals cope with the emotional burden associated with endometriosis, whereas the emotional representation IP gauges the extent of the emotional impact related to endometriosis. Additionally, no evidence of multicollinearity between these variables was found within the current study. This suggests that they likely capture distinct facets of participants' experiences, indicating that DP plays a more profound role in influencing mental health than the emotional representation of endometriosis. Moreover, it hints at the possibility that the emotional representation of endometriosis may drive the utilisation of DP as a coping mechanism.

Taken together, perceptions around clinical elements (i.e., symptomology and anticipated timeline) appear to have the greatest, singular longitudinal impact on HRQoL, pain, and disability, suggesting that the development of effective treatment is likely to have the greatest impact on health and wellbeing outcomes in this population. However, for mental health outcomes, interventions focussed on increasing support and reducing the use of maladaptive coping strategies are likely to decrease psychological distress in this population.

Finally, as IPs appear to be dynamic in this context, the observed changes in IPs between baseline and follow-up (as detailed in Section 5.5.6) might raise concerns about the predictive validity of IPs. However, it is crucial to note that, even with the observed improvements in IPs between the baseline and follow-up phase, the incorporation of baseline IPs into all regression models consistently explained a substantial amount of variance in the follow-up outcomes. Notably, IP dimensions such as illness identity and the anticipated timeline remained robust predictors of outcomes over time. This suggests that, despite the dynamic nature of IPs, the baseline perceptions retained significant predictive power. Consequently, interventions focusing on IP dimensions may prove effective in supporting the long-term wellbeing of individuals with endometriosis.

5.6.3 Coping as a mediator between IPs and outcomes

Coping mediated the relationships between each IP measured at T1, and all outcome variables measured at T2.

DP was the most prominent mediator, partially and fully mediating the relationships between each IP dimension and HRQoL, anxiety, depression, and stress. As the use of DP increased, outcomes worsened. DP includes elements such as social withdrawal and rumination, and as such is an avoidant, maladaptive coping strategy. Therefore, the observation that DP negatively influences the relationship between each IP and wellbeing corroborates a wealth of research demonstrating a link between maladaptive coping strategies and decreased wellbeing (Kantidakis et al., 2021; Knowles et al., 2017; Woodhouse et al., 2017). This finding also upholds endometriosis-specific research, which has generally found the most substantial evidence for a negative impact of maladaptive coping on wellbeing outcomes, compared to a positive effect of proactive, action orientated coping on wellbeing (González-Echevarría et al., 2019; Roomaney & Kagee, 2016).

While DP played a central mediating role in several relationships, acting problem-oriented coping (APC) also emerged as a partial or full mediator in various instances. For example, APC partially or fully mediated the connections between all IPs (except timeline and concern) and depression. Similarly, APC influenced the relationships between all IPs and anxiety (except timeline and identity). APC had a protective effect on wellbeing outcomes, by reducing the impact of detrimental IPs on mental health and HRQoL aspects. However, the mediating effect of DP was consistently stronger than that of APC, reinforcing the notion that maladaptive coping exerts a more significant impact on wellbeing outcomes. Nevertheless, this finding suggests that incorporating action-oriented coping strategies may mitigate some of the negative consequences of IPs on wellbeing. Thus, interventions promoting problem-oriented coping may positively impact the wellbeing of individuals living with endometriosis.

Considering the role of alternate coping mechanisms, trust in medical care (TMC) mediated the relationships between each IP dimension and HRQoL, pain, and disability. Higher TMC related to lower pain and self-reported disability and improved HRQoL. TMC is characterised by following medical advice and trust in medical professionals. Therefore, it is perhaps unsurprising that those with a mistrust of treatment and medical support report a higher degree of pain and disability. However, when considering the scale used to measure this facet of coping (ECQ, Franke & Jagla, 2016), four out of five items relate to confidence and trust in medical treatments and support and it may be argued that, rather than a coping style, this dimension of the ECQ relates to general attitudes towards care. On the other hand, placing trust in medical care may itself be viewed as a way of coping and maintaining some level of control when experiencing a health threat. Further research into the specific types of coping employed by individuals with endometriosis would be beneficial to ascertain whether TMC is applicable as a coping strategy in this context. Understanding the coping strategies employed by individuals with endometriosis has the potential to inform targeted interventions to enhance wellbeing in this population.

Notably, the relationships between several IPs and both HRQoL and disability are negatively influenced by the adoption of ISE. This suggests that individuals who actively seek information and support related to endometriosis may experience higher levels of disability and lower HRQoL. The utilisation of this coping style appears to be related to specific IPs including the anticipated consequences and concern surrounding endometriosis. This mediating effect may be driven by conflicting and/or a lack of available quality resources on endometriosis. For example, an individual perceiving negative consequences related to endometriosis may seek further information, and, finding a lack of available resources, negative perceptions of the consequences of the condition may be exacerbated, leading to lowered QoL and higher perceived disability. Therefore, the creation of quality, informative, and realistic resources including self-help for endometriosis may reduce this effect.

Additionally, ASI exerted no influence on any of the relationships between IPs and the outcome variables. ASI measures the frequency of social outings and efforts to make new acquaintances or friends. However, the effectiveness of social integration as a coping strategy might depend on the quality of social connections established, rather than the quantity of social outings or friendships. Merely engaging in social activities may not be enough to moderate IPs relating to the consequences, emotional representation, and control surrounding endometriosis, for example.

Generally, the results of the mediation analyses performed within the current research uphold the key tenets of the CSM-SR – that IPs are related to the coping strategies adopted by participants, and these coping strategies mediate the relationship between IPs and outcomes. Therefore, interventions targeting both IPs and coping strategies are likely to be beneficial in supporting the QoL and wellbeing of individuals with endometriosis.

5.6.4 Content analysis

Additionally, participants were invited to articulate, in their own words, the key factors influencing their QoL in the context of their endometriosis diagnosis. Most prominently, participants described concern relating to the lack of effective treatment options for endometriosis, frustration surrounding the lack of endometriosis-related support across both societal and healthcare settings, and the routine dismissal and minimisation of their concerns in medical settings which fuelled diagnostic delays. These findings corroborate several research papers which have highlighted the detrimental impact of endometriosis-related healthcare experiences on psychological wellbeing (Cox et al., 2003; Evans et al., 2022; Van Der Zanden et al., 2020).

However, much of the existing research focusses on the adverse wellbeing impacts attributable to healthcare experiences pre-diagnosis, such as diagnostic delay. The findings of the current study indicate that support following diagnosis, including medical and psychological support may be just as important in supporting the wellbeing of individuals experiencing endometriosis. It would be useful to ascertain further information on the type of support and services that might be beneficial for individuals with endometriosis in future research, for example by surveying individuals or through focus groups. It would be particularly beneficial to design research involving both medical professionals and individuals with lived experience, to ascertain the support that is needed and what can feasibly be offered to individuals with endometriosis. Knowledge exchange between these groups might also contribute to restored trust in medical professionals and the services they offer.

Aside from healthcare experiences, participants often disclosed fear around their chances of conceiving. This is in line with several research papers that have observed a link between infertility and mental wellbeing (Hi-Kwan Luk & Yuen Loke, 2016; Dadhwal et al., 2022). However, at present, the extent to which endometriosis impacts on fertility is unknown. For example, some individuals have no problems conceiving, whilst others experience sub-fertility, or a delayed onset in becoming pregnant. Overwhelmingly, and likely because it has traditionally been viewed through the lens of a ‘reproductive condition’, endometriosis has been associated with infertility across medical settings (Heng & Shorey, 2022; Young et al., 2015), and this information is passed onto patients. However, there is no evidence at the time of writing to back up a cause-and-effect relationship between endometriosis and infertility (Stellar et al., 2016). Several participants in the current study had not yet tried to conceive, but indicated fear around their fertility which impacted upon their wellbeing and self-concept. This suggests that it may be fear itself around the consequences of infertility that drives declines in wellbeing, rather than fertility status itself. This notion is supported by the lack of a correlation between fertility status and wellbeing within the exploratory univariate analyses performed for the current study (see section 5.5.7). Fertility status was gauged by ascertaining the length of time between first attempting to conceive and conception (or, for individuals yet to conceive, the length of time they had been trying). Therefore, individuals who had not yet attempted to conceive did not have an opportunity to answer questions around their fertility within the survey. The free-text box, on the other hand, gave them to opportunity to discuss this, where it became clear that fear surrounding fertility underscored wellbeing for many. Therefore, it is essential that endometriosis patients are given realistic and accurate information about their condition and the associated symptoms to lessen such impacts on their wellbeing. The potential link between fertility and endometriosis requires further research attention. Educating medical professionals on the current research surrounding endometriosis and fertility is essential to ensure that up-to-date information is passed on to patients.

The content analysis also revealed the extent to which endometriosis impacts on the life trajectory of diagnosed individuals. Adverse effects on relationships, sex, work, and education were frequently highlighted by participants, both driven by and a driver of adverse wellbeing outcomes. This corroborates a wealth of research which has highlighted reduced functioning associated with endometriosis as a key driver of mental wellbeing and HRQoL (Facchin et al., 2021; Jones et al., 2004; Nnoaham et al., 2011). As functioning is strongly associated with endometriosis symptoms such as pain and disability, identifying effective treatment for endometriosis is likely to yield the strongest positive impact on HRQoL in this context. However, whilst effective treatment is sought, interventions to increase functioning and support in work and educational settings, as well as in the context of sex and relationships, may support the QoL of individuals experiencing endometriosis.

5.6.5 Strengths and limitations

The present research is among the first to link IPs to endometriosis outcomes. By identifying an association between these factors, it confirms the feasibility of targeting IPs in future psychological interventions with a view to supporting HRQoL in this population. Taking a longitudinal approach, the current study measures the predictive validity of a range of psychosocial variables in determining future outcomes. From this, it presents IPs and coping as key targets in future intervention designs. The inclusion of an open-ended question within the survey also allowed for participants to elaborate on their responses, drawing attention to factors that were not measured within the survey but are important to consider in the context of endometriosis-related QoL.

However, the current study must also be viewed in light of its limitations. A potential limitation of the study lies in the use of a health-specific measure of coping, namely the ECQ (Franke & Jagla, 2016), which primarily focuses on coping strategies related to health challenges. Whilst the ECQ is valuable for assessing coping styles in the context of endometriosis, it may overlook more generic coping mechanisms that individuals employ in various aspects of their daily lives, such as managing everyday functioning. A broader examination of coping, utilising a generic coping measure like the Brief COPE (Carver, 1997), might provide a more comprehensive understanding of the adaptive and maladaptive strategies employed by individuals dealing with the multifaceted impacts of endometriosis. Additionally, the authors of the ECQ themselves state that several aspects of the English version of the questionnaire, including the coping styles “trivialisation, wishful thinking and defence” (TWD) and “finding inner stability” lack reliability and validity. For example, TWD appears to measure several different aspects of coping, and therefore this sub-scale was dropped from analysis due to a lack of conformity between items on the scale. Nonetheless, utilising a health-specific measure of coping means that a more nuanced understanding of the coping styles adopted by participants in response to a health condition may emerge.

Furthermore, as has been the case in previous research, the cause dimension of IPs was omitted from analysis. This means that a full exploration of how IP dimensions might impact wellbeing elements cannot be provided. However, as described in chapter 1, there is currently no consensus on the aetiology of endometriosis, so it is likely that individuals with the condition simply do not know the cause, reflected in the lack of responses to this question within the current study. Of those who did respond, there was a lack of heterogeneity in responses, with the vast majority pinpointing genetic or biological explanations for their condition. Therefore, the ‘cause’ IP may have less practical relevance in the context of endometriosis than with alternate conditions, for example COPD where lifestyle factors as well as biological variables may play a causal role and subsequently shape wellbeing outcomes (Weldam et al., 2017).

Additionally, participants were predominantly recruited from social media and support groups. Individuals recruited in this way may: i) have worsened symptomology than those not attending these groups, leading them to source support; or ii) have more well-established support networks and coping strategies to sustain their HRQoL. Therefore, the generalisability of responses from this group may be limited. Thus, future research should endeavour to recruit a range of individuals from different backgrounds, including individuals with mild symptoms, who were relatively absent from the current research.

Finally, there was a lack of diversity in participant demographics, particularly with regards to ethnicity. For example, only 22 of the full sample identified as from Non-White backgrounds. This is problematic because individuals from diverse ethnic backgrounds have traditionally been underrepresented in research, leading to misconceptions about the frequency to which women's health conditions such as endometriosis impact individuals from Non-White ethnic backgrounds. For example, it is often suggested that Black women and individuals assigned female at birth experience endometriosis to a lesser extent than White and Asian women, however research increasingly suggests that this is a misconception borne out of a lack of research and knowledge on endometriosis prevalence across diverse ethnic groups (Bougie et al., 2022). Therefore, researchers must endeavour to establish tools and strategies to engage individuals from diverse ethnic backgrounds, to further our understanding of endometriosis and the generalisability of the currently available literature.

5.6.6 Future research directions

Based on the findings of the current research and in light of the strengths and limitations, several research directions may be considered for future study.

Firstly, given preliminary research suggesting that cognitive behavioural therapy is beneficial for the wellbeing of individuals with endometriosis (Donatti et al., 2022), it would be beneficial to ascertain how such interventions may impact on IPs and other psychosocial factors such as coping styles that appear to be instrumental to wellbeing. Additionally, although not yet extensively trialled in the context of endometriosis, there is growing evidence that acceptance and commitment therapy (ACT) is effective at decreasing mental distress in individuals experiencing chronic illness and pain (e.g., Fayazbakhsh & Mansouri, 2019). Therefore, it would be beneficial to ascertain the effectiveness of ACT in this population in future research, through randomised control trials, for example. This would support the development of future interventions aimed at supporting the HRQoL and wellbeing of individuals experiencing endometriosis.

Secondly, increasing the longitudinal timeframe may support greater understanding of how IPs and coping styles evolve over time in this population. Using a greater number of time points would also allow for statistical techniques such as latent growth curve modelling to be applied to the data to achieve a fuller understanding of the trajectory of psychosocial and outcome variables over time. Increasing the timeframe would be particularly beneficial out-with the challenges posed by COVID-19 induced lockdowns. Additionally, further longitudinal work would be advantageous to ascertain the effectiveness of psychosocial interventions in this population, for example by examining wellbeing prior to and following an intervention aimed at reframing IPs or coping strategies.

Additionally, applying more general measures of coping to data in future research may offer a broader understanding of the coping strategies used by participants not just towards their medical condition but to confront the everyday challenges posed by endometriosis, such as reduced functioning.

Finally, future research should aim to capture broader demographics, particularly with regards to diverse ethnic backgrounds. This would support our understanding of the way in which endometriosis impacts on the lives of individuals experiencing the condition, whilst ascertaining whether the existing literature is generalisable to people of Non-White ethnic backgrounds who have traditionally faced barriers to support and diagnosis.

5.6.6 Conclusion

To conclude, the current study positions IPs and coping mechanisms as central to the wellbeing of individuals experiencing endometriosis. Collectively, IPs contributed to all measured health and wellbeing outcomes, with perceptions of the timeline and symptoms associated with endometriosis predictive of HRQoL, mental wellbeing and clinical outcomes. The more negative the IP, the more adverse the impact on wellbeing. Additionally, IPs predicted the adoption of coping strategies. Generally, more negative IPs were related to the utilisation of maladaptive, avoidant strategies such as DP, and more positive IPs related to the adoption of problem-focussed coping styles. In turn, increased use of DP as a coping strategy predicted worsened mental health outcomes, over and above demographics, clinical factors and IPs. This strategy, characterised by social withdrawal and rumination, also mediated the relationships between all IPs and outcome variables, with the exception of pain and disability. Although APC had a protective impact on some of the relationships between IPs and outcomes, this effect was not as strong or pervasive, indicating that the use of avoidant coping strategies has a more profound impact on the relationships between IPs and outcomes than proactive coping styles. Participants also suggested that negative healthcare experiences were instrumental in shaping their long-term wellbeing. Whilst effective treatment for endometriosis is sought, research should investigate the effectiveness of psychosocial interventions, such as CBT or ACT-based therapy, in reframing IPs and coping strategies and mitigating the impact of endometriosis on wellbeing outcomes such as HRQoL.

5.7 Chapter summary

The current chapter provided an account of the longitudinal, two-wave survey conducted as part of the current thesis. The methods were briefly outlined, following on from a more in-depth outline in chapter 4. Several analytical tests were applied to the acquired data to determine the nature of the relationships between several psychosocial variables, including IPs and coping, and various wellbeing factors, including HRQoL, depression, and pain. The results demonstrated that IPs and coping were predictive of endometriosis-specific outcomes. Additionally, the relationships between IPs and coping were influenced, at least in part, by the coping mechanisms employed by participants. Finally, the discussion contextualised the results, considering the place of the current research in the existing literature, the implications of the present study, and potential future research directions.

The following chapter of the current thesis will outline the qualitative component of the present thesis.

CHAPTER 6

Study 2: A qualitative investigation into the role of illness perceptions and coping in endometriosis-related quality of life[1]

6.1 Abstract

Endometriosis is related to adverse health-related quality of life (HRQoL) and wellbeing outcomes. The way in which endometriosis is perceived by individuals experiencing the condition has not been directly considered, yet illness perceptions (IPs) are predictors of HRQoL in several chronic conditions. The current study aimed to gain an understanding of the IPs held by individuals experiencing endometriosis and their impact on HRQoL. Semi-structured, one-to-one interviews with 30 UK-based participants sought to gain an understanding of participant experiences and perceptions linked to endometriosis. Five themes were constructed through reflexive thematic analysis: i) invalidation of symptoms and disempowerment; ii) a life disrupted; iii) lost and fragmented sense of self; iv) complex emotional responses; and v) navigating life with endometriosis. Largely negative IPs were held by individuals experiencing endometriosis which, along with endometriosis-specific symptoms, fuelled fears for the future and reduced HRQoL. IP-based interventions may support the HRQoL of those experiencing endometriosis whilst effective treatment is sought.

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[1] A paper based on the results of this study has been published:
Moore, C., Cogan, N., & Williams, L. A qualitative investigation into the role of illness perceptions in endometriosis-related quality of life. *Journal of Health Psychology, 28*(12). https://doi.org/10.1177/13591053231183230

6.2 Introduction

The current chapter outlines the qualitative component of the present thesis. First, the study background and aims are described (6.3), followed by a brief outline of the methods adopted for the present research (6.4). Subsequently, the themes identified through reflexive thematic analysis are presented (6.5), before the results are discussed in relation to the existing literature (6.6). Within this section, the limitations and strengths of the current study are presented, along with suggestions for future research in this area. Finally, the chapter is summarised (6.7).

6.3 Study background and aims

As described in chapters 2 and 3, IPs have not yet been comprehensively or directly studied in the context of endometriosis, despite evidence demonstrating that they are linked to QoL and wellbeing in several other health conditions. Research has previously demonstrated that interventions focussed on reframing IPs can support the QoL and mental wellbeing of individuals living with chronic conditions (Keogh et al., 2011; Fischer et al., 2012; Sararoudi et al., 2016). Although not studied directly in endometriosis, qualitative literature provides clues that IPs, especially those around control and the anticipated consequences of endometriosis, may contribute to overall QoL and wellbeing within this population (Jones et al., 2004; Roomaney & Kagee, 2018; Young et al., 2015). Therefore, investigating IPs in relation to endometriosis has the potential to inform psychosocial interventions for individuals living with endometriosis to improve QoL.

The current study aimed to gain an understanding of the ways in which endometriosis is perceived and experienced by people diagnosed with the condition, and how these cognitions affect HRQoL. Additionally, the present research aimed to ascertain the applicability of the pre-defined IP categories in the context of endometriosis. To achieve this, identified themes were compared to the IP dimensions as described in the common-sense model of self-regulation (CSM-SR; Leventhal et al., 2016) to assess whether the illness-related beliefs of people experiencing endometriosis conform to or transcend these categories. A qualitative approach was taken within the current research to allow for a rich, in-depth account of participants’ thoughts, feelings, and experiences.

6.4 Method

This section of the chapter provides a brief outline of the methods used within the current study. For a full overview of the study method, including the methodological approach, the researcher’s own stance and experience, and ethical considerations, see chapter 4 (section 4.5).

6.4.1 Participants

Thirty participants who had previously completed the baseline questionnaire (see chapter 5) and indicated their interest in participating in an interview were recruited. A pragmatic approach to determining the sample size was taken. A sample size of 30 was deemed appropriate to provide an in-depth, reflective account of participants’ experiences. See chapter 4 (section 4.5.3.4) for further details on how the sample size was determined. A sampling matrix prioritising the recruitment of individuals with a range of ethnic backgrounds, ages, employment status’, household incomes, and educational attainment was used to ensure a diverse sample (see chapter 4, section 4.5.3.2).

Participants were given pseudonyms to preserve their anonymity. They were aged between 20 and 55 years (M = 35.6, SD = 9.49). Individuals were eligible to participate if they had been formally diagnosed with endometriosis (e.g., through laparoscopic investigation), were over the age of 18 and resided in the UK or Ireland. Participants had experienced endometriosis symptoms for 4 - 40 years (M = 14.83 years, SD = 9.18), and had been diagnosed for an average of 5 years (SD = 6.97). Eighteen had co-morbid conditions including gastrointestinal, autoimmune and psychological conditions. Further information on participants' demographics and the nature of their endometriosis is presented in chapter 4 (section 4.5.3.5).

6.4.2 Data collection

Data collection occurred between August 2021 and January 2022. Upon receiving ethical approval from the University of Strathclyde's ethics committee, the sampling matrix was used to identify potential participants who had previously indicated their interest in participating in an interview. An information sheet was sent to selected individuals via email (appendix I) and those interested provided written consent to be interviewed. Interviews were semi-structured and facilitated online by the first researcher. Interviews were audio recorded and lasted 42 to 90 minutes (M = 62 minutes). Participants reiterated their consent verbally before the interview commenced. Reflexive notes were taken throughout. Following the interview, participants were debriefed (appendix K) and offered a £20 Amazon e-voucher as compensation for their time.

A topic guide consisting of open-ended questions and prompts was developed (see appendix J). This included broad questions relating to participant's beliefs about their condition and more specific questions informed by the pre-existing IP model. The topic guide was piloted with 2 participants to ensure that questions were relevant and comprehensive. During the interviews, participants were asked to describe the impact of endometriosis on their lives, before answering questions surrounding their perceptions of endometriosis and how they cope with the condition. Topics included the perceived consequences of living with endometriosis, the emotional impact associated with the condition, and perceptions of control over endometriosis.

6.4.3 Analysis

Data was analysed in line with Braun and Clarke's (2006; 2019) guidelines for reflexive thematic analysis (RTA), due to the theoretical flexibility associated with this approach, and its capacity to reduce large quantities of data into comprehensive, accessible themes that provide a coherent, nuanced account of participant experiences (Braun & Clarke, 2012). An inductive approach was first adopted to develop themes out-with a theoretical framework, before a deductive approach was taken to compare the identified themes to pre-established IP dimensions (Leventhal et al., 1997). See chapter 4 (section 4.5.5) for further detail on the analytical process and RTA.

6.5 Themes

Following analysis of the data, five major themes were developed: i) Invalidation of symptoms and disempowerment, with two sub-themes: 1) intuition versus internalised, minimised symptoms, and 2) a fight for answers; ii) A life disrupted; iii) Lost and fragmented sense of self; iv) Complex emotional responses, with two sub-themes: 1) endometriosis as an emotional burden, and 2) emotional strength stemming from endometriosis; and v) Navigating life with endometriosis. Each theme mapped onto multiple pre-existing IP dimensions (see Table 6.1). Themes and sub-themes are presented in further detail below.

Table 6.1

Identified themes and their relation to IPs

Theme	*Illness perception*
Invalidation and disempowerment	• **Consequences**: Perceived impact of endometriosis • **Control**: Powerlessness over impact and treatment • **Timeline**: Perception of endometriosis as enduring • **Identity**: Perception of symptoms associated with endometriosis • **Coherence**: Understanding of endometriosis as progressive, incurable • **Emotional representation**: Emotions associated with endometriosis • **Concern**: Concern around impact, progression, future
A life disrupted	• **Consequences**: Perceived impact of endometriosis • **Control**: Powerlessness over impact and treatment • **Timeline**: Perception of endometriosis as enduring • **Identity**: Perception of symptoms associated with endometriosis • **Coherence**: Understanding of endometriosis as progressive, incurable • **Emotional representation**: Emotions associated with endometriosis • **Concern**: Concern around impact, progression, future
Lost sense of self	• **Consequences**: Perceived impact of endometriosis • **Control**: Powerlessness over impact and treatment • **Emotional representation**: Emotions associated with endometriosis
Complex emotional responses	• **Timeline**: Perception of endometriosis as enduring • **Identity**: Perception of symptoms associated with endometriosis • **Coherence**: Understanding of endometriosis as progressive, incurable • **Emotional representation**: Emotions associated with endometriosis • **Cause**: Unknown cause, “why?” • **Concern**: Concern around impact, progression, future
Navigating life with endometriosis	• **Consequences**: Perceived impact of endometriosis • **Control**: Powerlessness over impact and treatment • **Coherence**: Understanding of endometriosis as progressive, incurable • **Emotional representation**: Emotions associated with endometriosis

6.5.1 Invalidation of experience and disempowerment

When asked to consider the impact of endometriosis on their lives, all participants described the trivialisation of their symptoms and experiences by others, including family members, friends, and healthcare professionals. Participants felt unheard both within medical settings and by those closest to them, and this fuelled a sense of invalidation and disempowerment. Subsequently, participants often disclosed a negative impact on their self-esteem, self-concept, and mental wellbeing:

> “*I was in a really dark place through it and then I really did have, you know, I really did wind up having a lot of depression because you know from so many people telling you, you know, you're lying and there's nothing wrong with you, you know and just pull it together it's just a period*.” [Ash].

There was a sense amongst participants that endometriosis was little understood within both medical and societal settings, resulting in the frequent minimisation and apparent disregard of their symptoms. Upon seeking support for their symptoms, whether at a medical or personal level, many participants received inaccurate information, for example that the pain they were experiencing would subside with time and constitutes a natural part of menstruation. Upon first disclosing their symptoms, endometriosis was rarely considered a viable explanation for participants’ concerns:

> “*My mum and all the doctors thought it was just hormones, PMS or it was put down to things like depression and stuff like that, em, and something that all teenagers just go through a phase where all teenagers are tired*, *so all of this stuff was missed*.” [Emily].

> *"I've met some gynaecologists that were like 'women get period pain, you just have to deal with it'."* [Gemma].

This trivialisation of participant experiences, coupled with an apparent reluctance to investigate endometriosis-related symptoms within medical settings, left participants with a sense of powerlessness. Many felt disbelieved due to the lack of understanding associated with endometriosis and menstruation:

> "*Everyone thought I was making it up. Like, everyone thought I was just dealing-not able to deal with the pain and they were like 'oh it happens, some women get low pain threshold periods, some people get the higher pain threshold periods' – that was literally what I was told for 10 years*." [Iona].

> "*A lot of people just sort of dismiss it as one of those made-up illnesses that doesn't exist. I don't know if that's just because it affects only women, maybe, I don't know*." [Alex].

Participants experienced lengthy diagnostic delays which they attributed to the minimisation and dismissal of their symptoms through two pathways: i) a help-seeking delay, in which participants delayed seeking medical support due to internalised notions that their symptoms were normal; and ii) an apparent reluctance by medical professionals to investigate their symptoms further. There was a sense throughout participant accounts that the minimisation of endometriosis-related symptoms was reflective of the wider treatment of women's health, particularly within medical settings:

> "*Because we are so dismissed, um, like for most women they could easily be diagnosed in their teenage years, if only GPs listened to us and, you*

> *know, um, refer us to a gynaecologist and after that the gynaecologist also listens to us when we're telling them, okay can you please do the scans and stuff. Like if that doesn't, like, if medical field, if they don't change their bias towards women, we're never going to get anywhere near early diagnosis*." [Mary].

Correspondingly, lengthy diagnostic delays were considered by some participants as symptomatic of the pervasive and long-standing taboo surrounding menstruation. Several disclosed an initial reluctance to discuss their menstruation-related experiences with peers and/or medical professionals due to fears around breaking internalised societal norms such as menstrual etiquette, in which menstruation is expected to remain hidden and private (Moffat & Pickering, 2019). When participants did disclose their symptoms, they often described an initial sense of shame and/or embarrassment, and believed that their concerns were not taken seriously due to the nature of their symptoms:

> "*It's frustrating that we're not allowed to talk about it because either it's embarrassing for us or it's embarrassing for other people*." [Charlie].
>
> "*For some reason people think it's almost too taboo to talk about women's ovaries, are you kidding me? It's like come on [laughs] it's the 21st century and we're still having this issue*." [Iona].

Diagnostic delays and the trivialisation and/or dismissal of endometriosis-related symptoms within medical settings prompted anger and frustration in several participants. There was a sense of being "betrayed" [Evelyn] by the institutions in which participants' had placed their trust. Ultimately, participants felt disempowered by their experiences within medical environments:

> "*There are hundreds, thousands of women like me that are being let down by the medical profession because it's just, they just see it as, oh it's just normal period pains, deal with it. Shut up and move on. And that's what, that's what I'm angry about more than anything else*." [Robin].

Consequently, participants learned to suffer in silence rather than to reach out for support, leading to feelings of isolation and loneliness. Many internalised the minimisation of their symptoms, believing that it was their own reaction to the symptoms they were experiencing that was abnormal, rather than the symptoms themselves. Participants often voiced a sense of a "battle" [Mira], not between themselves and endometriosis, but between their own intuition and the invalidation they experienced in a landscape where their symptoms were minimised and dismissed. This battle may be described in two parts: i) an inner battle in which participants wrestled with internalised notions that their pain was not real or exaggerated; and ii) an external fight to be heard, particularly in medical settings, to secure a diagnosis and regain control over their lives.

i) Intuition versus internalised, minimised symptoms

The systematic dismissal and minimisation of participants' symptoms led many to question their knowledge and expertise of their own bodies. Many described internalising the notion that their symptoms were normal and/or exaggerated, leading to a sense that their intuitive concerns were deceptive and inaccurate. Participants often began to view themselves through the eyes of others, leading to a dichotomy between their physical symptoms and their internal voice:

> "*When someone's telling you it's all in your head you start to think 'is it all in my head*?'*"* [Charlie].

Through the internalisation of minimised symptoms, participants frequently voiced a sense that they did not know themselves, that they had lost their sense of self and identity. After repeated instances of their concerns being minimised and/or disregarded, many questioned their intuition and even their own "sanity" [Emily]. For several participants, this led to episodes of confusion and anxiety:

> "*After being told for so long this thing is in your head you actually start to question your sanity, like 'is there actually something mentally wrong with me, is that what's- am I making this up? Do I have this like Munchhausen's disease? Am I just making this up because I need, you know, because it's mentally imprinted in my head*?" [Ash].

The internalisation of symptoms as "imagined" [Charlie] or "exaggerated" [Polly] often led to withdrawal within social and medical settings, heightening feelings of anxiety and isolation. Participants frequently compared themselves to other menstruating individuals who appeared to have no menstruation-related problems, leading often to self-chastisement and frustration:

> "*I was starting to look at other people like my flatmates and how they seemed to live their lives that I was like 'how come I can't seem to function like a normal human being*?'" [Emily].

With no diagnosis or answers for their pain, participants increasingly turned their frustration inwards. At this time in their lives, many described themselves as "weak" [Rachel], "unable to cope" [Reece], and possessing a "low pain threshold" [Alina] compared to other menstruating individuals. Often, their mental health began to deteriorate, with many resigned to never having the answers to explain their symptoms:

> "*Whenever I got refused that* [gynaecology] *referral, that was when my mental health started to take a huge decline because I thought that I wasn't going to get any help.*" [Ash].

Although participants' confidence in their intuition was often called into question, they never lost the sense that something was wrong within their bodies. The strength of this feeling fluctuated, as participants wrestled between their intuition and internalised notions that their pain was characteristic of menstruation:

> "*You feel like something's there, but you keep getting told that nothing's there and then it's this anxiety of, I'm imagining things. I don't know what's real and what's not anymore.*" [Indra].

All participants described a turning point at which their confidence in their intuition and expertise in their bodies grew to eclipse feelings that their symptoms weren't real, or that they were merely "unable to cope" with "normal" menstruation [Reece]. This often occurred after participants sought support from others and/or heard the term 'endometriosis' for the first time, prompting an increase in self-assurance and trust in their inner voice:

> *"There was never a mention of endometriosis until a nurse I worked with who had it said, I think you have endometriosis and you need to go and speak to your GP."* [Iona].

> *"Someone that I had known from childhood was diagnosed* [with endometriosis]*, em, and she had been posting about it. […]. Em, so I'd started to google symptoms and endometriosis had come up. Em, and this girl was posting things about her experience of endometriosis and between the two of them things started to kind of click*." [Casey].

Restored trust in their intuition gave participants the confidence to approach medical professionals and fight for answers:

> *"I went back to the GP and said 'look, something is really bloody wrong'"* [Nathalia].

ii) *A fight for answers*

Participants described a newfound determination to gain explanations for their symptoms after their trust in their instincts was restored. Many voiced a refusal to be "fobbed off" [Jenny] by medical professionals, which was representative of growing assertiveness as participants' trust in their intuition and knowledge of endometriosis developed. Participants were unwilling to give up "fighting" [Abeni] until they received answers for their symptoms:

> "*For so, so long, I had been fighting tooth and nail with medical professionals, with nurses, doctors, anybody in between, just to try and start getting answers*." [Mira].

Many described a long and arduous process to gain answers, with several visits to their doctors to seek appropriate referral. Many participants opted for private healthcare after becoming disillusioned with the NHS and lengthy waiting times:

> "*I think I definitely still would be waiting for a diagnosis if I hadn't pursued* [private healthcare]*.*" [Jenny].

Due to the overlap in symptoms of endometriosis with several other conditions, coupled with a lack of understanding of how endometriosis manifests, many participants were initially misdiagnosed, especially with gastrointestinal conditions. There was a sense that specific symptoms, such as those resembling irritable bowel syndrome, were taken more seriously than symptoms such as pelvic pain. Furthermore, gastrointestinal symptoms were often viewed as a standalone condition by medical professionals rather than a symptom associated with endometriosis, despite widespread reports that these symptoms are often related to endometriosis (Saidi et al., 2020). Several participants were also diagnosed with mental health conditions such as anxiety and depression after disclosing their symptoms. Again, rather than being viewed as a symptom of an overarching condition, this was often treated independently:

> *"I was told when I first went in with the fatigue and everything it was like, oh well you're depressed. I was like, but I don't think I am depressed, but I was given counselling […]. Em, and then they told me I had anxiety and now I would say I don't have anxiety, what was happening was I had a medical condition that I was fighting against and that was making me anxious all the time.*" [Casey].

Importantly, some participants did not place the blame for lengthy diagnostic delays on medical professionals, but upon a lack of research into endometriosis meaning that differentiating endometriosis from other causes of pelvic pain was difficult:

> "*I suppose looking at it from their point of view, I don't know how they are able to, um, make a distinction between someone suffering from heavy and painful periods and someone having endometriosis. There's no kind of blood test or anything*." [Ava].

Most participants described a turning point at which one doctor or medical professional took their symptoms "seriously" [Iona], was knowledgeable in endometriosis and empathetic, and offered them further support and/or investigation. This left participants with a feeling of validation and hope:

> "*That's the first doctor that said it could be endometriosis, um, and, you know, it was a massive relief and I finally felt some validation."* [Alina].

After crossing paths with this healthcare professional, participants often received diagnostic surgery and much needed answers for their symptoms:

> "*Had I not stumbled across [doctor's name], I, I would still be going through multiple operations, um and not be diagnosed.*" [Reece].

Receiving an endometriosis diagnosis led to further validation, relief, and empowerment for many, who had often been searching for answers for many years. However, participants generally had mixed feelings around diagnosis. Receiving a diagnosis, although validating, left participants with "nowhere left to run" [Mira]. Many already had knowledge of endometriosis and its incurable nature, leading to feelings of hopelessness, with the realisation that their condition was long-term and progressive often prompting feelings of anxiety and sadness. Others who had little knowledge of endometriosis prior to diagnosis discovered the lack of treatment for endometriosis, leading to concerns around their future:

> “*So when I got a diagnosis it was like, I felt a bit of relief I think and then I guess the first few days were a bit like, oh this actually really sucks. I think, it was, it was emotional but for a lot of reasons I think* [voice breaking].” [Rowan].

> “*I think personally the diagnosis itself was, it’s, it’s like a double-edged sword, sort of. Um, on the one hand it was great to actually have a name for what I’m going through […]. But at the same time, the more I did research on, on my illness and the more I tried to get actual treatment for it, I realised how limited the research was, um, regarding endometriosis as well as how limited the treatment available was as well.*” [Mary].

As participants’ knowledge of endometriosis grew, many voiced growing fears around the future due to the progressive and incurable nature of the condition. Several expressed sadness stemming from their diagnosis, owing to the potential consequences endometriosis may have on their lives:

> “*I was so shocked because I knew it had no cure, I knew I’d always have it, I knew that it grows basically as it wants. I also felt like I was being weighed down by this terrible knowledge now. And once I knew I can’t unknow it and it was horrible. I think after that week I was diagnosed I started getting really upset. I was upset for like months I want to say*.” [Polly].

6.5.2 A life disrupted

Participants all referred to the multiple and varied life disruptions that were an inevitable consequence of experiencing endometriosis. Many disclosed that endometriosis prevented them from living the life they wanted and felt that their potential in life had not been realised due to the debilitating symptoms they experienced. What constituted participants' potential varied between accounts. Often, potential was defined in terms of career or education goals, although some described their potential in relation to their relationships or fertility. Regardless of this definition, there was a sense of lost time and missed opportunities attributed to endometriosis:

> "*It's* [endometriosis] *taken away my youth and it's taking away from all of the things that I aspire to do and that I could have done and could have achieved*." [Ash].

> "*it's disappointing because I'm kind of wasting life doing not much when I could be doing more or want to do more*." [Indra].

This sense of loss was woven throughout participant accounts, encompassing several life domains including education, work, relationships, and day-to-day functioning. Participants stressed that no aspect of their lives was left untouched by the impact of endometriosis:

> "*It's an everyday thing that impacts on my actual ability to just function in life*." [Morgan].

The language used by participants implied a sense of powerlessness attributed to endometriosis, which manifested itself in participants' life trajectories. Several perceived endometriosis as "controlling" [e.g., Alina] their lives, and saw their life trajectories as dictated by the progression of the condition:

> "*I feel like I'm not in control of my life, this illness is*." [Abeni].

Perceived disruption to life trajectories often prompted a negative emotional response. Participants described sadness and frustration in relation to their circumstances, with some experiencing anxiety and depression attributed to endometriosis-related life disruption(s). Adverse impacts on QoL and mental wellbeing were emphasised by several participants, largely facilitated by functioning detriments triggered by endometriosis (e.g., social functioning, work functioning, day-to-day functioning):

> "*It's actually not the pain that's the worst part of the disease, it's the impact that it has on my life and how it prevents me from doing things that has affected my mental health more than anything.*" [Emily].

This impact on wellbeing was associated with several life domains including work and relationships. Negative mental health outcomes were particularly pertinent for participants experiencing infertility or uncertainty around their fertility. It must be noted that participants differed widely in their thoughts, feelings, and experiences with regards to fertility and parenthood, with several childfree by choice, some actively trying to conceive and others who had successfully conceived. Nonetheless, several participants described feelings of helplessness, powerlessness, and anxiety related to their fertility, particularly when conceiving was difficult or unsuccessful:

> "*I worry will I ever have children, what lies ahead for me?"* [Indra].

> "*I was in complete tears yesterday because it's, it's getting faced with that reality of – I would love a family but I might not be able to have one*." [Mira].

> "*I start getting like upset and like is this going to impact me having children, like I'm 38 and I need, I just want one child, I'm not even greedy I*

> *just want one, do you know what I mean? Like and that then can kind of upset me, thinking is this just going to be or, I think it's more the what ifs. I think you can drive yourself crazy with the what ifs*". [Rachel].

Uncertainty and fears surrounding fertility often led to concerns around the longevity of intimate relationships, and heightened the perceived disruption to participants' relationships:

> "*I was like well what does that mean for my future though? Will I be able to have children? Um, I was in a long-term relationship, and it was like what does this mean for us*?" [Skye].

On the other hand, several participants described delays to their treatment due to a persistent focus on fertility preservation within medical settings. Many felt that their treatment choices were limited due to the focus on endometriosis as a 'reproductive' condition, and that in this process, their wants and needs were side-lined. Furthermore, where participants did not want to have children biologically, several felt that their cases were viewed as less important than those for whom fertility was important. This led to delayed treatment and, consequently, additional disruption to their lives:

> "*If I was a woman who cared about fertility, maybe there's a chance that people would push me through the system faster because I have a goal. Because I, I don't have a goal, I'm being forced into a corner.*" [Polly].

Participants often viewed the focus on fertility preservation as characteristic of the treatment of women's health conditions, in which fertility and childbearing have traditionally been prized above overall health and wellbeing. Participants often felt that their bodily autonomy was taken away, and expressed frustration at delayed treatment and further life disruption:

> "*A woman will go I want to have a hysterectomy. Rather than going okay this woman, she's an adult, she's a consenting adult, she knows what she wants with her life and her body, rather than just going okay here's a safe way of us giving you a hysterectomy, let's prepare you for it, instead it's like oh no maybe some man is going to come into her life and get her pregnant, that's more important than her having autonomy over her own body and I think that's, that's something that I think the medical field really needs to, you know, catch up on in society now*." [Mary].

> "*She was like 'well you and your husband can come in and discuss fertility' and every rebuttal I had to this she'd be like 'well things change. You don't know. Things might change, you might want to have children.'*" [Polly].

Beyond fertility, there was a general sense of fear and apprehension surrounding the future woven throughout participant accounts. Fear was often fuelled by historic disruptions to participants' life trajectories (e.g., in work, relationships), and the incurable nature of endometriosis, leading many to speculate that their symptoms would last forever. Participants demonstrated awareness of the progressive nature of their condition, often driving fears that symptoms might worsen and dictate their future outcomes:

> "*It can grow as it likes, it has no cause that's known, there's no treatment plan, the pain is excruciating and it will never go away. And I think that to me felt like, this thing is going to colonise my life*." [Polly].

However, participant responses were complex and diverse, and as such some did not share the same apprehension towards the future as described above. Several described “taking one day at a time” [Jackie] and focussing on the present to prevent fears surrounding the future from taking hold:

> “*I don’t look too far ahead because this time 6 months ago I was in a completely different place so, you know, I just take every day as it comes and make the most of it*.” [Violet].

> “*It’s better to just think step-by-step, day-by-day, it’s a lot more, em, it’s a lot easier to deal with that way, in my opinion anyway, that’s been my experience*.” [Iona].

Similarly, some participants had found ways to live with the life disruptions associated with endometriosis, for example by seeking employment with flexible working patterns, or keeping diaries of their symptoms and triggers to pre-empt endometriosis flare-ups and prepare for impending symptoms. Several participants had found ways to re-frame their perception of endometriosis, away from something that controlled their life to something they live with and manage as much as possible:

> “*I’ve modified my life so it has the lowest impact it can have and so, um, I’ve given it my best shot. I, I want to overcome it so, or live with it, have it as, rather than have it as an enemy I have it as just a kind of accepted companion* [laughs] *maybe. That’s how I kind of analysed it*.” [Ava].

Clear through each participant’s account was their resolve to regain the control thought lost through endometriosis:

> “*I’m going to be able to live with this, it’s not going to take my life.”* [Sarah].

6.5.3 Lost, fragmented sense of self

Participants generally felt that their identity was moulded and driven by endometriosis. Several described their sense of self as “lost” [Violet], often stating that they felt like a “different person” [Robin] owing to the impact of endometriosis on their lives:

> “*I don’t think I’ll ever be the person I was, I think this* [endometriosis] *has changed me forever*.” [Becky].
>
> “*I feel like if I, if I didn’t suffer with this I would possibly be a different person.*” [Sarah].

Some participants described the heavy emotional burden associated with experiencing a progressive, often debilitating condition. There was a sense that endometriosis slowly eroded participant’s sense of self, that the longer this emotional burden was carried, the more significant the impact on their self-concept:

> “*…having to put up with years of pain and sort of like losing yourself to the disease, you feel like you’re, you feel like you’re not yourself anymore. You’re someone, you’re someone different. You sort of become the illness in a way.*” [Abeni].

This sense of the self as lost to endometriosis was often interlinked with feelings of vulnerability elicited by the symptoms associated with endometriosis. For many, pain and fatigue progressed with the condition, provoking a shift in self-perception. Some defined themselves as increasingly “sick” [Indra], or “unwell” [Alex], and there was a sense amongst many that endometriosis had eroded previously salient aspects of their identity:

> "*I did change and, um, I became a victim. Um, and that wasn't me before, you know, I was always independent, stood on my own two feet and didn't rely on anybody and with, with the pain and everything else I became a different person*." [Robin].

Widespread perceptions of the self as increasingly "unwell" [Alex] along with functioning detriments elicited by endometriosis symptoms prompted shifts in specific aspects of the identity. Several participants relied on walking and mobility aids for their day-to-day functioning, and there was a sense that these aids were a visual representation of their condition, heightening feelings of vulnerability and increasing perceptions of the self as "unwell". Some who relied on walking aids felt that strangers viewed them with "pity" [Mary], prompting a sense of discomfort:

> "*It's the looks I get from other people. And this is random strangers, you know, looking at me different, um, the look of pity in people's eyes that I see it's like, oh god, poor thing sort of a, an issue or, you know, um, they think you're injured because of my age*." [Mary]

However, others viewed their mobility aids more positively, in that they enhanced day-to-day functioning, allowing them to overcome some of the functioning detriments associated with endometriosis:

> "*I have a walking stick which was a revelation, um, I don't always use it but, but having that, you know, it means I can do a little bit more and that's quite nice*." [Casey].

Additionally, femininity and the feminine identity was particularly impacted by endometriosis. Many described themselves as "less of a woman" [Emily; Abeni] due to their endometriosis-related symptoms and the impact of endometriosis on their lives. This sentiment was particularly relevant to specific symptoms such as bloating and dyspareunia which were intrinsically related to participants' body confidence and, subsequently, their identity as a woman:

> "*I'm really bloated so that means I can't wear that nice dress that I want to wear, I can't wear heels* […]*, now I have to go and find something that doesn't dig into my stomach and is more floaty and- you know, like, in terms of like, self-confidence as a woman, that's really taken a big hit*." [Nathalia].

Several participants felt that they could not wear the clothing they enjoyed wearing prior to the progression of their endometriosis. For many, this had an impact on their sense of self:

> "*I was like I can no longer wear heels, that's an issue, um, because I love wearing heels* […]. *When you're in heels you're a lot more elegant when, when it comes to walking*." [Mary].

> "*There's certain clothes I can't wear that I used to a couple of years ago, a lot of it is comfortable clothing now*." [Jaime].

Furthermore, sexual identity was impacted by endometriosis and was intrinsically linked to femininity, in that specific symptoms (e.g., dyspareunia, fatigue, bloating) eroded participant's sexual drive which then dismantled perceptions of femininity. This sense of diminished femininity then further impacted sexual drive:

> "*I just physically can't* [have sex]. *I don't feel feminine, I don't feel sexy because I'm in pain.*" [Nathalia].

Reduced sexual functioning led to a shift in the self-concept for several participants, particularly when sex had been an important element of their identity prior to the progression of their condition:

> "*I think a lot of my identity in my 20s like, I really enjoyed sex.* […] *I was very kind of carefree and enjoyed being sporadic and I can't do that now.*" [Casey].

Participants addressed reduced sexual functioning in several ways, including "putting on a performance for male partners" [Emily], ending romantic relationships, and avoiding sexual activity. Several described feelings of guilt and shame surrounding sex, largely due to the perceived impact on their sexual partners:

> "*We haven't done anything for like a year, maybe more now. And I feel so guilty. I deal with that guilt every day.*" [Morgan].

Contrarily, several participants described positive steps they had taken to regain their sexual identity, including sexual experimentation, and moving away from traditional definitions of sex:

> *"We haven't had penetration in our sex life and it hasn't impacted our intimacy* […]*. Em, we can both experience pleasure that doesn't involve me being in agony and crying because that isn't fun for anyone. Re-framing that definition* [of sex] *has helped me to feel better about myself as a woman."* [Emily].

As demonstrated by this extract, restructuring pervasive and negative perceptions around the destructive nature of endometriosis led to improvements in self-esteem, allowing this participant to reconnect with their feminine identity.

Importantly, not everyone who experiences endometriosis identifies as feminine or female. One non-binary participant described the impact of living with endometriosis on their own self-perception. Living with symptoms such as menstrual bleeding and chronic pelvic pain activated a sense of gender dysphoria in them, and left them feeling "confused", "isolated" and with a fragmented sense of their own gender identity:

> "[diagnosis] *didn't help with the old gender identity because they're very much, this is a woman's disease, this is a woman's illness. This is a thing that happens to women. And I'm just over here like, oh no*." [Morgan].

This participant often felt excluded from support groups and invalidated in their own experiences due to the gendered nature of endometriosis, in which individuals experiencing the condition are often assumed to identify as cisgender women within both medical and support settings. This, in turn, adversely impacted their mental wellbeing:

> "*There are trans people, there are non-binary people. It, like we exist but it really doesn't feel like we exist because it's so heavily gendered and that really, that doesn't help with the mental health side of things*." [Morgan].

This participant discovered a support group that disallowed gendered language and championed the inclusion of all with endometriosis, regardless of their gender identity. This had a marked impact on their wellbeing, lifting some of the isolation they felt when sourcing support from other avenues:

> "*I moderate on a Facebook group and they, they are really good. They actually have it in their rules about inclusivity, please use, you know, um, inclusive language and that's nice*." [Morgan].

Correspondingly, shifts in the self-concept were not only linked to endometriosis symptomology, but the broader treatment of endometriosis within societal and medical settings. Theme 1 describes the impact on the self-concept derived from the internalisation of minimised symptoms and a “fight” for answers as described by several participants. Participants often felt invalidated in their experiences, and this sense of invalidation often remained even after diagnosis. Many expressed a sense that others did not appear to grasp the seriousness of their condition:

> “*The last employer who I worked for would have absolutely laughed me out of the office for suggesting that, um, I need any kind of time or support for essentially women’s problems, em, which is what they would have classified it as.*” [Casey].

Consequently, several participants felt that defining endometriosis as a disability would offer them further protection and validation in such scenarios. Some felt that defining themselves as disabled was empowering, demonstrating to others the seriousness of their condition, potentially leading to improvements in their confidence:

> “*Defining myself as someone who has a dynamic disability has helped a lot in my identity and self-esteem as well, and it’s helped me feel a bit more accepting of myself, em, and my situation and feel a bit more actually confident within myself, em, being a disabled person*.” [Emily].

Contrarily, others felt that defining endometriosis as a disability would have a negative impact on their self-concept, in that it would disempower them and allow endometriosis to define them:

> "*They've mentioned that there is a possibility I think in the UK maybe to classify it as a disability and I got upset and really angry. […] I don't know, would we be comfortable classifying this as a disability because we don't want this to overrule our lives. We are trying to live a normal life as much as possible. I think as soon as you box it in there, you're putting us in a special category and, that for me, it just didn't feel right or sit right*." [Jaime].

Correspondingly, despite the wide-reaching impact of endometriosis on the sense of self, there was a general determination amongst participants not to allow endometriosis to completely seize their identity:

> "*It doesn't define me, this is just something that I deal with and I cope with*." [Sarah].

Additionally, some reflected on the positive ways in which endometriosis had shaped their identity, specifically highlighting patience, understanding, resilience and strength:

> "*…it's only recently that I've looked back on everything and thought you know what, I am strong, I'll push for things and I'm brave and I'll talk about things and I'm not shy about it and, um, you know, I think that's sort of changed my identity*." [Alina].

> "*It has taught me a lot of patience*." [Jessie].

> "*I more identify myself as quite understanding now because, you know, even before I'd say I've always been an empathetic person but because I've been from high to low and, you know, everywhere in between, I sort of, I identify as more understanding.*" [Alina].

6.5.4 Complexity of emotional response

Participants' endometriosis-related experiences prompted several emotions. Emotions varied widely but can be separated into two categories: i) endometriosis as an emotional burden; ii) endometriosis as a facilitator of emotional strength. Participants generally described emotions in each of these categories, highlighting the complexity of their feelings surrounding endometriosis.

i) Endometriosis as an emotional burden

Frustration was the most prominent emotion described in relation to participants' experiences of endometriosis. Feelings of frustration often stemmed from knowledge of the incurable and progressive nature of endometriosis, and the lack of effective treatment. The unknown cause of endometriosis also gave rise to such feelings:

> "*How are there people that don't end up suffering? Obviously you wouldn't wish it on anyone but it's just that understanding of why certain people get it and why other people don't and it makes you feel frustrated*" [Jenny].

Widespread misunderstanding of endometriosis, diagnostic delays, and the minimisation of participant experiences in medical settings as described in theme 1 was also a common source of frustration amongst participants:

> "*It's been frustrating that no-one would take me seriously, frustrating that lead times on appointments were too long, frustrating that, you know, it's*

> *something we've known about for hundreds of years and yet we still don't know anything about it."* [Becky].

Frustration pre-empted feelings of anger for many participants. Anger was often intertwined with the perceived negative impact of endometriosis on the life trajectory and identity, and was linked with feelings of powerlessness:

> "*I am raging inside that I've got to be kind of forced into a position of being weak and not being able to do what I want to do*." [Reece].

> "*I definitely feel angry at the fact that I've got this and how much it has impacted my life and I think there's things, situations and things I could have done more in, or I could have done better in, or my relationships I could have done better if this wasn't holding me back*." [Sarah].

As with frustration, anger was also directed at the misunderstanding and lack of treatment available for those experiencing endometriosis, as well as lengthy diagnostic delays within medical settings:

> "*The first thing that came to mind probably was anger, but I'm not angry at the condition or how I feel, I think I'm probably angry at healthcare professionals that didn't help me when I think they knew that they should*." [Rowan].

Feelings of sadness and hopelessness were also described by several participants. As above, sadness tended to revolve around a sense of powerlessness over the condition. Participants often voiced a sense of being "attacked" [Ava] by their own body, leading to sadness and hopelessness:

> "*Sometimes I'm like I can't believe my body is betraying me, it's like really just rubbish, why does, you know, so that's quite, I would say, a little bit upsetting* [crying]." [Evelyn].

> "*It's pretty depressing but, you know, it's hopeless in terms of I can't fight through anymore. Usually my motto, my mantra has been like, just get your head down and just carry this enormous load and I just can't do it anymore*." [Reece].

As exemplified by the above quotes, sadness was often linked to perceptions of control surrounding endometriosis. Many described feeling powerless against endometriosis, and voiced a lack of hope that treatment will improve their circumstances:

> "*I think it's quite sad. It, it, it feels quite sad and it's, that it's taken so long and even after all these years it's still not something that I have a handle on or can properly control and it's still quite up in the air. It can't be helped because there's not better healthcare for it either*." [Skye].

Guilt was another prominent emotion throughout participant accounts. Guilt tended to surround the impact of endometriosis on relationships, for example, being physically unable to engage in sexual activity with intimate partners or rejecting social invitations due to endometriosis-related symptoms. Participants with daughters also often shared a sense of guilt and dread at the prospect of their children inheriting the condition:

> "*What kills me is I've just had a baby, and when I found out it was a girl it was definitely in my head that this is something that I'm now going to pass*

> *on to her and she's now going to have to live with this and that part made me upset*." [Sarah].

One participant described the emotional impact of their daughter receiving a diagnosis of endometriosis:

> "*Unfortunately, about two and a half years ago, my older daughter got diagnosed with endometriosis. Em, and the guilt, the guilt was unreal. For about 6 months, the guilt, my God, I was devastated. I was crying and I kept blaming myself for it. I kept thinking, well if I didn't have this she wouldn't have it*." [Abeni].

Furthermore, participants often described feelings of loneliness, prompted by a sense that their experiences were misunderstood by others due to a widespread lack of understanding and education surrounding endometriosis:

> "*I have went for the better part of about 13 years going no-one else experiences what I experience. Having no one else that understands it is very, very isolating*." [Mira].

> "*There's no-one that relates, that can relate to you. So it's highly isolating. There's no-one to truly talk to that will actually understand what you are going through. Like, like I said before, people think that they understand but they never truly will unless they actually suffer from it*." [Mary].

For some, the emotional pain they experienced due to endometriosis progressed into longer-term mental health concerns. Many described enduring long periods of low mood and symptoms of depression:

> “*It [endometriosis] affected my mental health big time. I woke up in the morning and just felt like there was this black cloud above my head and I didn’t want to get up, I just wanted to hide away.*” [Abeni].
>
> “*It’s like a constant black cloud. Um, it just always hangs over me*.” [Nathalia].

ii) Emotional strength stemming from endometriosis

Although the emotions described by participants in relation to endometriosis were predominantly negative, some participants described finding emotional strength through their experiences of endometriosis. This strength was often forged through learning about endometriosis, and establishing coping mechanisms to mitigate the mental health impact of the condition:

> “*I'm stronger and I know more about it and I've got more confidence in myself.*” [Ash].
>
> “*I think it’s had to make me a stronger person because I’ve just had to deal with it, it’s just something that, that’s part of my life*.” [Sarah].

The notion of “dealing with” endometriosis implies a sense of control over the condition, indicating that emotional strength may be derived from challenging the feelings of powerlessness that are so often linked to endometriosis.

When asked to describe the emotional impact of endometriosis, one participant highlighted an increase in resilience derived from their endometriosis experiences:

> "*I like to think that I was probably quite a resilient person but I think my resilience has definitely been developed by having it and having to deal with it and what it throws at you*." [Ava].

Another participant highlighted increased patience and an improvement in their own self-worth owing to the resilience they developed through experiencing endometriosis:

> "*It [endometriosis] has taught me a lot of patience. I like myself more now. So, that's a good thing*." [Jessie].

One participant described endometriosis as giving them a sense of "pride" [Casey]. Positive feelings and emotions were often forged by resilience and an increase in self-efficacy to continue to live a fulfilling life with endometriosis:

> "*There's some, there's some actual joy when I'm, you know, I'm at the point now where I was, you know, I was low, I was not able to do things I wanted to do and at the moment I can so there's like a real relief in that*." [Alina].

Overall, the emotional responses arising from living with endometriosis were as complex as the condition itself. Participants stressed that their emotions towards endometriosis were dynamic and changeable:

> "*Emotionally, you go through a lot of different feelings about it and towards it*." [Jenny].

6.5.5 Navigating life with endometriosis

Despite the multiple and varied ways in which endometriosis impacted their lives, participants voiced a clear determination to live a fulfilling life with endometriosis. A will to reclaim control from endometriosis was often described, particularly around the life trajectory and identity. Although it was recognised that some aspects of endometriosis could not be predicted or controlled, such as symptom progression and treatment effectiveness, disentangling these factors from the aspects of living with endometriosis that may be controlled was often helpful in navigating life with endometriosis:

> "*I can't control my body. I can't control my pain. And I can't control what's going on around me. The only thing I can do is control the way I deal with it and the way I live with it.*" [Iona].

Participants employed several coping strategies to allow them to navigate life with endometriosis. Many of these strategies were pro-active, such as seeking support and setting boundaries, whilst others were avoidant, including distraction and ignoring symptom triggers. Developing coping strategies was pivotal to the wellbeing of participants, particularly in the context of experiencing an incurable and progressive condition:

> "*I now have a coping style. I think for a long time I was just not coping, and not even knowing that I wasn't coping.*" [Casey].

Distraction was the most prominent coping strategy employed by participants. Participants distracted themselves from their symptoms in several ways, including watching television, listening to music, reading, drawing, sleeping, light exercise and working. Distraction was a means of quieting the mind and directing thoughts away from the symptoms and the negative emotions associated with experiencing endometriosis:

> "*I'm quite good at, at self-directing myself to something else, em, where I, I, I class it as 'busy work' so it keeps my brain busy so I, I don't think about things that annoy me or stress me out or, things like that*." [Iona].
>
> "*I don't give myself much time to think about it.* […]*. This is something, um, it may or may not get better so there's no point in me sitting and wallowing at home,* […]*, this is a part of my life and I need to make sure I know how to manage it and deal with it because the option to sit at home and just think about, um, oh my god, you know, the pain, the ovary, the sadness, that's not an option for me because what kind of life is that?*" [Evelyn].

For some, distraction was a means of supporting their mental health and keeping their mind focussed to prevent negative thoughts and emotions materialising:

> "*Heat, electric blankets, distraction straight away. I have to be distracted. I have to be actively distracting myself all the time, um, because of the depression that is made worse by endometriosis*" [Jessie].

Whilst some forms of distraction, particularly those involving relaxation, self-care, and creativity, had a protective effect on participants' mental health, several participants "soldiered on" [Indra] through endometriosis symptoms by continuing to live life as normal and ignoring their symptoms. Carrying on and blocking out symptoms did have a positive impact for some participants, in which they emphasised not allowing endometriosis to "beat" them [e.g., Sarah] by continuing to live as “normal” [Jaime] a life as possible. However, several participants described a fine line between carrying on as normal and disconnecting from their bodies, leading to worsened endometriosis symptoms and adverse mental health consequences:

> “*I know that I just need to, em, get on with it. And I think that’s what always my attitude has been, it’s a case of, this is where I’m at, this is what I need to do. Just get on with it. Em, and that’s probably why I crumbled in the summer*.” [Riley].

> “*Rather than be empathetic with myself, I’ve had to push through, I’ve had to turn off all of those emotions of needing rest or needing time or actually, I’m in incredible pain, and just ignore it. And that’s the sad part to me like, actually, you know, that was really a struggle. And I'm so sorry that I had to go through that*.” [Reece].

Another prominent coping strategy used by participants to navigate life with endometriosis was support seeking. All participants drew on some kind of support to mitigate the impact of endometriosis on their lives, whether from friends, family, medical professionals, or online support groups. Support provided a shield against the negative mental health impact of endometriosis, lifting the isolation many participants experienced due to their diagnosis:

> “*It almost, it was almost like I had to open up or, or, almost suffer alone*.” [Iona].

> “*If I didn’t have the support, you know, I’d just- I would crumble*.” [Nathalia].

Many participants described an initial reluctance to source support. Several initially saw support seeking as relinquishing their independence, leading to a delay in reaching out, adverse wellbeing impacts, and increased isolation:

> "*It's hard to seek support because I've never been that person who says I need help, I've always dealt with things myself, I've never really shared with anyone saying 'oh I need help with this can you help me' or- my first was always do it myself. And it was so hard to realise that I couldn't do this by myself, I needed others.*" [Iona].

Others saw their condition as a "burden" [Mira] which they did not wish to place on others. This prevented them from reaching out for support:

> "*I would try and not make people that I care about worry. So I might not actually want to share sometimes because I don't want them to be concerned and I don't want them to be thinking about it. I'm not okay but you don't want to worry people.*" [Alina].

For many, there was a turning point at which the emotional burden of endometriosis became too heavy to carry alone, leading to support seeking. Many joined established support groups, either online or by attending face-to-face groups to discuss their experiences. Participants often experienced a sense of community for the first time upon joining these groups, built on shared understanding and empathy. There was a sense of relief amongst many participants upon finding a place to vent their frustration without guilt or expectation. Participants highlighted the importance of shared understanding and experiences, and for many these groups represented the first time participants had felt understood:

> “*It’s the validation from it as well, unlike where I’ve had all the experiences with the doctors and getting made to feel that I’m absolutely nuts or I’m making it up and it’s like from them* [support group]*, ‘yea I get that pretty regularly, you’re not the only one that’s experiencing it, this is how I deal with it’. And you even get suggestions on coping mechanisms and stuff and it’s fricking fantastic. Honestly, I don’t know what I would have done without that group this year. It’s unbelievable the sense of community they’ve managed to create.*” [Mira].

> “*I couldn’t cope without that support group, they’re amazing. They’re an amazing bunch of girls. And you know what makes them more amazing is that they’re going through this too. Em, but they’re always there, they’re always there to talk to, they’re always there to listen, and all the other girls on that group.*” [Abeni].

Contrarily, some participants, especially those who were active in online spaces such as support forums and groups, described “taking a step back” [Violet] from these spaces to protect their mental health. Many left groups or spent less time interacting in support spaces as they gained means of coping with their condition. Several found the focus on endometriosis detrimental to their own wellbeing:

> “*It’s not, it’s not uplifting, you know, and obviously I do feel really sorry for people, I can relate to people but, I don’t know, personally for me a lot of the time I don’t feel that it’s helpful. It just doesn’t feel constructive, like, it’s not really doing anything for me, personally.*” [Rowan].

> “*I find reading people who are having really negative experiences and post like really negative things about it, I just find that quite difficult. I just find*

> *for me that doesn't help. Um, it doesn't help your mood and if you're sore when you read it, it just impacts, it's like hmm this is never going to get any better, it's awful sort of thing*." [Skye].

Most participants emphasised the importance of finding a balance between using support groups and taking time away to focus on themselves. Overall, although support spaces were viewed as a useful and supportive environment where individuals felt heard and less alone, the majority of participants felt that taking breaks from these environments was important for their mental health:

> "*I sometimes have to take breaks because, em, we need to distract ourselves from this whole, whole world, em, and sometimes I find that if I'm in the* [online] *community too much then I can stay in the pain, em, and it can bring up a lot of stuff for me emotionally as well. But it's definitely gave me a purpose to the pain, helping other people. And its other people being so open about endometriosis, em, that helped me. I would feel 10 times more alone and confused, em, if I didn't have the online community I think. It's really, really helped me a lot*." [Emily].

Additional coping strategies employed by participants included setting boundaries and limits as they became more confident to prioritise their own needs, whether at work, in social situations or relationships. Participants also used self-medication. Aside from over-the-counter painkillers, cannabis and alcohol were used most prominently. Although it did not erase the pain, taking cannabis seemed to ease endometriosis-related symptoms for some participants:

> "*I'd rather be kind of high on weed or a joint than that horrible sicky feeling that the opiates give me, and I still have- you know, neither of them get*

rid of the pain, um, but I, I prefer my way because otherwise I just feel disgusting." [Nathalia].

However, alcohol ultimately exacerbated the adverse mental health impacts of endometriosis:

> "*Something I did do for years was I would use alcohol to, to get through the pain as well. Like, I didn't want this pain to stop me from living my life and so I was just drunk all, constantly like if I wasn't out with my friends I would drink in the house like either alone or with my mum just like watching the TV because it masked and helped me kind of deal with the pain. I used alcohol to cope with the pain in really, really unhealthy ways.*" [Emily].

Additionally, benefit finding was common amongst participants, indicating a determination to mitigate the negative emotional impact associated with endometriosis and to live a full life with the condition. Participants often derived empowerment and strength by using their experiences to advocate for others, which gave value and meaning to their experiences. Many emphasised the importance that their suffering was not for nothing:

> "*I think being able to talk to other people now, to do things like talking to you and talking to my friends about how to self-advocate or, you know, to kind of support them, em, with it and seeing the usefulness in what I went through. I remember talking to my friends about it and being like, it's just bleak, I can't see the point in any of it. Whereas now, I can see the value in what I went through.*" [Casey].

> "*It's almost like having a little piece of wisdom that you get from unfortunate circumstances.*" [Alina].

> "*I've done a lot of work like helping other people which has gave me a bit of like purpose and again something good that's come out of it where at least I've been able to help other people whether it's to give advice and support or just to listen and tell them 'I understand what you're going through'*." [Emily].

Similarly, a sizeable minority of participants described arriving at a point of acceptance in their condition. For many, this sense of acceptance in their condition grew over time, as they found ways to cope with the unpredictability and frustration associated with endometriosis. Arriving at a point of acceptance supported the mental health and wellbeing of participants by reducing apprehension around the future and adverse mental health outcomes:

> "*I think that's an acceptance thing. Like, if I accept that this might be as good as it gets, um, and, and, know that even if it gets worse, I know better how to cope with it than I ever did before so it's never going to be as scary and isolating and painful, like the pain is never going to be as overwhelming*." [Casey].

Importantly, acceptance is not linear, and this was reflected in participant accounts. One participant described the dynamic and changing nature of acceptance, likening this to the five stages of grief:

"*It is hard, it is very hard to accept and there is a lot of grief that comes with that and the final stage of grief is the acceptance, I'm hoping I get there eventually but I think it's not linear. There's some days where I can accept it and feel okay about it, and just accept that this is where I'm at in my life and this is the hand that's been dealt, just try and focus on getting through each day and get the treatment that*

I’ve been offered and just hope that it helps. But then there’s days where I’m like, I feel really angry and I feel like devastated and I’m like depressed and all that, like it’s, it’s not linear the grief. It can come and go in all these different stages.” [Emily].

Of those who did not reach a point of acceptance, many described moments of hope that their lives did not belong to endometriosis, and that they could live a fulfilling life with the condition. Hope gave participants the will to continue, even on their bad days:

“*…hope is one of those things that keeps a lot of people going, you know if you have hope you can kind of, you can carry on*.” [Becky].

6.6 Discussion

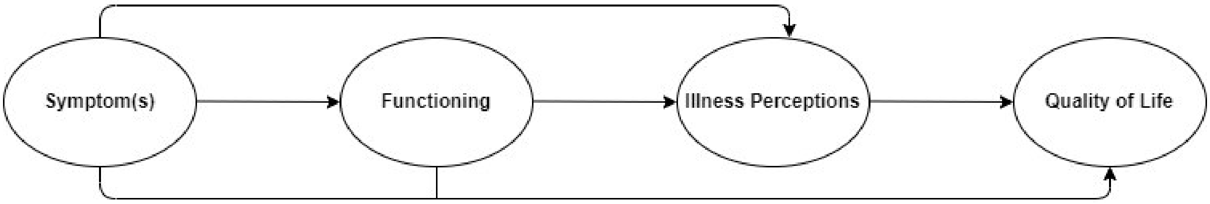
The current study is the first to qualitatively explore endometriosis-related IPs and their relation to HRQoL amongst individuals experiencing endometriosis. An inductive and deductive approach to analysis allowed for IPs to be considered both organically and within a theoretical framework.

6.6.1 General discussion

Broadly, the findings reflect previous research suggesting that endometriosis has a detrimental impact on the HRQoL and wellbeing of those experiencing the condition (Wang et al., 2021). There were, however, disparities within participant accounts regarding the extent to which endometriosis impacted aspects of HRQoL, with some recounting a pervasive, debilitating effect on their lives, and others describing a more manageable, fluctuating impact. This nuance in participant experience is likely associated with discrepancies in endometriosis symptomology. Previous literature has highlighted vast disparities in the way in which endometriosis symptoms manifest and are experienced by individuals living with the condition, even amongst those with identical classifications of endometriosis stage and severity (Vercellini et al., 2007). Similarly, there are differences in treatment effectiveness between individuals (Becker et al., 2017) which may be reflected in participant accounts of their HRQoL. Symptom severity has a direct impact on HRQoL (Forquet et al., 2011; Soliman et al., 2017) and pre-empts functioning detriments which are further associated with adverse QoL outcomes (Roomaney & Kagee, 2016). Although the findings of the current study conform to the notion that endometriosis symptomology is inherently and irreversibly linked to HRQoL, they also add to the existing literature by highlighting additional mechanisms by which endometriosis may impact HRQoL and wellbeing, specifically by moulding IPs which, within this participant group, were linked to salient dimensions of QoL such as the life trajectory, identity, and wellbeing. IPs were shaped directly by endometriosis symptomology and indirectly through functioning detriments (see figure 6.1).

Figure 6.1

Relationship between symptoms, functioning, illness perceptions and QoL as described by participants



Each inductively identified theme mapped on to multiple pre-defined IPs (see table 6.1). Research has already highlighted the detrimental impact of the minimisation of patient experiences within both medical environments and social settings on patient wellbeing (Mikesell & Bontempo, 2022). Individuals with endometriosis often feel unheard upon disclosing their symptoms, leading to decreased confidence and adverse wellbeing outcomes (Evans et al., 2021; Mikesell & Bontempo, 2022). Theme 1 captures these effects. Participants' early experiences in medical settings moulded their expectations around their future care and treatment for endometriosis, shaping the perceived consequences of experiencing the condition and participants' expectations of treatment control. There was a clear emotional response derived from feeling disbelieved and the minimisation of endometriosis-related symptoms, with many participants experiencing low mood, frustration, and anxiety as a direct consequence of their experiences following symptom disclosure. This corresponds with research suggesting that negative experiences within medical environments adversely affects mental wellbeing in people diagnosed with endometriosis (Pettersson & Berterö, 2020; Young et al., 2019). A strong sense of powerlessness was also voiced by participants, mapping onto the control dimension of the pre-existing IP model and corroborating previous qualitative literature indicating that people experiencing endometriosis have low perceptions of control over their condition and treatment (Denny, 2009; Jones et al., 2004). Additionally, participants' growing knowledge and coherence of endometriosis deepened fears over the future and the anticipated consequences of endometriosis.

The way in which participants were treated following symptom disclosure, particularly within medical settings, had a ripple effect. Firstly, a lack of understanding led to dismissal and/or the minimisation of symptoms, which increased diagnostic delays. This then impacted the life trajectory. There was a sense that, in the absence of a diagnosis, participants were in a state of limbo.

Without adequate treatment or a name for their symptoms, participants often felt unable to live life in the way that they wanted, for example by progressing in their careers or starting a family, mapping onto the ‘consequences’ dimension of the IP framework. Participants’ self-concept was clearly impacted due to the minimisation and, often, dismissal of their symptoms. Many began to question their expertise in their own bodies, their perception of themselves, and their mental stability leading them to query how well they knew themselves. This illustrates the diminishing sense of control experienced by participants. The minimisation of participants’ concerns surrounding the pelvic pain they were experiencing implies an underlying belief that menstruation is expected to be painful, and therefore pelvic pain is viewed as an acceptable pain to be endured by people who menstruate. The apparent acceptability of this pain may be reflective of the notion that conceiving children has been, at least historically, considered more important than the comfort of the individual, due to the significance placed upon reproduction within both societal and healthcare settings (Purdy, 2006). Correspondingly, many participants voiced a sense that preserving their reproductive function (e.g., by keeping the reproductive organs intact) was prized above their wants and needs within healthcare settings, even when they were adamant that they did not want any or more children. This further diminished perceptions of control surrounding endometriosis. Participants’ descriptions of the prioritisation of reproductive function over physical and mental wellbeing may reveal underlying biases which feed into the relative dearth of research and treatment associated with not only endometriosis but a plethora of women’s health conditions which are little understood, including polycystic ovary syndrome and adenomyosis (Hillman et al., 2019; Vannucini & Petraglia, 2019). There is vast sociological discussion on such biases which may underpin the lack of treatment and research on women’s health conditions (e.g., Dwass, 2019) which feeds into this idea, although a full discussion is beyond the scope of this thesis.

Given that societal misunderstanding and diagnostic delay led to negative IPs and mental wellbeing outcomes for participants, it is reasonable to suggest that increased understanding and support, particularly within medical settings, may lead to more positive perceptions around care and treatment, potentially leading to increased wellbeing and HRQoL for those experiencing endometriosis. Increasing awareness and understanding of endometriosis is therefore pivotal. Based on the accounts of participants, understanding may be facilitated in two ways:

1. Educational programmes in schools. Menstrual education may be helpful in breaking down long-standing taboos by increasing societal awareness of periods and related conditions such as endometriosis. In New Zealand, an educational programme on pelvic pain and endometriosis delivered in schools led individuals with symptoms of endometriosis to seek support earlier, and increased awareness of endometriosis amongst adolescents (Bush et al., 2017). Although endometriosis and menstrual wellbeing is now to be taught in schools in England (Endometriosis UK, 2022), Scotland has not yet committed to menstrual wellbeing education. Future research could investigate how and when to implement such interventions to maximise the positive impact, and the effect of these interventions on endometriosis awareness and help-seeking in a cohort of Scottish students.
2. Mandatory training on the signs and symptoms of endometriosis for GPs and doctors who are often the first port-of-call for individuals presenting with symptoms of endometriosis. Increasing awareness of the warning

> signs of endometriosis is likely to result in more timely recognition of endometriosis-related symptoms, earlier diagnosis, and a reduced impact on the life trajectories of individuals experiencing endometriosis. It is reasonable to suggest that more positive experiences within medical environments may lead to more positive IPs, particularly relating to control and the consequences of experiencing endometriosis. However, current NICE guidelines still recommend the treatment of suspected endometriosis with hormonal treatments (e.g., the contraceptive pill, intra-uterine devices) prior to investigative surgery, which is likely to influence diagnostic delays as endometriosis can only be diagnosed through surgical investigation or, occasionally, through scans. Therefore, the impact of specialist medical training programmes on endometriosis waiting times should be investigated prior to implementation.

The pervasive, negative impact of endometriosis on life domains such as relationships, work and education, and sex and fertility is well detailed in existing literature (Della Courte et al., 2020; Halici et al, 2023; Missmer et al., 2021). Theme 2 encapsulates these effects, demonstrating the wide-ranging negative anticipated and actual consequences of endometriosis on participants’ life trajectories. Participants often highlighted specific symptoms such as pain and fatigue as the cause of disruption to their expected life trajectories, indicating a lack of control over endometriosis and the subsequent impact on their lives. This is perhaps unsurprising, given the incurability of endometriosis and research demonstrating that treatment is ineffective for many (Nirgianakis et al., 2020). Indeed, participants demonstrated a strong awareness and knowledge of their condition, including the incurable nature of endometriosis and the potential progression of symptomology, and this was instrumental in cultivating feelings of powerlessness. Furthermore, there was a widespread belief that endometriosis symptoms would persist throughout participants’ lifespan. Perceptions of the enduring timeline of endometriosis were linked to fears associated with the consequences of endometriosis on life outcomes and perceptions of control over the condition. Research suggests that endometriosis symptoms may persist even after menopause (Secosan et al., 2020), potentially fuelling the prolonged fears for the future voiced by participants. The perceived consequences of endometriosis on the life trajectory elicited a strong emotional response from many participants, who described detrimental wellbeing effects stemming from the disruption and anticipated disruption to their lives, including anxiety and sadness. However, importantly, some participants described re-framing their perceptions around the consequences of endometriosis, leading to improvements in their self-esteem. It is important that future research investigates this potential link further to establish whether interventions to re-frame IPs may be beneficial for individuals experiencing endometriosis.

Corresponding with previous research suggesting a link between endometriosis and the identity (Cole et al., 2021), theme 3 highlights a fragmented and lost sense of self attributable to participants’ endometriosis experiences. Although identity is a pre-defined IP, ‘identity’ within this theme transcends the definition offered by the CSM-SR, in which it is centred around perceptions of the symptoms associated with the condition rather than the sense of self. In the current study, identity refers to the broader self-concept and theme 3 explores participants’ perceptions of how this is moulded by endometriosis. This is interlinked with theme 2, as many of the perceived changes to identity stemmed from the impact of endometriosis on specific life domains such as work and relationships. This corresponds with research demonstrating that the sense of self is intrinsically linked to social aspects including career choice (Fryers, 2006), relationships (Anderson & Chen, 2002) and sex (Hensel et al., 2011). In turn, the self-concept is linked to QoL in other chronic conditions (Octari et al., 2020), suggesting that IPs may indirectly impact endometriosis-related QoL by shaping the identity. Additional longitudinal research is required to examine this potential link further.

Within the current study, participants used terms such as “lost” to describe their identity, implying a sense of powerlessness surrounding their sense of self. However, using the term “lost” rather than, for example, “broken” or “gone” suggests a sense that the self-concept may be recovered, as found amongst people experiencing other chronic conditions (Golub et al., 2014; Cogan et al., 2016). This implies an underlying hope that control of the identity might be regained from endometriosis. Furthermore, this corresponds with the dichotomy observed within some participant accounts, in which the self-concept was described as driven by endometriosis but, simultaneously, there was a determination to prevent endometriosis from taking over the identity.

Examining participants’ experiences and perceptions of their identity through an IP lens revealed shared experiences amongst participants such as the internalised trivialisation of endometriosis-related symptomology, which corresponds to broader social themes including the treatment of women’s health conditions in medical and societal environments. There is vast sociological discourse on the treatment of women’s health conditions that corresponds with participant accounts of the minimisation of their symptoms at both societal and medical levels (Alexander et al., 2020). Within the current study, participants often questioned their knowledge and expertise in their own bodies, with some doubting their experiences and even their ‘sanity’. Thus, many appeared to experience a sense of externalised self-perception (Jack & Dill, 1992) in which they viewed themselves through the lens of others. This is described as an act of self-silencing, which may be activated when individuals experience a strong fear of rejection through voicing their own thoughts and feelings (Jack & Dill, 1992). Self-silencing is associated with an underlying fear that internal thoughts and feelings are inaccurate, particularly when they contradict societal norms (Maji & Dixit, 2019). As stigma surrounds menstruation, self-silencing is particularly pertinent to endometriosis (Cole et al., 2021) and is evident within participant accounts throughout this chapter.

Similarly, sex was often related to the feminine identity and notions of ‘womanhood’, which relates to broader sociological discourse surrounding femininity and sexual pleasure (Carter et al., 2019). Importantly, participants often equated sex to penetration, but in moving away from traditional definitions of sex to identify alternate ways to enjoy sexual activity, some participants experienced increased confidence and intimacy with their partners. This suggests that interventions focussed on reframing traditional definitions of sex may be beneficial for individuals experiencing endometriosis with dyspareunia. Future research should therefore investigate subjective definitions and experiences of femininity and the intersection between femininity and sexual desire in endometriosis.

Perceptions of femininity were negatively impacted by endometriosis, with a clear link between body image and perceptions of the self as ‘feminine’. Previous research has indicated that individuals experiencing endometriosis have a more negative body image than others (Van Neikerk et al., 2022; Volker & Mills, 2022). For example, Geller et al. (2021) reported that the relationship between perceived health status and depression is mediated by body image and self-criticism, with negative perceptions of the body heightening the risk of depression for individuals with endometriosis. For participants involved in the current study, bloating often elicited distress, with many expressing a desire to cover their bodies when they experienced bloating around their stomach due to endometriosis. This implies an underlying sense of shame linked to the body, which manifested itself in the clothing participants felt comfortable to wear. This speaks to what many participants believed to be “feminine” – a body without bloat and ‘imperfection’, and an easy-to-ignite desire for sexual intercourse. If participants fell short of these ‘ideals’, self-criticism increased, with participants often referring to themselves as “less of a woman” compared to individuals without endometriosis. According to sociological discourse on this topic, beauty and feminine ideals are almost impossible to achieve and maintain, but due to the onus on such standards within modern, Western society, there is still a tendency for assigned-female-at-birth individuals to compare themselves to such ideals (MacCallum & Widdows, 2018), often fuelling low body confidence. This effect is likely to underlie negative perceptions of the body amongst participants. Bloating may also provide a visual representation of their condition, leading to heightened distress surrounding this symptom. Future research could investigate the factors underlying the relationship between endometriosis and poor body image, for example the impact of societal messaging (e.g., advertisements, media etc.) on the body image and body familiarity of individuals experiencing endometriosis. It would also be useful to compare differences in perceived body image in people living with endometriosis between cultures to ascertain whether this is an issue in Western cultures or a cross-cultural effect. Interviewing individuals with endometriosis and a positive body image would also be useful, to support the design of interventions focussed on improving body image for those who may have more negative perceptions of their bodies.

It is important to reiterate that not all individuals with endometriosis identify as female, or feminine. One non-binary participant found it difficult to reconcile their diagnosis of endometriosis with their gender identity due to the gendered nature of the condition. This participant felt locked out of support groups that didn’t recognise their gender, leading to loneliness and isolation. Loneliness is an important risk factor for the development of depression in individuals who do not identify as cisgender (Herrmann et al., 2022; Reisner et al., 2016). Importantly, an inclusive support group welcomed this participant, leading to increased confidence and reduced isolation, and demonstrating that inclusivity may mitigate the potentially damaging impact of loneliness and isolation for transgender and non-binary people with endometriosis. Due to a current lack of research in the context of endometriosis, it is important that future research investigates the unique challenges faced by individuals who do not identify as cisgender, to allow their voices and experiences to be heard.

A strong emotional response to endometriosis was woven throughout participant accounts, and this is described in theme 4. Feelings of anger and frustration correspond with previous qualitative research where they are often intertwined with endometriosis-specific factors such as treatment effectiveness and diagnostic delay (Jones et al., 2004). Within the current study, the emotional response was interlinked with perceptions of control, coherence, consequences and the anticipated longevity of endometriosis symptoms. Negative emotional responses were prominent throughout participant accounts, corresponding with previous literature suggesting that frustration, fear and sadness are common amongst people experiencing endometriosis (Young et al., 2015). However, perhaps surprisingly, some participants described a positive emotional impact associated with endometriosis, emphasising resilience, pride and strength cultivated by their experiences. This effect may be linked to self-preservation, in that if participants did not identify the value in their experiences, they may have been more susceptible to low mood and adverse HRQoL outcomes. The positive emotions and experiences described by participants were linked to a sense of hope for the future, as well as an intrinsic need to find value in their experiences. Benefit finding was a commonly used strategy within this participant sample to lessen the impact of endometriosis. This corresponds with research suggesting that finding value and benefit in experiencing a chronic condition can lead to reduced suffering and increased mental wellbeing (Danoff-Burg & Revenson, 2005; Soltani et al., 2018). Hope is associated with increased wellbeing and a decreased risk of depression and anxiety for individuals with chronic pain (Katsimigos et al., 2021), strengthening the notion that participants in the current study identified positive aspects of their endometriosis-related experiences in an act of self-preservation that was imperative to their wellbeing. The extent and impact of benefit finding and hope on wellbeing and HRQoL has not yet been researched in relation to endometriosis, and therefore constitutes an important area for future study.

Participants listed numerous coping strategies they used to allow them to navigate life with endometriosis, and these are captured in theme 5. Aligning with previous research, participants with more pro-active coping strategies, such as seeking support and future planning, derived a greater wellbeing benefit than those using avoidant coping strategies, such as ignoring their symptoms and forgoing support (Durosini et al., 2022; Eriksen et al., 2008). Almost all participants used distraction to varying degrees of success. Distraction was most useful when it involved focussing the mind on creative, restorative, and calming activity, such as meditation, reading, art, and light exercise, in line with research suggesting that mindfulness may benefit those experiencing endometriosis by reducing pelvic pain and improving mental health outcomes (Moreira et al., 2022). Conversely, distraction strategies which promoted a disconnect and/or avoidance from the body, such as ‘soldiering on’ and attending work, often led to burnout, anxiety, and worsened symptoms. However, even when successful, distraction was not a long-term fix, suggesting that a combination of multiple coping strategies may have the most pronounced impact on wellbeing. From participant accounts, seeking support, mindful distraction, and setting boundaries and limits appeared to have the most positive impact on wellbeing and HRQoL. Successful coping strategies increased perceptions of control over the condition and decreased fears for the future related to their diagnosis. Exchanging experiences and advocating for others also increased participants’ wellbeing, by allowing them to find value and benefit in their experiences. This corresponds with research suggesting that benefit finding may indirectly improve wellbeing by increasing resilience in conditions causing chronic pain (Yeung et al., 2012).

However, some participants described adopting destructive coping strategies, such as the overuse of alcohol, to cope with their pain. This corresponds with research suggesting a link between chronic pain and substance use (Maleki et al., 2019; Reif et al., 2022). Up to a third of individuals presenting at drug and alcohol clinics report chronic pain (Alford et al., 2016), suggesting that this form of self-medication is a common coping mechanism for people experiencing several chronic conditions. The problematic use of alcohol has negative consequences including further physical and mental health deterioration (Boissoneault et al., 2019) and diminished QoL (Howren et al., 2022), often prompting a vicious cycle which can be difficult to break. Therefore, deeper understanding around the prevalence of alcohol use as a coping mechanism in endometriosis is required. Qualitative interviews with individuals who have used alcohol as self-medication for their endometriosis symptoms would be beneficial to aid understanding of the risk factors for substance use in this population. Similarly, two participants disclosed using cannabis to medicate their endometriosis symptoms. Unlike alcohol, both participants described positive effects on their QoL, as cannabis eased their pain-related symptoms with few adverse effects, offering them a sense of control. This is in line with previous research which suggests that cannabis can successfully reduce pain in individuals diagnosed with endometriosis (Reinert & Hibner, 2019; Sinclair et al., 2020). However, there is currently a dearth of well-designed studies examining the long-term effects of cannabis and cannabis-based products in the treatment of endometriosis (Mistry et al., 2022) which should be addressed before recommendations are made surrounding the use of cannabis for endometriosis.

IPs in this participant sample could be matched to each of the pre-defined IPs as described in the CSM-SR (table 6.1, p.286). Most prominent in this sample were perceptions of control and consequences, which were clearly linked to participants' medical experiences, life trajectories, sense of self and emotional and coping responses. Less clear however was the role of the illness identity (i.e., the symptoms associated with endometriosis by participants) or the perceived cause of endometriosis. As there is no known cause for endometriosis, perceptions around causation may not be particularly strong within this population, which may be reflected in the results of the current study. However, the absence of a known cause often prompted a negative emotional response in participants, suggesting that this in itself may impact negatively on wellbeing. Therefore, future research may endeavour to establish how the lack of knowledge surrounding the aetiology of endometriosis may affect wellbeing.

Considering the findings of the current research, namely that the experiences of participants are linked to IPs, and that shifts in some IPs appear to prompt positive QoL and psychological outcomes, it is possible that IP-based interventions may partially mitigate the detrimental impact of endometriosis on QoL outcomes. This is not to say that psychological intervention can replace effective treatment, but that it may support the wellbeing of individuals diagnosed with endometriosis whilst reliable treatment is sought. Due to the dearth of research on this topic, future research may assess IPs with a large sample of individuals using pre-established measures of IPs such as the Revised Illness Perception Questionnaire (Moss-Morris et al., 2002) to further investigate the appropriateness of studying endometriosis within a CSM-SR framework before corresponding interventions are trialled. The current thesis includes one such study (see chapter 5), which upholds the results of the present research by suggesting that IPs play a role in shaping wellbeing and HRQoL outcomes in this population.

Additionally, throughout the transcripts, participants detailed the multiple and varied coping strategies they adopted to support their wellbeing, which in and of itself may be useful for individuals living with the condition to consider. Furthermore, the findings suggest that interventions aimed at challenging maladaptive and avoidant coping strategies may be useful in supporting the wellbeing of those experiencing endometriosis. Importantly, several participants also drew upon the importance of reframing their perceptions, particularly around sex and the feminine identity. Therefore, interventions to challenge widely-held perceptions impacting upon the self-concept may be useful in improving IPs and overall wellbeing in this population. Relatedly, Acceptance and Commitment Therapy (ACT) aims to support mental wellbeing by promoting ‘living well’ within the context of experiencing a chronic condition. Due to the importance placed upon reaching a point of acceptance with endometriosis by participants within the current study, ACT presents a viable and potentially beneficial avenue for future intervention within this population.

6.6.2 Strengths and limitations

To our knowledge, this is the first study to qualitatively consider the IPs of individuals experiencing endometriosis. The current study extends existing knowledge on the mechanisms underlying adverse QoL outcomes in people experiencing endometriosis by suggesting that IPs may contribute to QoL alongside known predictors of wellbeing such as pain. In exploring participant experiences through an RTA framework, the current study offers a rich narrative of the experiences of individuals living with endometriosis, adding to literature highlighting the pervasive and enduring impact of endometriosis.

However, the current study must be viewed in light of its potential limitations as well as strengths. Firstly, participants were recruited through social media and support groups, indicating that many had sought support for their condition. People involved in support groups may hold views unreflective of the wider population in two distinct ways: i) they may have worsened symptomology and more negative experiences leading them to seek support; ii) they may have a more positive outlook regarding their endometriosis diagnosis due to increased support. Furthermore, several participants (60%) experienced co-morbid conditions, so functioning and HRQoL detriments may be attributable to living with multiple medical conditions rather than endometriosis alone. However, the potential impact of this may be mitigated as the interview focussed solely on endometriosis rather than general health.

Additionally, the interview topic guide was underpinned by the CSM-SR and many questions related to pre-existing IPs. Therefore, although an inductive approach was taken in constructing themes, the information yielded from the interviews may have been heavily slanted towards the CSM-SR's depiction of IPs. Therefore, important IPs held by participants but existing out-with this theoretical framework may have been missed and the role of pre-established IPs over-emphasised. However, by investigating IPs within a pre-established framework, the current research lays the groundwork for future investigation into the role of IPs in endometriosis-related outcomes by suggesting that these cognitions likely contribute to HRQoL and wellbeing outcomes.

Furthermore, participants resided in the UK and Ireland. Due to cultural differences in attitudes towards menstruation, the results may therefore not reflect the experiences of individuals residing elsewhere. Consequently, future research could consider whether the IPs of individuals experiencing endometriosis are universal or differ between cultures.

Finally, participants were not asked to disclose their gender. One participant identified as non-binary, and discussed the isolation and loneliness they felt due to experiencing endometriosis as an individual who does not conform to their assigned gender at birth. Future qualitative research should therefore endeavour to increase understanding around the barriers and issues faced by non-cisgender individuals in accessing endometriosis-related support.

6.6.3 Conclusion

The current study highlights the complex and dynamic nature of the IPs held by individuals experiencing endometriosis. Endometriosis-specific symptoms such as pain appeared to be the main driver of HRQoL detriments, and these symptoms and their associated impact cultivated and moulded endometriosis-related IPs. Whilst effective treatment is sought for endometriosis-related symptoms, research should continue to investigate the factors that may mitigate the detrimental impact of endometriosis on HRQoL and wellbeing. These findings offer clear indications that interventions based on endometriosis-related IPs may support the QoL of individuals experiencing endometriosis, and suggests that future research explore the link between IPs and HRQoL in endometriosis further.

6.7 Chapter summary

The current chapter detailed the methods, results and discussion relating to the qualitative interviews conducted as part of this project. Initially, the methods employed were briefly outlined. The results indicated that participants held largely negative IPs in relation to their endometriosis diagnosis, which had an impact on salient aspects of their QoL such as their life trajectory, sense of self, emotions and coping mechanisms. Negative perceptions of control (both with regards to treatment and life with endometriosis) and perceived consequences were particularly prominent in this participant sample. Adopting healthy coping mechanisms was instrumental in supporting participants to regain some of the control thought lost to endometriosis, and in cultivating a more positive future outlook. The results illustrate that psychological interventions based on re-framing IPs may support the QoL of people living with endometriosis, whilst effective treatment continues to be sought.

CHAPTER 7

Overall discussion and integration of mixed methods data

7.1 Introduction to the chapter

The present chapter provides an overall discussion of the current thesis. First, a summary of the key findings from the qualitative and quantitative elements of the current thesis is presented (7.2), followed by the integration of both components (7.3). Next, an overall discussion is provided to contextualise the findings (7.4), before an exploration of the strengths and limitations of the current research is given (7.5). The implications of the findings are then considered (7.6), followed by a conclusion to the thesis (7.7).

7.2 Summary of findings so far

The overarching objective of the current research was to aid understanding of the mechanisms underpinning the relationship between endometriosis and reduced wellbeing. Specifically, the current thesis had 5 key aims:

i) To investigate the longitudinal predictors of HRQoL and wellbeing outcomes in endometriosis;

ii) To determine if IPs predict HRQoL and wellbeing outcomes over and above demographic and clinical factors;

iii) To determine the stability of IPs in the context of endometriosis;

iv) To investigate coping as a potential mechanism explaining the link between IPs and outcomes, as theorised by the common-sense model of self-regulation (CSM-SR);

v) To gain an in-depth understanding of the IPs held by individuals experiencing endometriosis.

To address these aims, a mixed-methods framework was employed. This allowed for broad, generalisable data as well as rich, in-depth information relevant to the experience of endometriosis to be obtained. The following sections outline the findings, organised by each aim.

7.2.1 Investigate the longitudinal predictors of HRQoL and wellbeing in endometriosis

A longitudinal two-wave survey completed over the course of one year determined several longitudinal predictors of HRQoL and wellbeing. Specifically, demographic variables, clinical experiences (e.g., diagnostic delay, co-morbid conditions), IPs, and coping together explained a significant proportion of the variance in HRQoL, anxiety, depression, stress, pain, and disability scores recorded at the follow-up stage. However, singularly, few variables predicted these outcomes. For example, only the anticipated timeline of endometriosis, the illness identity, and age significantly predicted HRQoL 12 months' later, whilst only depressive processing, a coping style characterised by social withdrawal and rumination, significantly predicted anxiety at the stage of follow-up. However, the collective effect of all predictor variables on each of the measured HRQoL and wellbeing outcomes was significant, suggesting that factors such as IPs and coping strategies work together to produce an overall significant and enduring impact on mental wellbeing and HRQoL.

Interviews with 30 individuals experiencing endometriosis further cemented this notion, with participants positioning coping, negative IPs, and adverse experiences within healthcare settings as central to their wellbeing. In particular, the detrimental impact of the invalidation and dismissal experienced by participants within healthcare settings on their mental health was enduring, affecting the life trajectory and moulding IPs.

7.2.2 Determine if IPs predict HRQoL and wellbeing outcomes over and above demographic and clinical factors

A two-wave survey completed by 278 participants found that, collectively, IPs longitudinally predicted outcomes including mental wellbeing, HRQoL, pain, and disability over and above demographic and clinical factors, including diagnostic delay. More negative IPs predicted adverse outcomes. Perceptions of the timeline and symptoms associated with endometriosis appeared to exert the greatest, singular impact on health and HRQoL outcomes.

7.2.3 Determine the stability of IPs in the context of endometriosis

The longitudinal survey component of the current thesis revealed significant improvements in the IPs held at the stage of follow-up, compared to baseline 12-months earlier. Specifically, perceptions of the consequences, symptoms, concern, and emotional impact relating to the experience of endometriosis had significantly improved. This indicates that IPs are indeed dynamic and changeable in this population. However, there was no change to perceptions around the timeline, control or coherence surrounding endometriosis, indicating that these IP dimensions are more stable. Additionally, the broader context should be borne in mind when interpreting this finding – the baseline survey was distributed during the height of COVID-19 induced lockdowns within the UK, where treatment and medical intervention was limited, whilst the follow-up survey was circulated following the lifting of UK-wide lockdown restrictions.

7.2.4 Investigate coping as a potential mechanism explaining the link between IPs and outcomes, as theorised by the CSM-SR

Additionally, alongside IPs, coping was observed to be a longitudinal predictor of HRQoL, depression, and anxiety, with maladaptive coping strategies exerting the strongest and most negative impact on outcomes. Coping also mediated all relationships between IPs and outcomes, with avoidant coping strategies such as depressive processing (DP) exerting the strongest impact on these relationships. The use of proactive coping strategies had a protective effect on wellbeing, however the adoption of avoidant and maladaptive coping strategies such as DP strengthened the relationship between negative IPs and adverse wellbeing outcomes. Even where proactive coping exerted a protective impact on wellbeing, maladaptive coping strategies had a more pronounced impact on outcomes.

The findings of the qualitative component of the current thesis reinforces the notion that coping mediates the relationship between IPs and wellbeing outcomes, by suggesting that coping strategies such as distraction and seeking support were informed by IPs such as perceptions surrounding control and the consequences of endometriosis. These coping strategies then directly influenced wellbeing outcomes. Participants also highlighted a direct relationship between their IPs, such as perceptions of the timeline of endometriosis, and QoL outcomes.

7.2.5 Gain an in-depth understanding of the IPs held by individuals experiencing endometriosis

Additionally, analysis of the 30 in-depth interviews held with individuals experiencing endometriosis revealed widespread feelings of disempowerment amongst participants with endometriosis, particularly in relation to the trivialisation and minimisation of their symptoms. Participants felt that their lives were dominated by endometriosis, and that their sense of self and identity was moulded by the condition. They voiced complex emotional responses to the condition, incorporating feelings of isolation, anger, and sadness, but also a sense of pride and resilience. Additionally, participants noted the strategies they’d adopted to allow them to live a fulfilling life with endometriosis. Seeking support, setting boundaries and self-care were central to arriving at a point of acceptance in their condition. It is important to note however that acceptance in this context was dynamic, with participants moving in and out of this state over time. Each theme mapped on to multiple IPs, most prominently perceptions around the consequences of experiencing endometriosis, the level of control around the condition, and the emotional representation of endometriosis.

To provide a comprehensive overview of the data in relation to the central research aims, the findings of the quantitative and qualitative results will next be integrated.

7.3 Integration of quantitative and qualitative results

7.3.1 Method

To ensure a comprehensive and nuanced understanding of the mechanisms underlying adverse health and wellbeing outcomes in the context of endometriosis, the quantitative and qualitative findings from each study were integrated. Morgan's (2019) approach to integrating mixed-methods research has been adopted. This approach determines the extent of convergence, complementarity, and divergence across the datasets. By considering these aspects during the process of integration, Morgan's (2019) approach lends itself to a comprehensive understanding of the data and, consequently, a holistic perspective of the research area. Therefore, this approach was selected for the current research.

Convergence involves comparing the results of qualitative and quantitative data to ascertain similarities across the data. It focuses on identifying commonalities, patterns, and trends across the findings of both types of research (Creswell, 2015). By directly comparing the quantitative and qualitative results to determine similarities, convergence reduces the risk that the findings were observed due to the inherent biases associated with either method, enhancing the credibility of the findings (Morgan, 2019).

On the other hand, complementarity emphasises the notion that quantitative and qualitative data can complement each other by providing different perspectives, insights, and details about the topic under investigation (Javdani et al., 2023; Morgan, 2013). By searching for points of complementarity between quantitative and qualitative approaches, a more complete understanding of the phenomena may emerge. Each method contributes its own distinct strengths to achieving a common goal, and in doing so the strengths of one method can compensate for the limitations of the other (Morgan, 2019).

Finally, divergence examines points of difference between the findings obtained from each method. Traditionally, divergence was considered to stem from methodological errors and inconsistencies, however here it is recognised as a starting point for constructive dialog, potentially presenting opportunities for further research to investigate these differences (Morgan, 2019).

7.3.2 Results

Table 7.1 displays the results from the process of integration.

Table 7.1

Integration of quantitative and qualitative results

	Quantitative Results	*Qualitative results*
Convergent findings	1. Endometriosis has a detrimental impact on HRQoL and wellbeing	
	Descriptive statistics show that depression (M = 2.83), stress (M = 8.76), and anxiety (M = 3.1) are lower in the study population than within the general population (see section 5.5.1)	*"It's* [endometriosis] *taken away my youth and it's taking away from all of the things that I aspire to do and that I could have done and could have achieved*."
	2. The way in which endometriosis is perceived (i.e. illness perceptions) plays a key role in driving emotional and behavioural responses	
	Combined, IPs were the strongest predictors of all outcomes, including HRQoL, depression, and anxiety, within each regression model (see section 5.5.8)	*Links between participants perceptions around control and the consequences of experiencing endometriosis and their QoL were uncovered within interviews (see chapter 6, table 6.1)*
	3. Coping styles are shaped by illness perceptions and drive wellbeing	
	Mediation analyses illustrated coping styles such as depressive processing and action, problem oriented coping as influential in the relationships between all IPs and outcomes (see section 5.5.9)	*Participants described the pervasive impact of their coping strategies in response to endometriosis, for example through social withdrawal and distraction, on their wellbeing (see section 6.5.5)*
	4. Medical experiences have a detrimental and enduring impact on wellbeing and HRQoL, especially with regards to the lack of available treatment and dismissal of symptoms	
	Content analysis of free text showed the lack of effective treatment as the most prominent concern amongst participants in relation to their wellbeing (see section 5.5.4)	"*I really did wind up having a lot of depression because you know from so many people telling you, you know, you're lying and there's nothing wrong with you.*"
	5. Participants have concerns around their ability to conceive	
	Content analysis revealed fears around conception and carrying	"*I was in complete tears yesterday because it's, it's getting*

	a baby to term (see section 5.5.4)	*faced with that reality of – I would love a family but I might not be able to have one.*”
Complimentary findings	1. Maladaptive coping is detrimental to wellbeing	1. Specific coping styles such as ignoring symptom triggers and distraction (avoidant) were most detrimental to wellbeing
	Avoidant coping styles such as depressive processing were strongly positively correlated with depression ($r =.552$, $p<.01$)*, anxiety* ($r = .497$, $p<.01$)*, and stress* ($r = .585$, $p<.01$)	*Interviewees described a detrimental impact of avoidant coping on their mental wellbeing, with tuning out of the body often associated with bodily disconnection* (see section 6.5.3)
	2. Proactive coping has a protective effect on anxiety, stress, and depression	2. Coping styles such as seeking support and setting boundaries supported mental wellbeing
	Active, problem-oriented coping had negative relationships with depression ($r = -.276$, $p<.01$), *anxiety* ($r = -.227$, $p<.01$)*, and stress* ($r = -.349$, $p<.01$)*. It also mediated the relationships between negative IPs and these outcomes.*	*Interviewees outlined the adaptive coping styles that supported them to live a fulfilling life with endometriosis, including seeking support through groups and family members, and setting boundaries and limits where required (see section 6.5.5)*
	3. Endometriosis negatively impacts sexual functioning	3. Adverse effects on sexual functioning stem from endometriosis specific symptoms, and are both driven by and drivers of negative body image and decreased identification of the self as feminine
	Within the content analysis (see section 5.5.4), the negative impacts of endometriosis on participants’ sex lives and fulfilment was a prominent theme.	*“I just physically can’t* [have sex]. *I don’t feel feminine, I don’t feel sexy when I’m in pain.”*
	4. Clinical IPs are the most prominent drivers of	4. Participants believed their symptoms would never

	HRQoL, but combined, IPs had the strongest impact on HRQoL and wellbeing	recede or lessen, and highlighted several symptoms they associated with endometriosis including pain, infertility, and fatigue. These perceptions impacted HRQoL directly, and indirectly through colouring alternate IPs such as anticipated consequences/emotional representations
	Combined, IPs explained 21.6% of the variance in participants' HRQoL scores. Perceptions surrounding the timeline (p=.002) and identity (p<.001) of endometriosis had a significant singular impact on HRQoL scores.	*"I knew it had no cure, I knew I'd always have it, I knew that it grows basically as it wants. I also felt like I was being weighed down by this terrible knowledge now. And once I knew I can't unknow it and it was horrible. I think after that week I was diagnosed I started getting really upset."*
	5. Perceived level of social support is related to wellbeing outcomes, but is not a prominent driver of these outcomes after IPs and coping have been accounted for, with the exception of depression	5. Many participants used endometriosis support groups as their primary source of social support. There were different opinions on the effectiveness of these groups in alleviating some of the impact of endometriosis on mental wellbeing
	Social support was correlated with all measured wellbeing outcomes (see table 5.7, section 5.5.2.2). However, social support was not predictive of any outcome in the regression models, with the exception of depression (p = .006)	"*I sometimes have to take breaks because, em, we need to distract ourselves from this whole, whole world, em, and sometimes I find that if I'm in the* [online] *community too much then I can stay in the pain."*
Divergent findings	1. There was no strong impact of perceived control on health, wellbeing and HRQoL outcomes	1. Perceptions of control, particularly around the treatment of endometriosis, had a marked impact on wellbeing

	Perceived control did not emerge as a singular predictor of any measured outcome (see section 5.5.8)	“*I feel like I’m not in control of my life, this illness is*.”

The integrated findings presented in table 7.1 provide an overview of the nuanced relationships uncovered within the present research. Convergent findings highlight the consistently negative impact of endometriosis on HRQoL and wellbeing. IPs and coping styles are positioned as central to adverse health and wellbeing outcomes across both datasets, and treatment within medical settings appears to exert lasting negative effects on these outcomes.

Several complementary findings are also highlighted in table 7.1. Qualitative accounts often fleshed out findings from the quantitative component of the current thesis. Combined, both methods offered a rich and compelling account of the coping strategies used in response to endometriosis-related symptoms, the most prominent IPs amongst the study population, and the impact of endometriosis on daily functioning. Additionally, the qualitative results provide a plausible explanation as to why social support was not a prominent driver of wellbeing outcomes in the quantitative component.

There was little divergence across the datasets, as exemplified in table 7.1. However, perceptions of control were prominent indicators of wellbeing in the qualitative component of the present thesis, but were not strong drivers of outcomes in the quantitative element.

7.4 Discussion

The findings from the qualitative and quantitative components of the present research largely converged and complemented one another to provide a well-rounded account of the mechanisms underlying HRQoL and wellbeing in the context of endometriosis. This section of the current chapter aims to contextualise these findings. Primarily, aspects of convergence across the datasets will be considered, followed by points of complementarity and divergence.

7.4.1 Convergence

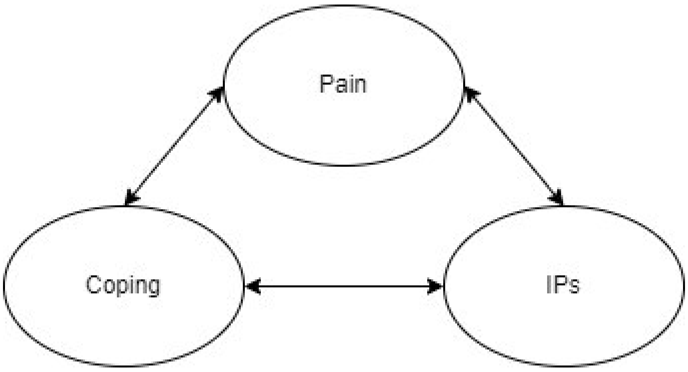
Clear through both elements of the current mixed-methods study was the detrimental impact of endometriosis on the life trajectory and wellbeing. This observation aligns with numerous studies that have identified a relationship between endometriosis and reduced HRQoL (Gao et al., 2006; Gete et al., 2023; Jia et al., 2012; Kalfas et al., 2022; La Rosa et al., 2019; Marinho et al., 2018; Vitale et al., 2017) and mental wellbeing (Lorençatto et al., 2004; Mellis et al., 2015; Sepulcri & do Amaral, 2009). Alongside convergence, there were also points of complementarity between the datasets in relation to this observation. For example, whilst the quantitative component of the current study revealed adverse HRQoL and wellbeing effects related to endometriosis, the qualitative interviews highlighted specific aspects of experiencing endometriosis, such as disruption to the life trajectory, invalidation, and the adoption of maladaptive coping strategies, as central to these detriments. These findings complement not only the quantitative component of the current thesis but also previous literature indicating that factors such as invalidation and maladaptive coping negatively affect wellbeing (Cox et al., 2003; Young et al., 2020). The consistent observation of adverse wellbeing effects associated with endometriosis, as seen in the current study and across the existing literature, suggests a lack of effective psychosocial support. It also implies that currently available psychological interventions might not be reaching those who require them. However, at the time of writing, it is not routine for individuals diagnosed with endometriosis to be offered any form of psychological intervention (APPGE, 2020) when diagnosed through the NHS within the UK. Bearing in mind the detrimental impact of endometriosis on mental health, psychological support options are fundamental in this population. Therefore, future research should aim to build upon the current study by uncovering further detail on the mechanisms underlying adverse wellbeing effects in this population, with the goal of trialling various psychosocial interventions for people experiencing endometriosis. Promising research has suggested that cognitive behavioural therapy (CBT) may prompt positive changes to QoL and mental wellbeing in the context of endometriosis (Van Niekerk et al., 2019), although good quality research, especially randomised control trials, are necessary to corroborate these findings.

With that being said, the available literature, including the findings from the qualitative component of the current research, positions pain and endometriosis-related symptoms such as fatigue as central to HRQoL and wellbeing outcomes in this population (Facchin et al., 2015; Schneider et al., 2020). Therefore, although psychological interventions may support the mental wellbeing of individuals with endometriosis, effective treatment aimed at reducing the frequency and severity of endometriosis-specific symptoms is likely to yield the most positive impact on HRQoL and wellbeing outcomes. Nonetheless, whilst such treatment continues to be sought, psychosocial interventions may ameliorate some of the detrimental impacts of endometriosis on HRQoL and wellbeing outcomes.

Relatedly, both elements of the current research outlined IPs as key drivers of emotional wellbeing and HRQoL, corroborating a wealth of literature positioning IPs as central to wellbeing in several chronic conditions (Dempster et al., 2015; Knowles et al., 2020). Interestingly, IPs not only moulded wellbeing but also influenced clinical factors such as pain and disability. Several previous studies have positioned pain and disability as key factors underlying wellbeing in endometriosis (Centini et al., 2013; Facchin et al., 2015), and it has been suggested that pain and wellbeing are cyclical, with each influencing the other in a perpetual cycle (Facchin et al., 2015). However, research has rarely examined the influence of alternate psychosocial mechanisms on endometriosis-related pain. By identifying IPs, along with coping styles, as drivers of pain and disability in this context, the current findings suggest a cyclical relationship in which the level of pain experienced impacts IPs, which then influences coping and pain perception (see figure 7.1).

Figure 7.1

Cyclical relationship between pain, IPs, and coping



This finding corroborates previous research which has linked more negative IPs to increased self-reported pain in alternate chronic conditions, including chronic back pain (Ginnerup-Nielsen et al., 2022) and orofacial pain (Galli et al., 2010). Therefore, targeting IPs in psychosocial interventions for endometriosis may prompt increases in wellbeing directly, and indirectly through lessened pain perception. However, the pain derived from endometriosis can be severe and debilitating, and as there is likely a cyclical relationship with pain also influencing IPs, interventions aiming to promote more positive IPs may exert minimal effect on pain perception itself. Therefore, establishing effective and reliable treatments for endometriosis is key to supporting the wellbeing of this population through pain reduction. Nonetheless, IP-based interventions may reduce the impact of endometriosis-specific symptoms such as pain and fatigue on mental wellbeing and HRQoL outcomes and are therefore worthy of further investigation.

Additionally, both components of the current mixed-methods study positioned IPs as central to wellbeing by impacting on HRQoL, mental distress, pain, and disability directly and indirectly through driving the coping strategies used by participants in response to their endometriosis-related experiences. This observation corroborates the CSM-SR, which situates coping strategies as mediators between IPs and health-related outcomes (Leventhal et al., 2016). More negative IPs, such as negative perceptions related to the consequences of endometriosis, were related to heightened use of maladaptive and/or avoidant coping strategies, such as social withdrawal. Subsequently, increased use of maladaptive coping strategies predicted worsened outcomes. This aligns with previous research that has identified adverse wellbeing implications associated with avoidant or maladaptive coping in endometriosis (Eriksen et al., 2008). Therefore, interventions focussing on minimising the use of maladaptive coping strategies may be beneficial for individuals experiencing endometriosis by mitigating some of the impact of negative IPs on HRQoL and wellbeing outcomes such as stress, depression, and anxiety.

There was further convergence between both elements of the current project regarding the adverse impact of negative experiences within medical settings on wellbeing and HRQoL. Specifically, lengthy diagnostic delays were associated with worsened wellbeing outcomes, aligning with existing research highlighting the detrimental effects of prolonged diagnostic delays on mental health and wellbeing in this population (Cox et al., 2003; Evans et al., 2022). However, in the quantitative study, diagnostic delay did not independently predict any of the measured outcomes after IPs and coping were entered into the regression models. This indicates that the combined impact of IPs and the coping strategies employed by individuals with endometriosis are stronger predictors of wellbeing and health outcomes than diagnostic delay alone. However, it is important to note that IPs and coping strategies appear to be themselves moulded by medical experiences, including diagnostic delay, and therefore it is difficult to fully disentangle this effect.

Furthermore, it is unlikely that diagnostic delays work independently to impact on mental wellbeing and HRQoL. The quantitative element of the current research solely measured the duration of time an individual awaits a diagnosis of endometriosis, and consequently, it may not fully capture the combined impact of several factors that emanate from diagnostic delay and contribute to the impact on wellbeing. For example, as described in chapter 1, diagnostic delays often arise from a lack of effective diagnostic tools (Simko & Wright, 2022), and the minimisation of patient concerns surrounding endometriosis symptoms which themselves may negatively affect HRQoL and mental wellbeing (Grundström et al., 2018; Rowe et al., 2021). Additionally, an inevitable consequence of diagnostic delay is treatment delay, and given the progressive nature of endometriosis, prolonged waiting for a diagnosis may exacerbate symptoms. Therefore, diagnostic delay may need to be considered in line with factors such as the dismissal of symptoms, the number of excursions to a GP, and treatment delays to provide a more comprehensive understanding of the direct and indirect consequences of diagnostic delays on health and wellbeing outcomes in this population. Evidence for the interconnectedness between these factors can be found in the qualitative component of the current research, which positions negative experiences in healthcare settings as limiting HRQoL and exerting a detrimental impact on mental health. For example, participants frequently disclosed a sense of invalidation as a result of the dismissal of their symptoms in medical settings, which lengthened diagnostic delays. There was a sense of a ‘battle’ with medical professionals for a diagnosis and, ultimately, for relief from their symptoms through the provision of effective treatment. In this way, the qualitative component of the current research complements the quantitative data, by providing an account of how diagnostic delay interacts with additional factors to produce a marked effect on wellbeing and HRQoL. Further upholding this observation is the response from participants on the open-ended question included at the end of the baseline questionnaire, in which participants described the lack of understanding surrounding endometriosis, invalidation, and the dearth of effective treatment options as detrimental to their mental health and wellbeing. Therefore, it is perhaps too simplistic to investigate whether diagnostic delay in isolation impacts on health and wellbeing outcomes in people experiencing endometriosis, and instead it is important to acknowledge and explore the complex interconnections between various clinical and social factors which work together to negatively impact the health and wellbeing of diagnosed individuals. Future quantitative research could therefore consider a broader range of factors when examining the impact of diagnostic delays on health and wellbeing in this population.

The final point of convergence identified between the qualitative and quantitative components of the present research relates to participants' concerns surrounding their fertility. Across qualitative accounts, participants disclosed fears around their ability to conceive with a diagnosis of endometriosis. This was particularly prominent amongst individuals who had not yet attempted to conceive but were concerned about their ability to carry a child with a diagnosis of endometriosis, indicating fears surrounding the future. Similarly, in the open-ended question presented to participants at the end of the baseline survey, participants also highlighted fears around fertility as detrimental to their mental wellbeing. At the time of writing, there is little research specifically surrounding fertility in endometriosis, but some qualitative research has observed similar fears around the prospect of infertility in this population (Heng & Shorey, 2022), suggesting that these concerns may be widespread. However, no cause-and-effect relationship between infertility and endometriosis has yet been identified (Stellar et al., 2016). Despite this, there is a focus within medical settings on fertility preservation within this population (Young et al., 2016). This is potentially exacerbated due to the categorisation of endometriosis as a reproductive condition in medical settings. The focus of endometriosis as a reproductive condition means that diagnosis is often accelerated for those pursuing fertility treatments, with research observing that as many as 40% of individuals seeking support for infertility or subfertility go on to be diagnosed with endometriosis (Young et al., 2016). Correspondingly, the framing of endometriosis as a reproductive issue is also likely to impact the mental wellbeing of those for whom fertility is not a concern or problem, due to potentially lengthier waits for diagnosis and treatment. Across qualitative accounts obtained through the present research, several participants who did not want children felt that medical professionals did not take their needs seriously, anticipating that they might change their mind in relation to having children. Such notions meant that some participants were denied potentially life-changing surgeries such as hysterectomies and partial removal of the reproductive organs. At present, there is a lack of research specifically gauging the experiences of individuals with endometriosis with regards to their fertility. Qualitative research would be beneficial to further explore the way in which the framing of endometriosis as a reproductive condition impacts upon the wellbeing of diagnosed individuals, including those who have conceived successfully, those experiencing infertility, and those for whom fertility is not a concern. This would further our understanding of the impact of endometriosis on fertility specifically, whilst exploring the appropriateness of continuing to frame endometriosis as a reproductive condition, which has contributed to the prioritisation of fertility preservation in this population. Establishing the pervasiveness of infertility in this population would also be beneficial – it is commonly stated that 30-50% of individuals with endometriosis experience infertility (e.g., Bulletti et al., 2010) but this observation is based on a study from 1938 (Counsellor, 1938). Over time, awareness of endometriosis has accelerated, and with it, an increase in diagnoses has been observed (Morassutto et al., 2016). Additionally, women and individuals assigned female at birth were banned from clinical trials and medical research prior to the 1990s (Schiebinger, 2003), so the data that this statistic is based on is unclear. It is likely therefore that this estimation is outdated, and future research should endeavour to ascertain the true prevalence of infertility and subfertility in this population.

Broadly, the points of convergence identified within the current research support each of the outlined aims, by positioning IPs and coping styles as central to the long-term HRQoL and wellbeing of individuals with endometriosis. The findings align with the CSM-SR, which positions coping strategies as mediators between IPs and health-related outcomes.

7.4.2 Complementarity

The complementary findings observed within the present research elucidate the intricate connections between various aspects of the experience of endometriosis and wellbeing outcomes.

Primarily, the quantitative component of the current study highlights that avoidant and maladaptive coping strategies such as social withdrawal and rumination are detrimental to wellbeing. This finding is coloured by participant narratives throughout the qualitative element of the current study, which underscore their awareness of the adverse consequences of withdrawal and rumination on their wellbeing and health. In response to these challenges, participants often engaged in a process of compensation, in which they consciously disregarded symptom triggers and persisted with daily tasks and social outings, often through painful and debilitating symptoms. Several participants noted that the adoption of this coping style often led to a disconnect from the body, which ultimately worsened wellbeing in the long-term by strengthening the severity of endometriosis-related symptoms. Therefore, key to the promotion of wellbeing was identifying a delicate balance between rest and self-care on the one hand, and maintaining usual routines on the other. This observation aligns with a central tenet of the CSM-SR, which asserts that coping styles are shaped by cognitive appraisals of their success (Leventhal et al., 2016). In this context, withdrawal and rumination were frequently determined as detrimental to both physical and mental health, prompting the adoption of alternate coping strategies such as the disregard of endometriosis symptoms. However, these strategies also proved ineffective in reducing symptom severity and enhancing well-being, leading to the exploration and adoption of additional coping mechanisms. These findings further align with several research studies which have observed adverse consequences related to avoidant and maladaptive coping strategies in individuals experiencing endometriosis (Eriksen et al., 2008; González-Echevarría et al., 2019; Roomaney & Kagee, 2016).

Additionally, the quantitative results suggest that adopting proactive, action orientated coping styles had a protective effect on mental health outcomes, such as depression, anxiety, and stress. The qualitative results further illuminate this finding by suggesting that specific coping styles such as sourcing support, setting boundaries and limits, and self-care through exercise, heat, and mindfulness may exert a positive impact on mental wellbeing. The use of boundary setting and support seeking amongst participants implies self-awareness that allowed participants to tune into their bodies and prioritise their own needs. However, the quantitative results suggest that, although proactive coping has a protective impact on mental wellbeing, this effect does not extend to HRQoL or clinical outcomes. Additionally, where proactive coping did influence wellbeing, maladaptive coping consistently exerted a stronger effect on such outcomes, suggesting that the negative impact of adopting coping strategies such as social withdrawal and rumination was more pronounced than the protective effect of adopting proactive strategies such as boundary setting and support seeking. This observation aligns with several studies which have also observed a more pronounced effect of maladaptive coping strategies on wellbeing compared to proactive coping styles (Knowles et al., 2017). Therefore, in this population, interventions aimed at reducing the use of avoidant and maladaptive coping strategies through CBT, for example, are likely to be more effective at increasing wellbeing compared to support to implement proactive coping styles. However, interventions to promote the adoption of proactive coping strategies such as self-care, support seeking, and boundary setting may lead to a natural decline in the use of maladaptive coping strategies and subsequent increases in wellbeing. Future research may aim to establish the effectiveness of coping-orientated interventions such as CBT in supporting the wellbeing of individuals experiencing endometriosis.

In addition to coping strategies, the findings from both the qualitative and quantitative components of the current research complemented one another with regards to the strength of clinical-related IPs on health and HRQoL outcomes in this population. Specifically, the quantitative element found that, although IPs exerted a strong, combined impact on all health and wellbeing outcomes, only perceptions around the identity and timeline of endometriosis singularly predicted HRQoL, pain, and disability at the stage of the follow-up survey. The findings from the qualitative element of the current research complements this observation by demonstrating that many participants believed their symptoms would never recede or lessen, and by highlighting that participants associated several debilitating symptoms with endometriosis. Such perceptions around the anticipated timeline and the identity of endometriosis impacted HRQoL directly, but also indirectly through influencing alternate IPs such as the anticipated consequences associated with endometriosis and the emotional representation of the condition. For example, the perception that endometriosis symptoms would persevere throughout the life course often had a marked impact on participants’ mood, impacting overall wellbeing. Consequently, participants often disclosed more negative perceptions of control around the condition, and more severe anticipated consequences across the life trajectory. This observation illustrates that IPs do not work in isolation, instead informing one another to create a substantial combined impact on wellbeing outcomes. Furthermore, it provides a plausible explanation for the quantitative finding that IPs seem to exert a strong, collective effect on all outcomes, but singularly, many IPs do not have a strong impact on health and wellbeing aspects. Additionally, previous chronic health research supports this notion by demonstrating the interconnectedness between IPs which inform one another along with coping and health-related outcomes (Homma et al., 2018; Knowles et al., 2017).

Aside from coping strategies and IPs, the qualitative and quantitative data derived from the current research also complemented one another with regards to the impact of sexual functioning. In the quantitative component, the ‘sexual intercourse’ element of HRQoL reflected anxiety surrounding sexual activity amongst participants. Additionally, in the open-ended question at the end of the baseline questionnaire, several participants stated that their sex lives were adversely affected by endometriosis, a finding that corroborates existing research findings demonstrating a link between endometriosis and reduced sexual functioning (Pluchino et al., 2016; Rossi et al., 2020). Concerns around sexual functioning and activity were also prevalent within the qualitative component of the current research. Throughout participant accounts, adverse effects on sexual functioning were often linked to endometriosis-specific symptoms such as pain, fatigue, and bloating. Many of these symptoms affected sexual desire directly through discomfort during sexual intercourse and a reduced sex drive, and indirectly, by impacting negatively on participants’ body image. Qualitative accounts alluded to negative body image as both driven by reduced sexual functioning, and a driver of adverse sexual functioning through negatively affecting participants' identity and self-esteem. Reduced sexual functioning and negative body image together negatively affected the self-concept, particularly with regards to the feminine identity. For example, participants often disclosed that their symptoms made them feel like "less of a woman", and this notion was particularly prevalent with regards to symptoms such as dyspareunia and bloating caused by endometriosis. Across qualitative accounts, participants often disclosed concerns surrounding the longevity of their romantic relationships as a result of reduced sexual functioning, culminating in a far-reaching impact on their wellbeing. However, across qualitative accounts, participants also disclosed the strategies they had employed to mitigate the detrimental impact of reduced sexual functioning on their wellbeing. Such strategies often involved the positive reframing of sex, for example, away from penetration to non-penetrative sexual activity. The positive reframing of negative or challenging situations is a commonly used strategy in acceptance and commitment therapy (ACT; Howell & Passmore, 2019), suggesting that employing this therapeutic approach may support the wellbeing of individuals experiencing endometriosis alongside reduced sexual functioning.

Finally, the results complemented each other in relation to the impact of social support on wellbeing outcomes. Specifically, although perceived social support was related to HRQoL and wellbeing outcomes within the quantitative element of the current research, it was not a prominent driver of these outcomes after accounting for IPs and coping strategies. This implies that the combined effect of IPs and coping supersedes the impact of social support on HRQoL and wellbeing outcomes in the context of endometriosis. However, this observation is at odds with research that has consistently identified a substantial, protective effect of social support on HRQoL and wellbeing outcomes (Alsubaie et al., 2019; Grey et al., 2020; Szkody & McKinney, 2019). The qualitative component of the current research offers another explanation as to why social support was not a prominent, singular driver of outcomes within the quantitative study. Throughout participant accounts, endometriosis support groups were cited as a key source of social support. Many found these groups to be beneficial in supporting their mental health and wellbeing by reducing isolation and offering them a safe space to share their thoughts and feelings. However, contrarily, others found these groups to have a detrimental impact on their wellbeing, by drawing their attention to their symptoms and the progressive nature of endometriosis. Although social support takes many different forms, given that participants were recruited largely from support groups for the current research, it is likely that this is amongst the most prominent forms of social support within the study population. Given the diversity in experiences between participants, it is possible that many considered themselves to have ample social support, yet its capacity to predict wellbeing and HRQoL may be stunted due to differing positive and negative experiences with this type of social support. Therefore, it is perhaps the quality, rather than the quantity, of social support that bears the most importance for wellbeing in this population. Further research should seek to further disentangle these effects, for example by ascertaining the relative impact of different types of support (e.g., support groups, psychological, medical, relational support) on mental health and HRQoL in endometriosis. Such insights may guide recommendations for how best to effectively support individuals with the condition.

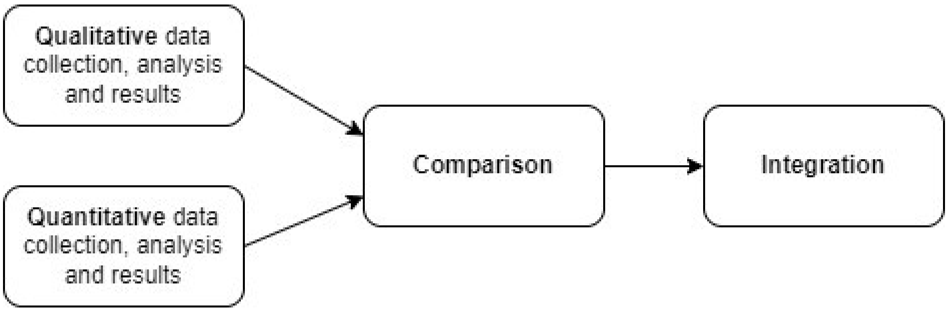
Broadly, the points of complementarity highlighted within this section of the current chapter paint a detailed picture of the nuanced nature of experiencing endometriosis. The qualitative component of the current research builds upon the data acquired through the quantitative element to provide a rich understanding of the impact of various psychosocial variables on wellbeing and HRQoL. Combined, the findings indicate that IPs and coping are prominent indicators of wellbeing in this population.

7.4.3 Divergence

Little divergence was detected between the results of the quantitative and qualitative elements of the current research. This is not entirely unexpected – the current research uses a convergent parallel design, in which both components of the overarching project were undertaken simultaneously, with each aiming to address similar research questions (see figure 7.2). The focus therefore was on corroborating evidence. Employing an alternate design, such as an exploratory sequential design in which the qualitative methodology and aims are dictated by the quantitative findings, may have yielded more divergent results.

Figure 7.2

Convergent parallel design



Adapted from Creswell & Plano-Clark (2011)

Alongside the study design, it is likely that the high degree of convergence and complementarity identified within the present research is reflective of participant homogeneity with regards to their perceptions of endometriosis. Within the quantitative component of the current research, for example, there was little variation between participants in their IPs and wellbeing outcomes, indicating that the majority of participants held negative views of their condition and were adversely impacted by endometriosis. As individuals were recruited from the quantitative survey for qualitative interviews, this is likely to hold true for the individuals recruited for this element of the research.

Nonetheless, one point of divergence between the qualitative and quantitative elements of the current research was identified. In the quantitative component, perceptions around treatment and personal control were weakly correlated with the measured outcome variables. Treatment control in particular demonstrated low correlation coefficients with each outcome variable. This is perhaps unsurprising due to the lack of effective treatment currently available for endometriosis (see chapter 1), meaning that most individuals likely perceive low control around their treatment. However, the qualitative component of the current research diverges from this observation, instead finding that perceptions of control, particularly around the treatment of endometriosis, had a marked impact on HRQoL and wellbeing. For example, many participants highlighted a sense of powerlessness surrounding their treatment options, which negatively impacted on their life trajectory by fuelling notions that their symptoms would never improve despite medical intervention. The idea that endometriosis was controlling their lives was voiced by several participants, which was directly linked to other IPs such as the emotional representation of the condition, anticipated consequences, and identification with symptoms.

One possible explanation for the observed divergence may be that interviewees had particularly negative experiences and perceptions around control. Although a sampling matrix was employed at the recruitment stage of the qualitative study, this was used to recruit a demographically diverse sample and as such the severity of endometriosis and IPs were not considered during recruitment. Future research of this nature may therefore aim to recruit a diverse sample of participants in terms of endometriosis severity as well as demographics. Additionally, it is likely that the quantitative element of the current study did not obtain enough information relating to control to capture the nuances within participant accounts. Specifically, there is a clear thread running throughout the qualitative component of the current study that perceptions of control do not work in isolation, instead they combine with and colour other IPs and the coping strategies employed by participants to collectively impact on HRQoL and wellbeing. By asking just one question related to treatment control within the B-IPQ (Broadbent et al., 2006), the interconnectedness between control and alternate psychosocial factors is potentially lost within the quantitative component of the current research. Therefore, it is only through obtaining more in-depth, rich data through qualitative work that these connections may be illuminated.

Considering that the treatment currently available for endometriosis-related pain and symptomology is often ineffective at relieving symptoms (see chapter 1, section 1.3.4), interventions focussed on increasing perceptions of control may exert minimal impact on HRQoL and wellbeing outcomes. Instead, it may be more appropriate for future interventions to support individuals to arrive at a point of acceptance with their condition. In this case, acceptance refers to recognising and coming to terms with the full spectrum of thoughts and feelings associated with endometriosis, rather than trying to avoid or change them (Hughes et al., 2017). Acceptance is the cornerstone of ACT. ACT has successfully prompted improvements in anxiety, depression, and functioning in chronic pain patients by increasing pain acceptance and promoting living well with chronic symptoms

(Hughes et al., 2017). Therefore, examining the effectiveness of ACT in improving HRQoL in the context of endometriosis would be beneficial.

7.5 Strengths and limitations

The current research is the first to comprehensively consider the role of IPs in predicting endometriosis-related outcomes. Establishing coping as a mediator between IPs and outcomes provides strong evidence in support of the CSM-SR (Leventhal et al., 2016), paving the way for the development of psychosocial intervention to support the wellbeing of individuals experiencing endometriosis. The mixed-methods nature of the present research means that broad, generalisable data is obtained as well as a rich, in-depth narrative of participants' experiences of living with endometriosis. The integration of quantitative and qualitative methodological approaches paints a detailed picture of the complex and nuanced experiences of those living with endometriosis, and the vast ways in which these experiences colour HRQoL and wellbeing. In addressing similar research questions, both elements of the current research establish psychosocial variables such as IPs and coping mechanisms as key to psychological wellbeing and HRQoL in this population.

Furthermore, the longitudinal nature of the current research means that the predictive validity of a range of psychosocial variables may be gauged. In turn, the interconnectedness between these psychosocial variables, such as IPs and coping, is highlighted within participants' accounts of their experiences. Collectively, the current research provides a compelling and rich account of the mechanisms underpinning wellbeing outcomes within this population. In chapter 1, it was highlighted that individuals with endometriosis often feel unheard, with their concerns dismissed and minimised regularly in both societal and medical settings (Grundström et al., 2018; Rowe et al., 2021). The current study acknowledges this, ensuring that participants' voices are front and centre within both elements of the research, by: i) providing a rich narrative of participant experiences within the qualitative component; ii) piloting the quantitative survey with a sub-group of participants to ensure it captured their experiences; iii) including an open-ended question at the end of the survey to allow participants to expand on their responses. Resultantly, participant accounts are rich and reflective.

A further strength of the current study lies in the use of a sampling matrix to recruit a diverse sample of individuals for the qualitative interviews. Taking this approach was essential to offset the issues arising from survey recruitment and to ensure that individuals from a range of demographic backgrounds were represented within the current research.

Nonetheless, the present research must be viewed in light of its potential limitations, as well as its strengths. Firstly, the research was conducted in the midst of COVID-19 induced lockdowns across the UK. This may have exerted an adverse effect on wellbeing and mood, particularly at the time that the first survey was distributed, and when interviews were conducted. General measures of depressed mood, stress, and anxiety were used within the current research, so it is likely that these variables were negatively affected by UK-wide lockdowns, which have been linked to increased psychological distress (O'Connor et al., 2021). The inclusion of a COVID-specific stress measure may have mitigated against this potential impact. However, at the time of designing the current research, COVID-specific measures were in their infancy and the validity and reliability of these scales was largely unknown. Additionally, COVID-19 did not emerge as a prominent driver of mental health and wellbeing outcomes during the interviews, indicating that other factors, such as invalidation, dismissal, and the anticipated consequences of experiencing endometriosis may be more strongly linked to wellbeing and HRQoL. Nonetheless, in both the qualitative and quantitative components of the current study, treatment delay was linked to wellbeing. COVID-19 derived lockdowns meant that access to medical support was limited amongst individuals experiencing endometriosis (Leonardi et al., 2020), and therefore it is likely that there was an indirect impact of COVID-19 on outcomes. Consequently, future research could endeavour to establish the impact of psychosocial variables such as IPs and coping on mental wellbeing and HRQoL out-with the challenges posed by COVID-19.

Additionally, previous research has linked several variables to endometriosis-related QoL and wellbeing, including trauma (Liebermann et al., 2018) and emotional trait intelligence (Barberis et al., 2022). These factors were missing from the current research, but may have influenced the outcomes. However, due to the wide-ranging scope of the current research, incorporating comprehensive assessments of trauma and emotional trait intelligence was beyond the capacity of the project. Future research may benefit from including these aspects to provide a more nuanced understanding of their potential impact on HRQoL and wellbeing amongst individuals with endometriosis. Moreover, exploring these variables may contribute to the development of more targeted interventions and support strategies for individuals affected by endometriosis.

A further limitation of the current study was the lack of demographical variation between participants. Within the quantitative element, participants were largely university-educated, in a relationship, and in full or part-time work. Additionally, the majority of participants who completed the longitudinal survey identified as White, and the lack of heterogeneity amongst participants meant that the impact of ethnicity on outcomes could not be gauged through quantitative analysis. The underrepresentation of individuals from non-White background is a prevalent issue in research on endometriosis, and serves as the catalyst for a snowball effect whereby the scarcity of data has fuelled misconceptions, including the notion that Black individuals are less likely to have endometriosis compared to White or Asian Pacific individuals (Bougie et al., 2022). This, in turn, has significant implications for diagnoses, in that individuals from non-White backgrounds may be more likely to experience dismissal or delays in obtaining a diagnosis of endometriosis (Bougie et al., 2022). It should be noted that the qualitative component of the current research endeavoured to recruit a diverse sample of participants to offset these potential issues. Correspondingly, during interviews, participants from diverse ethnic backgrounds disclosed shared barriers to support, including the dismissal and minimisation of their concerns. Ethnicity was not a prominent theme within participant accounts, and therefore, the barriers in support appeared to be universal. However, it must be noted that over two-thirds of the individuals who participated in the interviews (n = 21) identified as White, and the remaining 9 participants identified with varied ethnicities including Black, Asian, Indian, and Pakistani backgrounds. Therefore, the nuances in participant experience in relation to ethnicity may have been lost due to the lack of representation of specific ethnic backgrounds. For example, previous research has found that Black women face distinct barriers to diagnosis and support compared to women identifying with other ethnic backgrounds (Bougie et al., 2022), to the extent that it is commonly believed that Black women rarely develop endometriosis in the US (Kyama et al, 2007). As the qualitative component of the present study incorporated only 2 individuals identifying as Black, it is likely that such experiences are not common through the entirety of the transcripts and these experiences were therefore lost during analysis. Additionally, due to the nature of qualitative data, direct comparisons between individuals of different ethnic backgrounds are not feasible. Therefore, it is vital that future endometriosis research seeks to identify ways to include individuals from various ethnic backgrounds to dispel widespread misconceptions around the experience of endometriosis.

Finally, gender identity was not considered in the quantitative element of the current research. A small but growing number of studies have observed adverse healthcare experiences amongst non-binary and transgender individuals (Cicero et al., 2019). For example, through a series of focus groups, Bindman et al. (2022) found that non-binary individuals commonly experienced invalidation and dismissal in relation to their symptoms, and experienced the pathologising of their symptoms within medical settings. These findings are particularly relevant in the context of endometriosis, in which symptom dismissal and minimisation are widespread. Additionally, a qualitative systematic review including 874 transgender male participants revealed several challenges in navigating gynaecological healthcare (Sbragia & Vottero, 2020). Predominantly, the binary nature of healthcare, which does not allow for variation in gender, led to distress amongst transgender men, causing many to delay or reject support. Many experienced discrimination including misgendering and the pathologising of their symptoms. Although the quantitative element of the current research did not account for gender, one non-binary individual participated in the qualitative interviews. Their experience largely converged with previous research findings, in that they experienced invalidation and misgendering within gynaecological settings. Additionally, the participant noted a sense of gender dysphoria derived from their attendance at women’s health clinics and in gynaecological settings, which had a marked impact on their wellbeing and HRQoL. Therefore, future research may consider participants’ gender identity in the context of endometriosis, as it is likely that the barriers to gynaecological support experienced by non-gender conforming and transgender individuals impact upon their self-concept and overall wellbeing, which may subsequently impede on their HRQoL and wellbeing in this context.

7.6 Implications and future research directions

This section of the current chapter will consider the implications of the above findings, as well as potential avenues for further investigation.

The current research upholds the finding that endometriosis has a detrimental impact on both HRQoL and mental wellbeing. Pain and endometriosis-specific symptoms are key factors underpinning these detriments. Therefore, the identification of effective treatment for endometriosis-related symptoms is likely to yield the most positive and restorative effect on HRQoL and wellbeing outcomes in this population. Consequently, it is essential that research continues to seek a cure and/or effective treatment for endometriosis to aid wellbeing.

Nonetheless, it is clear through the findings of the current study that individuals living with endometriosis experience a lack of psychological and emotional support within medical settings following diagnosis, leading to a sense of isolation and adverse wellbeing outcomes. Therefore, the implementation of effective psychological interventions is likely to mitigate some of the negative impact of endometriosis on HRQoL and wellbeing. To build such interventions, it is essential that research continues to investigate the potential factors underpinning HRQoL, alongside pain and endometriosis-specific symptoms. Relatedly, the current research positions IPs and coping as key mechanisms underpinning HRQoL and wellbeing in this population. These findings uphold the CSM-SR (Leventhal et al., 2016), indicating that interventions based on this framework may be beneficial for individuals experiencing endometriosis. Specifically, psychological interventions targeting elements such as negative IPs and maladaptive coping strategies may support wellbeing within this population. Of particular interest in this context are CBT and ACT, which aim to challenge maladaptive coping styles and promote acceptance in the context of chronic illness.

The results of the current study indicate that IPs combine and influence one another to create an overall impact on wellbeing outcomes. Therefore, designing psychological interventions to improve collective IPs could be beneficial. Nonetheless, as IPs are interconnected, interventions aimed at improving one IP may prompt improvements in others. To exemplify, in the current study, perceptions around the negative consequences of endometriosis were prominent, particularly within the qualitative component. Consequently, interventions to reframe perceptions of the negative consequences associated with endometriosis may, for example, lead to improvements in the emotional representation and concern related to endometriosis, culminating in overall improvements in HRQoL and mental wellbeing. Therefore, future research may examine the effectiveness and appropriateness of IP-based interventions in this population by examining the impact on wellbeing associated with such support.

Additionally, the current study observed a negative effect of maladaptive and avoidant coping styles, such as withdrawal and rumination, on mental wellbeing. Although proactive coping strategies, such as support seeking, had a protective impact on mental wellbeing, the use of maladaptive coping styles exhibited a stronger effect on wellbeing outcomes. This indicates that interventions aimed at reducing the use of maladaptive, avoidant coping strategies would be particularly beneficial with individuals experiencing endometriosis.

As previously mentioned, CBT is often implemented to target and modify maladaptive coping styles (Khoo et al., 2019). CBT has been used with individuals experiencing several chronic conditions, including chronic pain and multiple sclerosis (Khoo et al., 2019; Shareh & Robati, 2020), with research indicating that this type of therapy is effective in supporting mental wellbeing (Khoo et al., 2019). For example, in a meta-analysis on chronic pain conditions, CBT was linked with improved mood and lessened pain catastrophising (Williams et al., 2012). In the context of endometriosis specifically, a small but growing number of studies have linked the provision of CBT-based therapies to improvements in depression, stress, and HRQoL (Donatti et al., 2022). However, at the time of writing there is a lack of high-quality research assessing the long-term impact of CBT-based therapies on wellbeing outcomes in this population (Van Niekerk et al., 2019). Therefore, additional longitudinal research is required before strong conclusions can be drawn around the effectiveness of CBT interventions in this population.

The current research highlights adaptation as central to mental wellbeing in the context of endometriosis. For example, individuals who had positively adapted in response to their endometriosis symptoms and experiences were more likely to reach a point of acceptance in their condition, as exemplified within the qualitative component of this study. This observation aligns with previous chronic pain research demonstrating a link between adaptive goal processes and mental wellbeing (Swindells et al., 2023). Psychological treatment approaches such as ACT have been linked to positive adaptation and a subsequent increase in mental wellbeing in a range of chronic conditions, including inflammatory bowel disease (Wynne et al., 2019) and type 2 diabetes (Fayazbakhsh & Mansouri, 2019). Within this type of therapy, there is a focus on acceptance and living well with a chronic health condition. As participants within the current research generally perceived low levels of control over endometriosis, this type of therapy may support individuals to positively reframe their condition, by focussing on living a fulfilling life with endometriosis. At the time of writing, there is little research examining the impact of ACT on endometriosis-related outcomes. However, one study which implemented a mindfulness and acceptance intervention reported improvements in HRQoL and emotional wellbeing in this population (Hansen et al., 2023), establishing ACT as a promising avenue for further investigation. It should be noted that ACT is grounded in the principles of CBT (McCracken et al., 2004) and it is therefore difficult to definitively decide between recommending a CBT or ACT approach (Van Niekerk et al., 2019). However, incorporating elements of both CBT and ACT into future interventions is likely to be beneficial in supporting the wellbeing of individuals experiencing endometriosis. A combination of both techniques, for example, may support individuals to reshape their coping strategies, leading potentially to positive changes in IPs and an overall improvement in wellbeing and HRQoL. Nonetheless, further high-quality research is necessary to assess the effectiveness of both interventions. Specifically, longitudinal randomised control trials examining the impact of both types of therapeutic interventions (i.e., CBT and ACT) on wellbeing outcomes and/or IPs would enhance our understanding of the longitudinal impact of such interventions in the context of endometriosis.

Aside from more formal intervention routes, the current findings may support individuals experiencing endometriosis by providing a roadmap of the coping styles linked to improved HRQoL and wellbeing from the perspective of individuals experiencing the condition. Whilst the quantitative portion of the current thesis suggests that maladaptive, avoidant strategies are detrimental to mental wellbeing, the qualitative component illustrates this point by providing a series of detrimental coping strategies, such as social withdrawal and focussing on symptomology. These findings may support individuals experiencing endometriosis in terms of self-managing their symptoms. On a broader scale, support organisations may use this information to shape support sessions and groups in this context.

7.7 Conclusion

Overall, the current thesis took a mixed-methods approach to compile a detailed, comprehensive account of the factors underlying adverse HRQoL and mental wellbeing outcomes in the context of endometriosis. Specifically, psychosocial factors such as IPs and coping strategies were instrumental in moulding wellbeing and HRQoL in this population. More generally, endometriosis exerted a substantial negative impact on the mental wellbeing of individuals, promoting lessened QoL, increased stress, heightened depression, and anxiety. Pain intensity and disability were also influenced by psychosocial variables such as maladaptive, avoidant coping and negative IPs. Additionally, participants’ negative experiences in healthcare settings appeared to drive long-term adverse effects on wellbeing.

The observed findings have important implications for researchers and healthcare professionals. Specifically, the results have the potential to inform future psychosocial interventions for endometriosis, with a view to improving wellbeing outcomes in this population. Additionally, the findings indicate the necessity of streamlining the diagnostic journey within healthcare settings, which begins with acknowledging the concerns of individuals who present with endometriosis-like symptoms.

It is clear that the establishment of effective treatment to reduce the severity of endometriosis symptoms would likely yield the strongest, most positive impact on wellbeing and HRQoL within this population. However, in the absence of effective treatment, psychosocial interventions are likely to mitigate some of the detrimental impact of endometriosis on mental health and wellbeing factors. Therefore, it is important that future research endeavours to design and implement psychological support for this population, placing factors such as coping strategies, IPs, and positive adaptation at the forefront of such support.

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Appendices

APPENDIX A

Social media blurb

Call for participants for endometriosis research

If you are over 18, live in the UK and have a diagnosis of endometriosis, please consider taking part in this research, which aims to capture the experiences of those living with endometriosis.

In particular, we want to understand the factors related to quality of life and wellbeing in endometriosis. Working with relevant charities and organisations, we will then share our learning. We hope our research will contribute to the development of resources to support those living with endometriosis, to be utilised alongside medical and surgical treatment.

Participation involves completing a survey now, and a further survey in 12 months' time. You can find out more detailed information on our research by clicking the link and reading the information sheet, or by messaging me directly on chloe.moore.100@strath.ac.uk.

Please note: if you click the link, you are under no obligation to complete the survey and can leave at any time. You may withdraw your response by contacting me. The survey will take around 20 minutes to complete.

APPENDIX B

Recruitment poster

University of Strathclyde
Humanities & Social Sciences

UKRI
Economic and Social Research Council

Request for participants for endometriosis and quality of life research

Are you over 18, diagnosed with endometriosis and living within the UK?

Please consider completing our 15-minute online survey and sharing your experiences, by scanning the QR code below

Survey can also be accessed by visiting:
https://hass.eu.qualtrics.com/jfe/form/SV_5nY3dlyPmnBL6tg

For further details, please see the information sheet (accessible by scanning the QR code), or contact Chloe Moore on chloe.moore.100@strath.ac.uk

APPENDIX C

Baseline information sheet and consent form

An investigation into the experiences of individuals living with endometriosis

Name of department: School of Psychological Sciences and Health
Title of study: An investigation into the experiences of individuals living with endometriosis

Introduction

This research is being conducted by Chloe Moore, a PhD student from the University of Strathclyde under the supervision of Dr Lynn Williams and Dr Nicola Cogan. The contact details for the researchers are presented at the end of this form in case you have any questions at all about the study. Before deciding whether to take part in this study, please make sure that you read the sections below. You can return to this survey at a later stage as long as you access it from the same device as you are currently using to read this information. This means you can take all the time you need to decide whether you wish to continue with the study. Please note that if you change to a different device, you will be required to restart from the beginning of the survey.

What is the purpose of this research?

This project aims to investigate the experience of living with endometriosis. In particular, we want to understand the factors that are related to the quality of life and wellbeing of individuals living with endometriosis. Working with relevant charities and organisations, we will then share our learning, to help identify the types of support which may be helpful for individuals living with endometriosis.

Do you have to take part?

No, you do not – participation in this study is voluntary. Even if you do decide to start the survey, you can exit it at any stage up until the point of completion. As we will be asking for your contact details in order to invite you to take part in future surveys, you can request the withdrawal of this information from the project at any time by contacting the researcher using the contact details provided on this form. Doing so will mean that we will not contact you again to take part in any further research. In addition, when we do contact you to take part in a further survey or interview, you can still decide not to take part.

What will you do in the project?
Participation involves the completion of two online surveys. One of these will be completed now, and another will be sent to you in 12 months’ time. The survey will take around **20** minutes to complete and there is a progress bar for you to track how far through the survey you are. The follow-up survey at 12 months will include repeated questions from this initial survey to allow us to examine any changes over the year, however the number of questions will be slightly reduced. There is no time limit in which to complete the survey and you can return later to finish it so long as you use the same device you are currently accessing the survey on.

Why have you been invited to take part?

Anyone with a confirmed diagnosis of endometriosis, who is over the age of 18 and living in the UK is eligible to participate. Endometriosis diagnosis must be confirmed by a medical professional (e.g. following scan, surgery or other medical investigation which has identified endometriosis).

What are the potential risks to you in taking part?
Whilst we anticipate no risks to participants during this online survey, we understand that some of the questions ask you about your endometriosis and how you cope with it, and this may be uncomfortable for some participants. You can withdraw from the survey at any time if you are experiencing any discomfort or distress by closing the window. At the end of the survey you will also be presented with the contact details of the researchers and details of various support organisations should you feel any distress or discomfort. We have also provided details of these organisations below.

What information is being collected in the project?
The survey will first ask some information about you and your household and some information on your endometriosis diagnosis and symptoms. The next stage of the survey will ask you about your wellbeing, health-related quality of life, pain severity and several psychosocial factors, including your perceptions of your endometriosis and the way you cope. At the end of the questionnaire, you will be given the opportunity to write freely about the impact of endometriosis on your life. Please feel free to leave this box blank. We will also ask you to provide your email address and telephone number to allow us to get in contact with you for our second survey. You can skip any questions if you do not feel comfortable answering them. Once your data collection in the project is complete we will remove your contact details from our files. After this, you will not be able to withdraw your data, as your answers will be

completely anonymous, which means we will not be able to identify your specific responses.

Who will have access to the information?

Only the named researchers (contact details below) will have access to the information collected through the survey initially. Once all identifying information (email address, name) has been deleted and responses are completely anonymised, we will make our data available to other researchers. Since all identifying information has been removed you will be completely anonymous. Making data available to other researchers means that the data collected can be used for additional research aimed at understanding endometriosis and supporting those living with the condition, without collecting the same data again. It also allows for our analysis to be scrutinised and verified by others. Please note that any information you provide within the free-text box at the end of the survey will not be shared with any other researcher, to ensure your anonymity. We aim to publish results in peer reviewed journals and will write a short summary of our results which will be available through social media. We will share this summary with charities and support groups so our results may be used to develop resources to support individuals living with endometriosis. You can request a copy of the summary by contacting the researchers.

Where will the information be stored and how long will it be kept for?

During and after the study all information and data will be stored on the University of Strathclyde's secure servers. Your identifying information will be kept separate from your responses in a password protected spreadsheet, of which only the researchers listed on this sheet will have access to. We will allocate you a participant number and link this with your contact details to allow us to track your responses across the two stages of data collection. Following completion of the second survey, we will delete all identifying information and this password-protected spreadsheet before analysing the data. Once all data is completely anonymous, it will be shared through data sharing organisations to allow other researchers to analyse our data. No identifiable information will ever be shared. Thank you for reading this information – please ask any questions if you are unsure about what is written here. Please also read our Privacy Notice for Research Participants.

What happens next?

If you decide to participate, please select the "NEXT" option at the bottom of this page. You will be presented with a consent form to confirm that you wish to participate in this research. You can leave the study at any time, or return to the survey at a later date provided you are using the same device. If you do not wish to participate in this research, you can leave this webpage now. Thank you for your interest and attention. We cannot provide individual feedback on the outcomes of this research, however please contact any of the researchers (details below) if you have any queries or require further information.

Researcher contact details:
If you have any questions about this study, you can contact the researcher on the email address provided:

Chloe Moore
chloe.moore.100@strath.ac.uk

Chief Investigator details:
Chloe Moore is being supervised by Dr Lynn Williams and Dr Nicola Cogan. You can contact Dr Lynn Williams on lynn.williams@strath.ac.uk, and Dr Nicola Cogan on nicola.cogan@strath.ac.uk.

This research was granted ethical approval by the University of Strathclyde Ethics Committee.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:
Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G1 1QE
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Sources of Support:
If you are feeling uncomfortable, distressed or down, the following websites offer helpful support:

EXPPECT website:

https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-for-patients/helpful-links - contains a number of useful links and support for individuals living with endometriosis and/or pelvic pain.

Endometriosis UK:

https://endometriosis-uk.org/ - provides far-reaching support and in-depth information specifically for individuals living with endometriosis.

Mind:

www.mind.org.uk/: Mind provides comprehensive support and information for any issue regarding mental health. They also have a webchat for information and links to support including helplines and their own support community, called Side by Side. You can directly access the support community, Side by Side, by following this link: sidebyside.mind.org.uk/.

SHOUT text service:

If you are feeling distressed and need to speak with someone immediately, the SHOUT crisis text service will connect you instantly to a trained crisis worker who will speak with you through text. To access this service, text SHOUT to 85258. More information can be found here:
giveusashout.org/

Consent Form

Please check or tap each box below to confirm your consent / agreement with the following statements:

☐ I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.

☐ I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long.

☐ I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up until the data has been anonymised, without having to give a reason and without any consequences.

☐ I understand that I can request the withdrawal of my personal information from the study (i.e. my name, email address and telephone number) and that whenever possible researchers will comply with my request.

☐ I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.

☐ I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.

☐ I consent to be a participant in the project.

APPENDIX D

Full baseline survey

Please confirm whether you have been medically diagnosed with endometriosis (e.g. surgically, through laparoscopy, histologically, by scan):

○ I have been medically diagnosed with endometriosis

○ I have not been medically diagnosed with endometriosis

Display This Question:

If Please confirm whether you have been medically diagnosed with endometriosis (e.g. surgically... = I have not been medically diagnosed with endometriosis

Thank you for your interest in this survey.

The scope of this questionnaire is limited to those who have been medically diagnosed with endometriosis only due to crossover in symptoms between endometriosis and other chronic pelvic pain conditions. We understand that research into the experiences of those pre-diagnosis is required, and hope to be able to address this in future studies.

If you have any questions or require further information, please get in touch with Chloe Moore, on chloe.moore.100@strath.ac.uk.

Thank you again for your interest in the survey.

Skip To: End of Survey If Thank you for your interest in this survey. The scope of this questionnaire is limited to those... Is Displayed

End of Block: Screening

Start of Block: Contact Details

This is a two-part study that involves the completion of the following questionnaire and a second questionnaire in 12 months' time.

So that we can contact you for the second survey in 12 months' time and connect your first response to your second response, we will require your name and email address. This will be stored in a password-protected file and only accessible by the researchers. Once we have completed the project, any identifying and personal information will be removed and your data will be completely anonymised. Your contact details will only ever be used to contact you with regards to this project.

Please enter your details below:

○ Name: ____

○ E-mail address: ____

In the next 6 months, a researcher will get in contact with a small number of participants to invite them to an online interview to discuss their experiences further. This may take up to an hour.

Are you happy for us to contact you to invite you to take part in this **interview**? We can interview you over the phone or online using Zoom, Skype or Teams. No video footage will be recorded, but we will record audio - audio recordings will be anonymised and deleted as soon as the researcher has written a transcript of the conversation.

○ Yes, I would be interested in being contacted to participate in an online interview.

○ No, I would not like to be contacted to participate in an online interview.

End of Block: Contact Details

Start of Block: Demographics

In the following questions, please tell us about yourself:

What is your current age?

▼ 18 (1) ... Prefer not to say (50)

Please choose one option which best describes your ethnic group:

▼ Bangladeshi (1) ... Prefer not to say (24)

How would you describe your relationship status?

▼ Married (1) ... Prefer not to say (7)

Which of the following best describes your highest educational attainment to date?

▼ Left school with no qualifications (1) ... Prefer not to say (10)

Which of the following categories best describes your employment status

▼ Employed full-time (1) ... Prefer not to say (13)

What is the combined annual income of your household? (This refers to the total combined gross income of anyone over 18 living in your household).

▼ £0 - £9,999 (1) ... Prefer not to say (12)

Who do you share a household with?

▼ I live alone (1) ... Prefer not to say (8)

What is your Country of residence?

○ England (1)

○ Northern Ireland (2)

○ Scotland (3)

○ Wales (4)

○ Other (5) ____

End of Block: Demographics

Start of Block: Endometriosis Information

This section of the questionnaire asks you for some information regarding your endometriosis diagnosis and treatment.

For how long have you experienced symptoms of endometriosis? *Please provide an estimate if you are unsure.*

▼ Less than 1 year (21) ... Prefer not to say (122)

How long has it been (in years only) since you were diagnosed with endometriosis? *Please provide an estimate if you are unsure.*

▼ Less than 1 year (4) ... Prefer not to say (111)

How long has it been (in years) since you first approached your GP due to your endometriosis symptoms? *Please provide an estimate if you are unsure.*

▼ Less than 1 year (5) ... Prefer not to say (106)

Is your treatment for endometriosis through the NHS or private?

○ Treatment completely through NHS (1)

○ Treatment completely private (2)

○ Some private treatment and some NHS treatment (3)

○ Prefer not to say (4)

Are you diagnosed with another condition as well as endometriosis?

○ Yes (1)

○ No (2)

○ Prefer not to say (3)

Display This Question:

If Are you diagnosed with another condition as well as endometriosis? = Yes

If yes, please indicate which of the following conditions you are diagnosed with:
Select as many as applicable:

- ☐ Gastrointestinal Condition (e.g. Irritable Bowel Syndrome; Gastroenteritis) (4)
- ☐ Autoimmune condition (e.g. Colitis; Crohn's Disease; Rheumatoid Arthritis; Diabetes Mellitus (Type 1)) (9)
- ☐ Bladder Condition (e.g. Interstitial Cystitis; Painful Bladder Syndrome) (5)
- ☐ Respiratory Condition (e.g. Asthma) (7)
- ☐ Psychological Condition (e.g. Depression, Anxiety) (8)
- ☐ Cardiovascular Condition (e.g. Angina, Myocardial Infarction) (10)
- ☐ Fibromyalgia (6)
- ☐ Polycystic Ovary Syndrome (13)
- ☐ Other (please state) (11) ____
- ☐ Prefer not to say (12)

Please select the type of treatment(s) for endometriosis you have received in the past:
(*Please select all that apply*)

☐ Painkillers (such as co-codomol, NSAIDs) (1)

☐ Hormonal treatment (including the combined oral contraceptive pill, IUS, progestogen pills, the Mirena coil, implant, GnRH-a or treatment used to induce menopause) (2)

☐ Surgical treatment to remove endometrial tissue (e.g. excision or ablation of endometriosis through key-hole surgery) (3)

☐ Surgical treatment to remove part or all of the organs affected by endometriosis (e.g. hysterectomy) (4)

☐ Psychological support (e.g. pain clinic groups, cognitive behavioural therapy) (5)

☐ Physiotherapy (6)

☐ Herbal / non-traditional treatment (e.g. Chinese medicine) (7)

☐ Other (please state): (8)
____

☐ Prefer not to say (9)

Have you ever had surgery for endometriosis?

○ Yes (1)

○ No (2)

○ Prefer not to say (3)

Display This Question:

If Have you ever had surgery for endometriosis? = Yes

How many surgeries have you had for endometriosis?

▼ 1 (1) ... Prefer not to say (14)

Have you ever or are you currently trying for a baby?

▼ Yes (1) ... Prefer not to say (3)

Display This Question:

If Have you ever or are you currently trying for a baby? = Yes

How long did it take you to conceive / how long have you been trying to conceive?

▼ Less than 6 months (1) ... Prefer not to say (5)

End of Block: Endometriosis Information

Start of Block: Illness Perceptions

This section of the questionnaire asks about your perceptions of your endometriosis diagnosis and symptoms.

For the following statements, please select the number that best corresponds to your views.

How much does endometriosis affect your life?

▼ 0 - No affect at all (2) ... 10 - Severely affects my life (12)

For how long do you believe your endometriosis symptoms will continue?

▼ 0 - A very short time (2) ... 10 - Forever (12)

How much control do you feel you have over endometriosis?

▼ 0 - Absolutely no control (2) ... 10 - Extreme amount of control (12)

How much do you think treatment can help your endometriosis?

▼ 0 - Not at all (2) ... 10 - Extremely helpful (12)

How much do you experience symptoms of endometriosis?

▼ 0 - No symptoms at all (2) ... 10 - Many severe symptoms (12)

How concerned are you about your endometriosis?

▼ 0 - Not at all concerned (2) ... 10 - Extremely concerned (12)

How well do you understand your endometriosis?

▼ 0 - Do not understand at all (2) ... 10 - Understand very clearly (12)

How much does your endometriosis affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

▼ 0 - Not at all affected emotionally (2) ... 10 - Extremely affected emotionally (12)

There is currently no known cause for endometriosis, however, some individuals may have a strong belief regarding the cause of their condition.

If applicable, please list in rank-order up to three important factors that you believe caused your endometriosis. The most important causes for me:

If not applicable, please feel free to skip this question.

○ 1. (1) ____

○ 2. (2) ____

○ 3. (3) ____

End of Block: Illness Perceptions

Start of Block: PHQ-4 & PSS-4

This section asks about your wellbeing.

Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all (1)	Several days (2)	More than half the days (3)	Nearly every day (4)
Feeling nervous, anxious or on edge (1)	○	○	○	○
Not being able to stop or control worrying (2)	○	○	○	○
Little interest or pleasure in doing things (3)	○	○	○	○
Feeling down, depressed or hopeless (4)	○	○	○	○

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate how often you felt or thought a certain way.

	Never (1)	Almost never (2)	Sometimes (3)	Fairly often (4)	Very often (5)
In the last month, how often have you felt that you were unable to control the important things in your life? (1)	○	○	○	○	○
In the last month, how often have you felt confident in your ability to handle your personal problems? (2)	○	○	○	○	○
In the last month, how often have you felt that things were going your way? (3)	○	○	○	○	○
In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? (4)	○	○	○	○	○

End of Block: PHQ-4 & PSS-4

Start of Block: Endometriosis Health Profile 5

This section of the survey will ask you about your health-related quality of life during the last 4 weeks.

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

	Never (1)	Rarely (2)	Sometimes (3)	Always (5)	Often (4)
Found it difficult to walk because of the pain? (1)	○	○	○	○	○
Felt as though your symptoms are ruling your life? (2)	○	○	○	○	○
Had mood swings? (3)	○	○	○	○	○
Felt others do not understand what you are going through? (4)	○	○	○	○	○
Felt your appearance has been affected? (5)	○	○	○	○	○

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

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	Not relevant (6)
Been unable to carry out duties at work because of the pain? (1)	○	○	○	○	○	○
Found it difficult to look after your child/children? (2)	○	○	○	○	○	○
Felt worried about having intercourse because of the pain? (3)	○	○	○	○	○	○
Felt the doctor(s) think it is all in your mind? (4)	○	○	○	○	○	○
Felt frustrated because treatment is not working? (5)	○	○	○	○	○	○
Felt depressed at the possibility of not having children / more children? (6)	○	○	○	○	○	○

End of Block: Endometriosis Health Profile 5

Start of Block: Essen Coping Questionnaire

This section of the questionnaire asks you about how you cope with your endometriosis diagnosis and symptoms.

How do you deal with your condition? Please read each statement and select the appropriate answer:

	Not at all (1)	Somewhat (2)	Moderately (3)	Strongly (4)	Extremely (5)
I actively look for information about my condition in books, magazines or the internet (1)	○	○	○	○	○
I visit other people or invite them to visit me (2)	○	○	○	○	○
I try to find distance and rest (3)	○	○	○	○	○
I make plans and stick to them (4)	○	○	○	○	○
I lose myself in daydreams (5)	○	○	○	○	○
I solve problems step by step (6)	○	○	○	○	○
I try to distract myself and recover (7)	○	○	○	○	○
I exchange experiences in dealing with the condition with other patients (8)	○	○	○	○	○
I recollect previous experiences with blows of fate (9)	○	○	○	○	○

I look for alternative cures or methods of treatment (10)	○	○	○	○	○
I pick myself up through prayer, meditation or intense contact with nature (11)	○	○	○	○	○
I try to actively tackle my problems (13)	○	○	○	○	○
I refuse to accept my condition (14)	○	○	○	○	○
I find out as much as possible about my condition (15)	○	○	○	○	○
I start to open up towards other people (16)	○	○	○	○	○
I follow the medical advice very closely (17)	○	○	○	○	○
I spend good times with other people (18)	○	○	○	○	○
I start to indulge myself (19)	○	○	○	○	○
I have doubts that my medical treatment is good enough (20)	○	○	○	○	○

I seek contact with other people who have experienced a similar situation (21)	○	○	○	○	○
I become irritated and impatient with other people (22)	○	○	○	○	○
I reassure myself (23)	○	○	○	○	○
I keep on living as if nothing has happened (24)	○	○	○	○	○
I trust my doctors (25)	○	○	○	○	○
I start feeling sorry for myself (26)	○	○	○	○	○
I start to see my situation realistically and act accordingly (27)	○	○	○	○	○
I try to figure out how to come to terms with my condition (28)	○	○	○	○	○
I start to see a purpose in the condition (29)	○	○	○	○	○
I withdraw from other people (30)	○	○	○	○	○

I start to show my feelings to other people (31)	○	○	○	○	○
I pray and seek solace in faith (32)	○	○	○	○	○
I go out with friends (33)	○	○	○	○	○
I mistrust the doctors and have the diagnosis checked (34)	○	○	○	○	○
I accept help from other people (35)	○	○	○	○	○
I am angry with my fate (36)	○	○	○	○	○
I seek success and self-affirmation (37)	○	○	○	○	○
I start to accept the condition as my fate (38)	○	○	○	○	○
I actively make new acquaintances or refresh old acquaintances (39)	○	○	○	○	○
I downplay the significance and importance (40)	○	○	○	○	○
I start to think and ponder (41)	○	○	○	○	○

I have a high degree of confidence in my medical treatment (42)	○	○	○	○	○
I regain my inner strength (43)	○	○	○	○	○
I do not think about my illness anymore (44)	○	○	○	○	○
I try to help other people (45)	○	○	○	○	○
I like to be looked after and taken care of (46)	○	○	○	○	○

End of Block: Essen Coping Questionnaire

Start of Block: Chronic Pain Grade

The severity of chronic pain can be graded based on its characteristics and its impact on a person's activities. Please select the option that best fits your experience:

How would you rate your pain on a 0-10 scale at the present time?

▼ 0: No pain at all (1) ... 10: Pain as bad as it could be (16)

During the past 6 months, how intense was your worst pain?

▼ 0: No pain at all (1) ... 10: Pain as bad as it could be (13)

During the past 6 months on average how intense was your pain?

▼ 0: No pain at all (1) ... 10: Pain as bad as it could be (13)

In the past 6 months how much has pain interfered with your daily activities?

▼ 0: No interference (1) ... 10: Unable to carry out any activities (13)

In the past 6 months how much has pain changed your ability to take part in recreational social and family activities?

▼ 0: No change (1) ... 10: Extreme change (13)

In the past 6 months how much has the pain changed your ability to work (including housework)?

▼ No change (1) ... 10: Extreme change (20)

About how many days in the past 6 months have you been kept from your usual activities because of your pain?

▼ 0-6 days (4) ... 30 days or over (7)

End of Block: Chronic Pain Grade

Start of Block: Self-efficacy

We would like to know how confident you are in doing certain activities. For each of the following questions, please select the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident do you feel that you can keep the fatigue caused by your endometriosis from interfering with the things you want to do?

▼ 0: Not at all confident (1) ... 10: Totally confident (11)

How confident do you feel that you can keep the physical discomfort or pain of your endometriosis from interfering with the things you want to do?

▼ 0: Not at all confident (1) ... 10: Totally confident (11)

How confident do you feel that you can keep the emotional distress caused by your endometriosis from interfering with the things you want to do?

▼ 0: Not at all confident (1) ... 10: Totally confident (11)

How confident do you feel that you can keep other symptoms or health problems you have from interfering with the things you want to do?

▼ 0: Not at all confident (1) ... 10: Totally confident (11)

How confident do you feel that you can do the different tasks and activities needed to manage your endometriosis so as to reduce your need to see a doctor?

▼ 0: Not at all confident (1) ... 10: Totally confident (11)

How confident do you feel that you can do things other than taking medication to reduce how much your endometriosis affects your everyday life?

▼ 0: Not at all confident (1) ... 10: Totally confident (11)

End of Block: Self-efficacy

Start of Block: Perceived Social Support

The next section of the questionnaire asks about the social support around you at present.

Please select the answer that best reflects your views:

	Not true at all (1)	Somewhat not true (2)	Unsure (3)	Somewhat true (4)	Very true (5)
I receive a lot of understanding and security from others (1)	○	○	○	○	○
There is someone very close to me whose help I can always rely on (2)	○	○	○	○	○
If I need to, I can borrow something from friends or neighbours without any problems (3)	○	○	○	○	○
I know several people with whom I like to do things (4)	○	○	○	○	○
When I am sick, I can ask friends or relatives to handle important things for me without hesitation (5)	○	○	○	○	○
If I'm very depressed, I know who I can turn to (6)	○	○	○	○	○

End of Block: Perceived Social Support

Start of Block: Free Text

Please feel free to use this box to provide any further details which have **not** already been covered in the questionnaire about the ways in which your endometriosis symptoms and diagnosis have affected your life, and about how you think and feel about your endometriosis.

You can also choose to leave this box blank.

____

____

____

____

____

End of Block: Free Text

Start of Block: Recruitment Stream

Where did you hear about this survey?

○ Endometriosis UK (1)

○ Endo Warriors WL (2)

○ Other Support group (6)

○ Twitter (3)

○ Facebook (4)

○ Word of mouth (5)

○ Other (please state) (7)

____

○ Prefer not to say (8)

End of Block: Recruitment Stream

APPENDIX E

Debrief for baseline survey

Debrief

Name of department: School of Psychological Sciences and Health
Title of the study: An investigation into the experiences of individuals living with endometriosis

Thank you for completing this survey. We hope that the results will help us to understand some of the factors related to the quality of life and wellbeing of individuals living with endometriosis. Once our second survey has been sent out and completed by our participants in 12 months' time, we will share our learning with relevant support groups and charities to help identify the types of support which may be helpful for individuals living with endometriosis. Once again, we would like to remind you that any personal information you have provided will remain confidential and no identifiable information will be used in any reports or publications arising from this research. Your contact details will be retained until you have completed our follow-up survey in 12 months' time, at which point they will be deleted and the information you have provided will be completely anonymised. If you would like to remove your personal information from our database before this time, please contact Chloe Moore (details below). Doing so will mean that we will not contact you again to take part in any further research and your details will be deleted.

Further contact from us: We will be in touch with you again via email in 12 months to ask you to complete another survey.

Sources of support: If you have any concerns regarding your own responses to the questions within this survey, we recommend that you contact your GP in the first instance. If you are feeling uncomfortable, distressed or down, the following websites offer helpful support:

EXPPECT website:
https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-

for-patients/helpful-links - contains a number of useful links and support for individuals living with endometriosis and/or pelvic pain.

Endometriosis UK:
https://endometriosis-uk.org/ - provides far reaching support and in-depth information specifically for individuals living with endometriosis.

Mind:
www.mind.org.uk/: Mind provides comprehensive support and information for any issue regarding mental health. They also have a webchat for information and links to support including helplines and their own support community, called Side by Side. You can directly access the support community, Side by Side, by following this link: sidebyside.mind.org.uk/.

SHOUT text service:
If you are feeling distressed and need to speak with someone immediately, the SHOUT crisis text service will connect you instantly to a trained crisis worker who will speak with you through text. To access this service, text SHOUT to 85258. More information can be found here:
giveusashout.org/

Contact details

If you have any questions about the study, please feel free to contact Chloe Moore on chloe.moore.100@strath.ac.uk.

Alternatively, you can contact Dr Lynn Williams, who is supervising the project, on lynn.williams@strath.ac.uk.

APPENDIX F

Information sheet and consent form for follow-up survey

An investigation into the experiences of individuals living with endometriosis: Follow-up

Name of department: School of Psychological Sciences and Health

Title of the study: An investigation into the experiences of individuals living with endometriosis

Introduction

This research is being conducted by Chloe Moore, a PhD student from the University of Strathclyde under the supervision of Dr Lynn Williams and Dr Nicola Cogan. The contact details for the researchers are presented at the end of this form in case you have any questions at all about the study. Before deciding whether to take part in this study, please make sure that you read the sections below. You can return to this survey at a later stage as long as you access it from the same device as you are currently using to read this information. This means you can take all the time you need to decide whether you wish to continue with the study.

What is the purpose of this research?

Last year, you participated in a survey about your experiences of endometriosis and were advised that we would like to follow-up with you 12-months after completion of the survey. Therefore, this survey aims to follow-up on your experiences of living with endometriosis over the last 12-months. This will help us to understand the factors related to the quality of life and wellbeing of individuals living with endometriosis. Working with relevant charities and organisations, we aim to share our learning, to help identify the types of support which may be helpful for individuals living with endometriosis.

Do you have to take part?

No, you do not – participation in this study is voluntary. Even if you do decide to start the survey, you can exit it at any stage up until the point of completion. Once you have completed this survey, your contact details will be removed from our system and you will not be contacted again. Therefore, your responses will be completely anonymous.

What will you do in the project?

You are being invited to participate in a 10-minute survey detailing your experiences of endometriosis. There is no time limit in which to complete the survey and you can return later to finish it so long as you use the same device you are currently accessing the survey on.

Why have you been invited to take part?
Anyone with a confirmed diagnosis of endometriosis, who is over the age of 18 and living in the UK is eligible to participate. Endometriosis diagnosis must be confirmed by a medical professional (e.g. following scan, surgery or other medical investigation which has identified endometriosis). You are specifically being contacted because you took part in the first wave of the survey last year.

What are the potential risks to you in taking part?
Whilst we anticipate no risks to participants during this online survey, we understand that some of the questions ask you about your endometriosis and how you cope with it, and this may be uncomfortable for some participants. You can withdraw from the survey at any time if you are experiencing any discomfort or distress by closing the window. At the end of the survey you will also be presented with the contact details of the researchers and details of various support organisations should you feel any distress or discomfort. We have also provided details of these organisations below.

What information is being collected in the project?
The survey will first ask about any treatment you have had in the last 12 months, since the completion of the initial survey. The next stage of the survey will ask you about your wellbeing, health-related quality of life, pain severity and several psychosocial factors, including your perceptions of your endometriosis and the way that you cope. You can skip any questions if you do not feel comfortable answering them. Once you have completed the survey, we will remove your contact details from our files and you will not be contacted by the researchers again. After this point, you will not be able to withdraw your data as your answers will be completely anonymous, which means we will not be able to identify your specific responses.

Who will have access to the information?
Only the named researchers (contact details below) will have access to the information collected through the survey initially. Once all identifying information (email address, name) has been deleted and responses are completely anonymised, we will make our data available to other researchers. Since all identifying information has been removed you will be completely anonymous. Making data available to other researchers means that the data collected can be used for additional research aimed at understanding endometriosis and supporting those living with the condition, without collecting the same data again. It also allows for our analysis to be scrutinised and verified by others. We aim to publish results in peer-reviewed journals and will write a short summary of our results which will be available through social media. We will share this summary with charities and support groups so our results may be used to develop resources to support individuals living with endometriosis. You can request a copy of the summary by contacting the researchers.

Where will the information be stored and how long will it be kept for?

During and after the study all information and data will be stored on the University of Strathclyde's secure servers. Your identifying information has been kept separate from your responses in a password protected spreadsheet, of which only the researchers listed on this sheet have access to. We have allocated you a participant number and have linked this with your contact details to allow us to track your responses across the two stages of data collection. Following completion of this final survey, we will delete all identifying information (i.e. contact information) and the password-protected spreadsheet before analysing the data. Once all data is completely anonymous, it will be shared through data sharing organisations to allow other researchers to analyse our data. No identifiable information will ever be shared.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

Please also read our Privacy Notice for Research Participants.

What happens next?
If you decide to participate, please select the "NEXT" option at the bottom of this page. You can leave the study at any time or return to the survey at a later date provided you are using the same device. If you do not wish to participate in this research, you can leave this webpage now. Thank you for your interest and attention. We cannot provide individual feedback on the outcomes of this research, however please contact any of the researchers (details below) if you have any queries or require further information.

Researcher contact details:
If you have any questions about this study, you can contact the researcher on the email address provided:
Chloe Moore: chloe.moore.100@strath.ac.uk

Chief Investigator details:
Chloe Moore is being supervised by Dr Lynn Williams and Dr Nicola Cogan. You can contact Dr Lynn Williams on lynn.williams@strath.ac.uk, and Dr Nicola Cogan on nicola.cogan@strath.ac.uk.

This research was granted ethical approval by the University of Strathclyde Ethics Committee. If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street

Glasgow
G1 1QE
Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Sources of Support: If you are feeling uncomfortable, distressed or down after completing this survey, the following websites offer helpful support:

EXPPECT website: https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-for-patients/helpful-links - contains a number of useful links and support for individuals living with endometriosis and/or pelvic pain.

Endometriosis UK: https://endometriosis-uk.org/ - provides far reaching support and in-depth information specifically for individuals living with endometriosis.

Mind: www.mind.org.uk/: Mind provides comprehensive support and information for any issue regarding mental health. They also have a webchat for information and links to support including helplines and their own support community, called Side by Side. You can directly access the support community, Side by Side, by following this link: sidebyside.mind.org.uk/.

SHOUT text service: If you are feeling distressed and need to speak with someone immediately, the SHOUT crisis text service will connect you instantly to a trained crisis worker who will speak with you through text. To access this service, text SHOUT to 85258. More information can be found here: giveusashout.org/

Consent Form
Please check or tap each box below to confirm your consent / agreement with the following statements:

- ☐ I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction. (1)

- ☐ I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long). (2)

☐ I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up until the data has been anonymised, without having to give a reason and without any consequences. (3)

☐ I understand that I can request the withdrawal of my personal information from the study (i.e. my name, email address and telephone number) and that whenever possible researchers will comply with my request. (4)

☐ I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study. (5)

☐ I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available. (6)

☐ I consent to be a participant in the project. (7)

APPENDIX G

Full follow-up survey

This is a follow-up survey for a questionnaire you completed last year.

So that we can connect your first response to your second response, we will require your name and email address. This will be stored in a password-protected file and only accessible by the researchers. Once we have completed analysis for the project, any identifying and personal information will be removed and your data will be completely anonymised. Your contact details will only ever be used to contact you with regards to this project, and once we have connected your responses we will remove your personal details from our system.

Please enter your details below:

○ Name (1) ____

○ E-mail address: (2) ____

End of Block: Contact Details

Start of Block: Endometriosis Information

This section of the questionnaire asks you for some information regarding your endometriosis diagnosis and treatment.

Please select the type of treatment(s) for endometriosis you have received in the **last 12 months**:
(*Please select all that apply*)

- ☐ Painkillers (such as co-codomol, NSAIDs) (1)
- ☐ Hormonal treatment (including the combined oral contraceptive pill, IUS, progestogen pills, the Mirena coil, implant, GnRH-a or treatment used to induce menopause) (2)
- ☐ Surgical treatment to remove endometrial tissue (e.g. excision or ablation of endometriosis through key-hole surgery) (3)
- ☐ Surgical treatment to remove part or all of the organs affected by endometriosis (e.g. hysterectomy) (4)
- ☐ Psychological support (e.g. pain clinic groups, cognitive behavioural therapy) (5)
- ☐ Physiotherapy (6)
- ☐ Herbal / non-traditional treatment (e.g. Chinese medicine) (7)
- ☐ Other (please state): (8) ____
- ☐ Prefer not to say (9)

Have you had surgery for endometriosis in the last 12 months?

- ○ Yes (1)
- ○ No (2)
- ○ Prefer not to say (3)

Display This Question:

If Have you had surgery for endometriosis in the last 12 months? = Yes

How many surgeries have you had for endometriosis in the last 12 months?

▼ 1 (1) ... Prefer not to say (14)

Have you ever or are you currently trying for a baby?

▼ Yes (1) ... Prefer not to say (3)

Display This Question:

If Have you ever or are you currently trying for a baby? = Yes

How long did it take you to conceive / how long have you been trying to conceive?

▼ Less than 6 months (1) ... Prefer not to say (5)

End of Block: Endometriosis Information

Start of Block: Illness Perceptions

This section of the questionnaire asks about your perceptions of your endometriosis diagnosis and symptoms.

For the following statements, please select the number that best corresponds to your views.

How much does endometriosis affect your life?

▼ 0 - No affect at all (0) ... 10 - Severely affects my life (10)

For how long do you believe your endometriosis symptoms will continue?

▼ 0 - A very short time (0) ... 10 - Forever (10)

How much control do you feel you have over endometriosis?

▼ 0 - Absolutely no control (0) ... 10 - Extreme amount of control (10)

How much do you think treatment can help your endometriosis?

▼ 0 - Not at all (0) ... 10 - Extremely helpful (10)

How much do you experience symptoms of endometriosis?

▼ 0 - No symptoms at all (0) ... 10 - Many severe symptoms (10)

How concerned are you about your endometriosis?

▼ 0 - Not at all concerned (0) ... 10 - Extremely concerned (10)

How well do you understand your endometriosis?

▼ 0 - Do not understand at all (0) ... 10 - Understand very clearly (10)

How much does your endometriosis affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

▼ 0 - Not at all affected emotionally (0) ... 10 - Extremely affected emotionally (10)

There is currently no known cause for endometriosis, however, some individuals may have a strong belief regarding the cause of their condition.

If applicable, please list in rank-order up to three important factors that you believe caused your endometriosis. The most important causes for me:

If not applicable, please feel free to skip this question.

○ 1. (1) ____

○ 2. (2) ____

○ 3. (3) ____

End of Block: Illness Perceptions

Start of Block: PHQ-4 & PSS-4

This section asks about your wellbeing.

Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all (1)	Several days (2)	More than half the days (3)	Nearly every day (4)
Feeling nervous, anxious or on edge (1)	○	○	○	○
Not being able to stop or control worrying (2)	○	○	○	○
Little interest or pleasure in doing things (3)	○	○	○	○
Feeling down, depressed or hopeless (4)	○	○	○	○

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate how often you felt or thought a certain way.

	Never (1)	Almost never (2)	Sometimes (3)	Fairly often (4)	Very often (5)
In the last month, how often have you felt that you were unable to control the important things in your life? (1)	○	○	○	○	○
In the last month, how often have you felt confident in your ability to handle your personal problems? (2)	○	○	○	○	○
In the last month, how often have you felt that things were going your way? (3)	○	○	○	○	○
In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? (4)	○	○	○	○	○

End of Block: PHQ-4 & PSS-4

Start of Block: Endometriosis Health Profile 5

This section of the survey will ask you about your health-related quality of life during the last 4 weeks.

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

	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
Found it difficult to walk because of the pain? (1)	○	○	○	○	○
Felt as though your symptoms are ruling your life? (2)	○	○	○	○	○
Had mood swings? (3)	○	○	○	○	○
Felt others do not understand what you are going through? (4)	○	○	○	○	○
Felt your appearance has been affected? (5)	○	○	○	○	○

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

	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)	Not relevant (-9)
Been unable to carry out duties at work because of the pain? (1)	○	○	○	○	○	○
Found it difficult to look after your child/children? (2)	○	○	○	○	○	○
Felt worried about having intercourse because of the pain? (3)	○	○	○	○	○	○
Felt the doctor(s) think it is all in your mind? (4)	○	○	○	○	○	○
Felt frustrated because treatment is not working? (5)	○	○	○	○	○	○
Felt depressed at the possibility of not having children / more children? (6)	○	○	○	○	○	○

End of Block: Endometriosis Health Profile 5

Start of Block: Chronic Pain Grade

The severity of chronic pain can be graded based on its characteristics and its impact on a person's activities. Please select the option that best fits your experience:

How would you rate your pain on a 0-10 scale at the present time?

▼ 0: No pain at all (0) ... 10: Pain as bad as it could be (10)

During the past 6 months, how intense was your worst pain?

▼ 0: No pain at all (0) ... 10: Pain as bad as it could be (10)

During the past 6 months on average how intense was your pain?

▼ 0: No pain at all (0) ... 10: Pain as bad as it could be (10)

In the past 6 months how much has pain interfered with your daily activities?

▼ 0: No interference (0) ... 10: Unable to carry out any activities (10)

In the past 6 months how much has pain changed your ability to take part in recreational social and family activities?

▼ 0: No change (0) ... 10: Extreme change (10)

In the past 6 months how much has the pain changed your ability to work (including housework)?

▼ No change (0) ... 10: Extreme change (10)

About how many days in the past 6 months have you been kept from your usual activities because of your pain?

▼ 0-6 days (1) ... 30 days or over (4)

End of Block: Chronic Pain Grade

Start of Block: Self-efficacy

We would like to know how confident you are in doing certain activities. For each of the following questions, please select the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident do you feel that you can keep the fatigue caused by your endometriosis from interfering with the things you want to do?

▼ 0: Not at all confident (0) ... 10: Totally confident (10)

How confident do you feel that you can keep the physical discomfort or pain of your endometriosis from interfering with the things you want to do?

▼ 0: Not at all confident (0) ... 10: Totally confident (10)

How confident do you feel that you can keep the emotional distress caused by your endometriosis from interfering with the things you want to do?

▼ 0: Not at all confident (0) ... 10: Totally confident (10)

How confident do you feel that you can keep other symptoms or health problems you have from interfering with the things you want to do?

▼ 0: Not at all confident (0) ... 10: Totally confident (10)

How confident do you feel that you can do the different tasks and activities needed to manage your endometriosis so as to reduce your need to see a doctor?

▼ 0: Not at all confident (0) ... 10: Totally confident (10)

How confident do you feel that you can do things other than taking medication to reduce how much your endometriosis affects your everyday life?

▼ 0: Not at all confident (0) ... 10: Totally confident (10)

End of Block: Self-efficacy

Start of Block: Social Support

The next and final section of the questionnaire asks about the social support around you at present.

Please select the answer that best reflects your views:

	Not true at all (1)	Somewhat not true (2)	Unsure (3)	Somewhat true (4)	Very true (5)
I receive a lot of understanding and security from others (1)	○	○	○	○	○
There is someone very close to me whose help I can always rely on (2)	○	○	○	○	○
If I need to, I can borrow something from friends or neighbours without any problems (3)	○	○	○	○	○
I know several people with whom I like to do things (4)	○	○	○	○	○
When I am sick, I can ask friends or relatives to handle important things for me without hesitation (5)	○	○	○	○	○
If I'm very depressed, I know who I can turn to (6)	○	○	○	○	○

End of Block: Social Support

APPENDIX H

Debrief for follow-up survey

Name of department: School of Psychological Sciences and Health
Title of the study: An investigation into the experiences of individuals living with endometriosis

Thank you for completing this survey. We hope that the results will help us to understand some of the factors related to the quality of life and wellbeing of individuals living with endometriosis. We will share our learning with relevant support groups and charities to help identify the types of support which may be helpful for individuals living with endometriosis.

Once again, we would like to remind you that any personal information you have provided will remain confidential and no identifiable information will be used in any reports or publications arising from this research. Your contact details will be deleted in 7 days' time, at which point your data will be completely anonymised and unavailable to the research team. You can request to withdraw your data within the next 7 days, however after this period we will be unable to identify specific responses and withdraw your answers as the data will be anonymous. You will receive no further correspondence from the research team after this point.

Sources of support: If you have any concerns regarding your own responses to the questions within this survey, we recommend that you contact your GP in the first instance. If you are feeling uncomfortable, distressed or down, the following websites offer helpful support:

EXPPECT website:
https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-for-patients/helpful-links - contains a number of useful links and support for individuals living with endometriosis and/or pelvic pain.

Endometriosis UK:
https://endometriosis-uk.org/ - provides far reaching support and in-depth information specifically for individuals living with endometriosis.

Endometriosis Association of Ireland:
Provides support for anyone living with endometriosis in Ireland: https://www.endometriosis.ie/

Mind:
www.mind.org.uk/: Mind provides comprehensive support and information for any issue regarding mental health. They also have a webchat for information and links to support including helplines and their own support community, called Side by Side. You can directly access the support community, Side by Side, by following this link: sidebyside.mind.org.uk/.

SHOUT text service:
If you are feeling distressed and need to speak with someone immediately, the SHOUT crisis text service will connect you instantly to a trained crisis worker who will speak with you through text. To access this service, text SHOUT to 85258. More information can be found here:
giveusashout.org/

Contact details:

If you have any questions about the study, please feel free to contact Chloe Moore at: chloe.moore.100@strath.ac.uk.

Alternatively, you can contact Dr Lynn Williams, who is supervising the project, at: lynn.williams@strath.ac.uk.

APPENDIX I

Information sheet for interview

Participant Information Sheet

Name of department: School of psychological Sciences and Health
Title of the study: An investigation into the experiences of individuals living with endometriosis

Introduction

This research is being conducted by Chloe Moore from the University of Strathclyde under the supervision of Dr Lynn Williams and Dr Nicola Cogan. Before deciding whether to take part in this study, please make sure that you read the sections below. Before you decide if you want to take part or not, we want to tell you why the research is being done, and what you can expect if you do take part. Please read what we have to say carefully. Ask us if you have any other questions. Please take as much time as you like to decide.

What is the purpose of this research?

This project aims to investigate the experience of living with endometriosis. In particular, we want to understand the factors that are related to the quality of life and wellbeing of individuals living with endometriosis. Working with relevant charities and organisations, we will then share our learning, to help identify the types of support which may be helpful for individuals living with endometriosis.

Do you have to take part?

No, you do not – participation in this study is voluntary. It is entirely up to you to decide whether or not you want to take part. Even if you do decide to start the interview, you can tell us that you want to stop it at any stage without giving a reason. During the interview, you can also tell us which questions you would like to answer, or not answer, again without giving a reason.

What will you do in the project?

You are being invited to participate in an interview. This interview will take around one hour but the time for an interview can vary, depending on how much we have to talk about. The interview will be conducted online (via Zoom) or over the telephone depending on your preference. We will use audio recording equipment to capture audio only from our interviews. No video recordings will be made. You will receive a £20 Amazon voucher as a thank you for your time and participation. If you decide that you would like to withdraw your interview data please contact the researcher using the contact information below. Please note that you will be able withdraw your data up to 14 days after your interview has taken place. After this time, your interview will have been transcribed and anonymised, and it will not be possible to identify your specific interview.

Why have you been invited to take part?

You have been invited to take part in this research based on your responses to our recent survey. In the survey, you told us about how you think and feel about your endometriosis. We would like to interview you to find out more about this. We will be interviewing a range of people about their experiences.

What are the potential risks to you in taking part?

Whilst we anticipate no risks to participants during this interview, we understand that some of the questions are of a personal nature and this may result in discomfort for some participants. You can skip any question that you are not comfortable with and can end the interview early if you are experiencing any distress or discomfort because of the subject matter. You can also take a break at any time. At the end of the interview you will be sent a list of support groups and information via email in case of any distress or discomfort. We have provided a note of these resources at the end of this information sheet.

What information is being collected in the project?
During the interview, the researcher will ask you questions about your endometriosis diagnosis, symptoms, and the impact of endometriosis on your life. We will ask you about your beliefs and feelings regarding your diagnosis, how these beliefs impact upon your day-to-day life and finally any support you believe would be beneficial to run alongside your medical treatment.

Who will have access to the information?
Interviews will be audio recorded and typed up word-for-word by the researcher. Only the interview will be audio recorded so our introductions including personal information will not be captured by the audio recording. The researcher will make you aware when the recording is due to begin. During transcription of this recording, any identifying information will be redacted and you will not be identifiable by the transcript. Once we have transcribed your interview data, your audio recording will be deleted and at this point we will not be able to identify you. Therefore, after 14 days, you will no longer be able to withdraw your data from the study. Only the research team will have access to this information.

We aim to publish the outcomes of our collective interviews in peer reviewed journals and will write a short summary of our results which will be available through social media. We will share this summary with charities and support groups so our results may be used to develop resources to support individuals living with endometriosis. You can also request a copy of the summary by contacting the researchers. The information you provide will be entirely anonymous and no identifiable information will be published or disseminated to others. We may include some quotations from the interview in our publications, however these quotes will be completely anonymised with no identifying information included.

Where will the information be stored and how long will it be kept for?
Audio recordings will be stored on secure audio devices and the University's secure servers. Once the interviews have been transcribed, audio recordings will be deleted straight away. The transcript will be stored on password protected secure servers within the University of Strathclyde for a maximum of 10 years. Only the researchers listed below will have access to this information.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

Please also read our Privacy Notice for Research Participants.

What happens next?
If you would like to participate in the research, please complete the consent form and return it to us via email. We will then be in touch to arrange a date and time that suits you for interview.

If you have decided you do not wish to take part in the interview, thank you for your time and attention.

We cannot provide individual feedback on the outcomes of this research, however please contact any of the researchers (details below) if you have any queries or require further information.

Researcher contact details:
If you have any questions about this study, you can contact the researcher on the email address provided:

Chloe Moore
chloe.moore.100@strath.ac.uk

Chief Investigator details:
Chloe Moore is being supervised by Dr Lynn Williams and Dr Nicola Cogan. You can contact Dr Lynn Williams on lynn.williams@strath.ac.uk, and Dr Nicola Cogan on nicola.cogan@strath.ac.uk.

This research was granted ethical approval by the University of Strathclyde Ethics Committee.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee
Research & Knowledge Exchange Services
University of Strathclyde
Graham Hills Building
50 George Street
Glasgow
G1 1QE

Telephone: 0141 548 3707
Email: ethics@strath.ac.uk

Sources of Support:

If you have any concerns regarding your own responses to the questions within this survey, we recommend that you contact your GP in the first instance. If you are feeling uncomfortable, distressed or down, the following websites offer helpful support:

EXPPECT website:
https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-for-patients/helpful-links - contains a number of useful links and support for individuals living with endometriosis and/or pelvic pain.

Endometriosis UK:
https://endometriosis-uk.org/ - provides far reaching support and in-depth information specifically for individuals living with endometriosis.

Mind:
www.mind.org.uk/: Mind provides comprehensive support and information for any issue regarding mental health. They also have a webchat for information and links to support including helplines and their own support community, called Side by Side. You can directly access the support community, Side by Side, by following this link:
sidebyside.mind.org.uk/.

SHOUT text service:
If you are feeling distressed and need to speak with someone immediately, the SHOUT crisis text service will connect you instantly to a trained crisis worker who will speak with you through text. To access this service, text SHOUT to 85258. More information can be found here:
giveusashout.org/

APPENDIX J

Interview topic guide

Interviewer introduction

Any questions?

Confirm consent

General questions

When you think about your experiences of living with endometriosis, how would you say it has affected your life?

How do you feel about endometriosis?

What thoughts come to mind when you think about your endometriosis and related experiences?

Prompts / illness perception category:
Relationships? Consequences and impact / support
Working life? Consequences and impact
Home life? Consequences and impact
Self-care and caring for others? Consequences and impact
Emotions toward endometriosis? Emotional representation
Images come to mind? Emotional representation / general IPs
Describe your symptoms/symptom severity? Identity
Understanding of endometriosis? Coherence/identity
Understanding changed since diagnosis? Coherence/identity
Control over endometriosis? Personal control
Control over treatment? Treatment control
How long do you expect symptoms to last? Timeline
Any specific thoughts around the cause of your endometriosis? Cause
Has your diagnosis altered the way you see yourself? Consequences/impact
Strategies to cope? Coping style
Any additional support that could be beneficial? Support

Can you tell me how you have found the interview*? Are there things you thought we would have talked about that we haven't yet? Are there things you would like to share with other people that we haven't talked about yet?*

APPENDIX K

Debrief for interview

Name of department: School of Psychological Sciences and Health
Title of the study: An investigation into the experiences of individuals living with endometriosis.

Thank you for participating in this interview. We hope that the results will help us to understand some of the factors related to the quality of life and wellbeing of individuals living with endometriosis. We will share our learning with relevant support groups and charities to help identify the types of support which may be helpful for individuals living with endometriosis.

Once again, we would like to remind you that any personal information you have provided will remain confidential and no identifiable information will be used in any reports or publications arising from this research. You can withdraw your data from this interview within the next 14 days by contacting Chloe Moore (details below). After 2 weeks, your audio recording will have been transcribed by the researcher and all identifiable information will be redacted from the transcript. Therefore, it will not be possible to identify your interview to withdraw this data after this time. Your interview data will be completely anonymous.

Sources of support:

If you have any concerns regarding your own responses to the questions within this survey, we recommend that you contact your GP in the first instance. If you are feeling uncomfortable, distressed or down, the following websites offer helpful support:

EXPPECT website:
https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-for-patients/helpful-links - contains a number of useful links and support for individuals living with endometriosis and/or pelvic pain.

Endometriosis UK:
https://endometriosis-uk.org/ - provides far reaching support and in-depth information specifically for individuals living with endometriosis.

Mind:
www.mind.org.uk/: Mind provides comprehensive support and information for any issue regarding mental health. They also have a webchat for information and links to support including helplines and their own support community, called Side by Side. You can directly access the support community, Side by Side, by following this link:
sidebyside.mind.org.uk/.

SHOUT text service:
If you are feeling distressed and need to speak with someone immediately, the SHOUT crisis text service will connect you instantly to a trained crisis worker who will speak with you through text. To access this service, text SHOUT to 85258. More information can be found here:
giveusashout.org/

Contact details

If you have any questions about the study or if you would like to receive a summary of our results once we have analysed the data, please feel free to contact Chloe Moore on chloe.moore.100@strath.ac.uk.

Alternatively, you can contact Dr Lynn Williams, who is supervising the project, on lynn.williams@strath.ac.uk.

APPENDIX L

Hierarchical Multiple Regression Results

Table L.1

Hierarchical multiple regression results with HRQoL as outcome variable

Model	*Predictor*	*β*	*p*	*R^2*	*ΔR^2*	*ΔR^2 sig*
1				.146	.146	<.001**
	Age	-.485	.003**			
	Educational attainment	-10.589	<.001**			
	Employment status	1.558	.359			
	Combined household income	-1.260	.003**			
2				.193	.047	.001**
	Age	-.679	<.001**			
	Educational attainment	-10.773	<.001**			
	Employment status	1.644	.324			
	Combined household income	-1.209	.004**			
	Help seeking delay	.101	.768			
	Delay in medical settings	.808	<.001**			
3				.454	.261	<.001**
	Age	-.414	.007**			
	Educational attainment	-2.910	.253			
	Employment status	1.783	.204			
	Combined household income	-.601	.089			
	Help seeking delay	-.300	.307			
	Delay in medical settings	.355	.063			
	Consequences	1.211	.181			
	Timeline	1.933	.002**			
	Personal control	-1.066	.048*			
	Treatment control	.678	.180			
	Identity	2.049	<.001**			
	Concern	.797	.278			
	Emotional response	1.678	.017*			
4				.485	.031	.008*

	Age	-.323	.034*			
	Educational attainment	-1.425	.574			
	Employment status	1.546	.265			
	Combined household income	-.546	.118			
	Help seeking delay	-.236	.413			
	Delay in medical settings	.246	.203			
	Consequences	.782	.387			
	Timeline	1.80	.003**			
	Personal control	-.924	.085			
	Treatment control	.898	.084			
	Identity	2.39	<.001**			
	Concern	.550	.446			
	Emotional response	.897	.213			
	Action orientated coping	-2.271	.204			
	Information seeking	1.811	.225			
	Depressive processing	3.545	.025*			
	Trust in medical care	-2.895	.098			
5				.487	.002	.628
	Age	-.337	.030*			
	Educational attainment	-1.412	.581			
	Employment status	1.460	.295			
	Combined household income	-.518	.141			
	Help seeking delay	-.252	.338			
	Delay in medical settings	.229	.240			
	Consequences	.849	.348			
	Timeline	1.787	.003**			
	Personal control	-.855	.119			
	Treatment control	.946	.071			
	Identity	2.354	.001**			
	Concern	.484	.507			
	Emotional response	.864	.234			
	Action orientated coping	-1.742	.354			
	Information seeking	1.704	.256			
	Depressive processing	3.134	.056			
	Willingness to accept help	1.706	.314			
	Trust in medical care	-2.533	.161			

	Self-efficacy	-.555	.409
	Social support	-.089	.617

*Significant at <.05 level
**Significant at <.01 level

Table L.2

Hierarchical regression results with anxiety as outcome variable

Model	*Predictor*	*β*	*p*	*R^2*	*ΔR^2*	*ΔR^2 sig*
1				.038	.038	.022*
	Educational attainment	-.334	.195			
	Employment status	.202	.179			
	Combined household income	-.070	.065			
2				.072	.034	.003**
	Educational attainment	-.335	.187			
	Employment status	.229	.122			
	Combined household income	-.067	.072			
	Delay in medical settings	.054	.003**			
3				.166	.094	<.001**
	Educational attainment	-.001	.997			
	Employment status	.191	.184			
	Combined household income	-.036	.319			
	Delay in medical settings	.035	.054			
	Consequences	.107	.254			
	Timeline	.058	.344			
	Personal control	-.082	.140			
	Treatment control	-.008	.878			
	Identity	.004	.959			
	Concern	-.010	.892			
	Emotional response	.168	.021*			
4				.244	.078	<.001**
	Educational attainment	.158	.535			

	Employment status	.163	.240			
	Combined household income	-.048	.178			
	Delay in medical settings	.033	.062			
	Consequences	.092	.313			
	Timeline	.043	.466			
	Personal control	-.046	.388			
	Treatment control	-.018	.729			
	Identity	.006	.935			
	Concern	-.028	.704			
	Emotional response	.068	.350			
	Action orientated coping	-.328	.092			
	Depressive processing	.674	<.001**			
	Search for social integration	.034	.847			
	Trust in medical care	.174	.318			
5				.248	.004	.524
	Educational attainment	.156	.541			
	Employment status	.152	.273			
	Combined household income	-.044	.215			
	Delay in medical settings	.030	.092			
	Consequences	.089	.334			
	Timeline	.044	.464			
	Personal control	-.041	.456			
	Treatment control	-.014	.782			
	Identity	.003	.968			
	Concern	-.036	.632			
	Emotional response	.067	.363			
	Action orientated coping	-.292	.140			
	Depressive processing	.632	<.001**			
	Search for social integration	-.091	.623			
	Trust in medical care	.226	.212			
	Self-efficacy	-.047	.492			
	Social support	-.017	.354			

*Significant at <.05 level
**Significant at <.01 level

Table L.3

Hierarchical regression results with depression as outcome variable

Model	*Predictor*	*β*	*p*	R^2	ΔR^2	ΔR^2 *sig*
1				.062	.062	<.001**
	Educational attainment	-.806	.001**			
	Combined household income	-.057	.108			
2				.088	.026	.008**
	Educational attainment	-.805	.001**			
	Combined household income	-.057	.113			
	Delay in medical settings	.047	.008**			
3				.203	.115	<.001**
	Educational attainment	-.420	.092			
	Combined household income	-.026	.441			
	Delay in medical settings	.026	.126			
	Consequences	.111	.213			
	Timeline	-.035	.552			
	Personal control	-.075	.156			
	Treatment control	-.029	.555			
	Identity	.028	.687			
	Concern	.024	.740			
	Emotional response	.170	.014*			
4				.301	.098	<.001**
	Educational attainment	-.213	.375			
	Combined household income	-.032	.322			
	Delay in medical settings	.023	.168			
	Consequences	.086	.319			
	Timeline	-.052	.352			
	Personal control	-.039	.444			
	Treatment control	-.032	.517			
	Identity	.033	.619			
	Concern	.001	.988			
	Emotional response	.051	.453			
	Action orientated coping	-.459	.013*			

	Information seeking	.087	.546			
	Depressive processing	.682	<.001**			
	Search for social integration	.049	.775			
	Trust in medical care	.083	.615			
5				.335	.033	.003**
	Educational attainment	-.223	.345			
	Combined household income	-.022	.503			
	Delay in medical settings	.016	.329			
	Consequences	.080	.344			
	Timeline	-.053	.338			
	Personal control	-.019	.713			
	Treatment control	-.019	.694			
	Identity	.023	.728			
	Concern	-.017	.802			
	Emotional response	.049	.466			
	Action orientated coping	-.342	.064			
	Information seeking	-.026	.858			
	Depressive processing	.573	<.001**			
	Search for social integration	.218	.211			
	Trust in medical care	.215	.196			
	Self-efficacy	-.137	.030*			
	Social support	-.046	.006**			

*Significant at <.05 level
**Significant at <.01 level

Table L.4

Hierarchical regression results with stress as outcome variable

Model	*Predictor*	*β*	*p*	*R^2*	*ΔR^2*	*ΔR^2 sig*
1				.104	.104	<.001**
	Educational attainment	-1.203	.004**			
	Employment status	.386	.112			
	Combined household income	-.189	.002**			
2				.169	.065	<.001**
	Educational attainment	-1.220	.003**			

	Employment status	.443	.061			
	Combined household income	-.189	.002**			
	Delay in medical settings	.106	.033*			
	Overall diagnostic delay	.022	.642			
3				.313	.144	<.001**
	Educational attainment	-.477	.235			
	Employment status	.340	.121			
	Combined household income	-.119	.034*			
	Delay in medical settings	.085	.068			
	Overall diagnostic delay	-.002	.954			
	Consequences	.240	.094			
	Timeline	.035	.707			
	Personal control	-.163	.055			
	Treatment control	-.078	.328			
	Identity	.064	.570			
	Concern	-.118	.311			
	Emotional response	.378	<.001**			
4				.396	.083	<.001**
	Educational attainment	-.184	.635			
	Employment status	.259	.216			
	Combined household income	-.130	.016*			
	Delay in medical settings	.075	.099			
	Overall diagnostic delay	.007	.859			
	Consequences	.224	.106			
	Timeline	.014	.880			
	Personal control	-.114	.116			
	Treatment control	-.061	.437			
	Identity	.067	.533			
	Concern	-.169	.130			
	Emotional response	.198	.073			
	Action orientated coping	-.802	.008**			
	Information seeking	.069	.768			
	Depressive processing	.937	<.001**			
	Search for social integration	-.168	.546			
	Trust in medical care	.084	.751			

5				.408	.012	.093
	Educational attainment	-.194	.616			
	Employment status	.234	.261			
	Combined household income	-.120	.025*			
	Delay in medical settings	.069	.132			
	Overall diagnostic delay	.007	.878			
	Consequences	.216	.118			
	Timeline	.013	.886			
	Personal control	-.092	.270			
	Treatment control	-.048	.542			
	Identity	.058	.591			
	Concern	-.188	.091			
	Emotional response	.196	.076			
	Action orientated coping	-.682	.025*			
	Information seeking	.004	.988			
	Depressive processing	.824	<.001**			
	Search for social integration	.010	.973			
	Trust in medical care	.224	.411			
	Self-efficacy	-.148	.151			
	Social support	-.047	.091			

*Significant at <.05 level
**Significant at <.01 level

Table L.5

Hierarchical regression results with pain as outcome variable

Model	*Predictor*	*β*	*p*	*R^2*	*ΔR^2*	*ΔR^2 sig*
1				.098	.128	<.001**
	Educational attainment	-11.227	<.001**			
	Employment status	3.063	.091			
	Combined household income	-.681	.146			
	Relationship status	5.780	.088			
2				.135	.036	.023*
	Educational attainment	-10.976	<.001**			
	Employment status	3.185	.078			
	Combined household income	-.634	.171			
	Relationship status	5.287	.114			

	Delay in medical settings	.490	.031*			
	Help-seeking delay	-.372	.301			
	Co-morbid condition	-3.953	.178			
3				.349	.215	<.001**
	Educational attainment	-3.742	.201			
	Employment status	2.989	.062			
	Combined household income	-.017	.968			
	Relationship status	5.361	.072			
	Delay in medical settings	.228	.268			
	Help-seeking delay	-.660	.042*			
	Co-morbid condition	-2.554	.334			
	Consequences	.875	.409			
	Timeline	2.152	.002**			
	Personal control	-.676	.264			
	Treatment control	.158	.782			
	Identity	3.391	<.001**			
	Concern	.091	.914			
	Emotional response	.600	.452			
4				.363	.013	.329
	Educational attainment	-3.829	.196			
	Employment status	2.924	.070			
	Combined household income	.111	.792			
	Relationship status	5.316	.077			
	Delay in medical settings	.193	.361			
	Help-seeking delay	-.613	.061			
	Co-morbid condition	-2.837	.288			
	Consequences	.745	.701			
	Timeline	2.130	.002**			
	Personal control	-.860	.164			
	Treatment control	.346	.562			
	Identity	3.387	<.001**			
	Concern	.081	.923			
	Emotional response	.884	.323			
	Action orientated coping	.573	.782			
	Information seeking	1.077	.537			
	Depressive processing	-2.7	.134			

	Trust in medical care	-2.961	.143			
5				.364	.001	.875
	Educational attainment	-3.738	.211			
	Employment status	2.970	.067			
	Combined household income	.092	.828			
	Relationship status	5.283	.082			
	Delay in medical settings	.203	.342			
	Help-seeking delay	-.618	.062			
	Co-morbid condition	-2.969	.271			
	Consequences	.703	.513			
	Timeline	2.119	.002**			
	Personal control	-.848	.180			
	Treatment control	.329	.585			
	Identity	3.427	<.001**			
	Concern	.136	.873			
	Emotional response	.816	.339			
	Action orientated coping	.292	.893			
	Information seeking	1.099	.531			
	Depressive processing	-2.572	.172			
	Trust in medical care	-3.193	.125			
	Self-efficacy	.067	.932			
	Social support	.104	.611			

*Significant at <.05 level
**Significant at <.01 level

Table L.6

Hierarchical regression results with disability as outcome variable

Model	*Predictor*	*β*	*p*	*R^2*	*ΔR^2*	*ΔR^2 sig*
1				.072	.072	<.001**
	Educational attainment	-.607	.042*			
	Employment status	.397	.021*			
	Combined household income	-.050	.257			
	Relationship status	.620	.053			
2				.114	.043	.004**
	Educational attainment	-.593	.043*			

	Employment status	.434	.011*			
	Combined household income	-.047	.278			
	Relationship status	.560	.076			
	Delay in medical settings	.068	.057			
	Overall diagnostic delay	.002	.949			
3				.328	.213	<.001**
	Educational attainment	.050	.857			
	Employment status	.415	.006**			
	Combined household income	.006	.878			
	Relationship status	.492	.081			
	Delay in medical settings	.071	.027*			
	Overall diagnostic delay	-.028	.349			
	Consequences	.116	.239			
	Timeline	.145	.022*			
	Personal control	-.039	.492			
	Treatment control	.050	.353			
	Identity	.291	<.001**			
	Concern	.023	.771			
	Emotional response	.103	.171			
4				.350	.022	.112
	Educational attainment	.157	.574			
	Employment status	.378	.013*			
	Combined household income	.017	.672			
	Relationship status	.532	.061			
	Delay in medical settings	.054	.095			
	Overall diagnostic delay	-.018	.537			
	Consequences	.081	.412			
	Timeline	.137	.032*			
	Personal control	-.048	.408			
	Treatment control	.066	.242			
	Identity	.296	<.001**			
	Concern	.001	.993			
	Emotional response	.058	.463			
	Action orientated coping	-.222	.253			
	Information seeking	.290	.079			
	Depressive processing	.048	.777			

	Trust in medical care	-.278	.142			
5				.364	.014	.093
	Educational attainment	.214	.442			
	Employment status	.383	.011*			
	Combined household income	.012	.756			
	Relationship status	.474	.094			
	Delay in medical settings	.060	.065			
	Overall diagnostic delay	-.025	.412			
	Consequences	.061	.534			
	Timeline	.133	.037*			
	Personal control	-.026	.662			
	Treatment control	.072	.201			
	Identity	.300	<.001**			
	Concern	.008	.921			
	Emotional response	.042	.589			
	Action orientated coping	-.216	.284			
	Information seeking	.274	.096			
	Depressive processing	.014	.935			
	Trust in medical care	-.297	.125			
	Self-efficacy	-.114	.118			
	Social support	.026	.167			

*Significant at <.05 level
**Significant at <.01 level

APPENDIX M
Multiple mediation results

HRQoL

Table M.1

Results of mediation analyses performed to assess coping as a mediator between IPs and HRQoL

Total effect (consequences – HRQoL)	Direct effect (consequences – HRQoL)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
6.034**	3.758**	Consequences – APC – HRQoL	.158	1.21	-.0435	.4578	No mediation
		Consequences – ISE – HRQoL	.281	1.45	-.0666	.6906	No mediation
		Consequences – DP – HRQoL	**1.049***	**3.421**	**.4735**	**1.6792**	**Partial mediation**
		Consequences – TMC – HRQoL	**.7883***	**3.141**	**.3211**	**1.3091**	**Partial mediation**

Total effect (timeline – HRQoL)	Direct effect (timeline – HRQoL)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
3.823**	2.34**	Timeline – APC – HRQoL	.103	.954	-.0428	.3797	No mediation
		Timeline – ISE – HRQoL	.091	.741	-.1216	.3766	No mediation
		Timeline – DP – HRQoL	**.600***	**2.796**	**.1713**	**1.126**	**Partial mediation**
		Timeline – TMC – HRQoL	**.688***	**2.987**	**.2681**	**1.188**	**Partial mediation**

Total effect (pers. control – HRQoL)	Direct effect (pers. control – HRQoL)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	

-2.586**	-1.186*	Pers. control – APC – HRQoL	-.148	-1.33	-.4102	.0299	No mediation
		Pers. control – ISE – HRQoL	.015	.162	-.1728	.2020	No mediation
		Pers. control – DP – HRQoL	**-.802***	**-3.48**	**-1.292**	**-.3873**	**Partial mediation**
		Pers. control – TMC – HRQoL	**-.465***	**-2.61**	**-.8563**	**-.1528**	**Partial mediation**

Total effect (treat. control – HRQoL)	Direct effect (treat. control – HRQoL)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-1.395*	.0020	Treat. control – APC – HRQoL	-.1728	-1.48	-.4451	.0124	No mediation
		Treat. control – ISE – HRQoL	.0609	.659	-.1049	.2741	No mediation
		Treat. control – DP – HRQoL	**-.381***	**-2.05**	**-.7583**	**-.0342**	**Full mediation**
		Treat. control – TMC – HRQoL	**-.904***	**-4.00**	**-1.365**	**-.4798**	**Full mediation**

Total effect (identity – HRQoL)	Direct effect (identity – HRQoL)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
5.359**	3.657**	Identity – APC – HRQoL	.1164	1.142	-.0194	.3724	No mediation
		Identity – ISE – HRQoL	**.2172***	**1.704**	**.0133**	**.5057**	**Partial mediation**
		Identity – DP – HRQoL	**.7742***	**3.356**	**.378**	**1.283**	**Partial mediation**
		Identity – TMC – HRQoL	**.5948**	**2.791**	**.2254**	**1.061**	**Partial mediation**

Total effect (concern – HRQoL)	Direct effect (concern – HRQoL)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	

4.672**	2.5998**	Concern – APC – HRQoL	.1708	1.215	-.0878	.4712	No mediation
		Concern – ISE – HRQoL	**.2361***	**1.718**	**.0126**	**.5382**	**Partial mediation**
		Concern – DP – HRQoL	**.9862***	**3.329**	**.4478**	**1.625**	**Partial mediation**
		Concern – TMC – HRQoL	**.6793***	**3.212**	**.3107**	**1.131**	**Partial mediation**

Total effect (emo. rep. – HRQoL)	Direct effect (emo. rep. – HRQoL)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
5.011**	2.632**	Emo. rep. – APC – HRQoL	.1797	1.010	-.1379	.5769	No mediation
		Emo. rep – ISE – HRQoL	.2782	1.621	-.0312	.6353	No mediation
		Emo. rep – DP – HRQoL	**1.139***	**3.387**	**.5181**	**1.837**	**Partial mediation**
		Emo. rep – TMC – HRQoL	**.7815***	**2.951**	**.3575**	**1.316**	**Partial mediation**

* = significant effect (p <.05)

** significant effect (p <.01)

As demonstrated by table M.1, the total, non-mediated effect of consequences on HRQoL was significant (b = 6.034, t = 5.737, p <.001), and this remained significant in the presence of the mediating variables ((b = 3.758, t(265) = 5.737, p <.001). There was a significant indirect effect of DP (b = 1.049, t = 3.421, p<.05) and TMC (b = .7883, t = 3.141, p<.05) in this relationship, indicating a partial mediating effect.

Additionally, the total, non-mediated effect of anticipated timeline on HRQoL was significant (b = 3.823, t = 5.812, p<.001). This relationship remained significant in the presence of the mediating variables (b = 2.340, t(265) = 3.899, p <.001). There was a significant indirect effect of DP (b = .600, t = 2.483, p <.05) and TMC (b = .688, t = 2.953, p <.05), indicating a partial mediating effect.

Table M.1 illustrates a significant total effect of personal control on HRQoL (b = -2.586, t = -4.695, p<.05). A significant direct effect of personal control is also outlined (b = -1.186, t(265) = -2.328, p = .021). There was a significant direct effect of DP (b = -.8015, t = -3.485, p <.05) and TMC (b = -.4648, t = 2.607, p <.05) indicating that the relationship between personal control and HRQoL was partially mediated by both DP and TMC.

As demonstrated by table M.1, there was a significant total effect of treatment control on HRQoL (b = -1.395, t = -2.448. p = .015). However, the direct relationship between these factors is non-significant (b = .002, t = .004, p = .997). There is a significant indirect effect of DP (b = -.040, t = -2.056, p<.05) and TMC (b = -.904, t = 4.002, p<.05), indicating that the relationship between treatment control and HRQoL is fully mediated by DP and TMC.

Additionally, table M.1 demonstrates a significant total effect of illness identity on HRQoL (b = 5.359, t = 9.763, p<.001), with this relationship remaining significant in the presence of the mediators as demonstrated by a significant direct effect (b = 3.657, t(265) = 6.75, p<.001). ISE (b = .217, t = 1.704, p<.05), DP (b = .774, t = 3.356, p<.05), and TMC (b = .595, t = 2.791, p<.05) all partially mediated the relationship between illness identity and HRQoL.

Penultimately, table M.1 demonstrates a significant total effect (b = 4.672, t = 8.248, p<.001) and direct effect (b = 2.6, t(265) = 4.474, p<.001) of concern on HRQoL. This relationship was partially mediated by ISE (b = .236, t = 1.718, .05), DP (b = .986, t = 3.33, p<.05) and TMC (b = .679, t = 3.212, p<.05), as demonstrated by significant indirect effects attributable to these coping styles.

Finally, a significant total effect (b = 5.011, t = 8.787, p<.001) and direct effect of emotional representation on HRQoL was observed (b = 2.632, t(265) = 4.125, p<.001). This relationship was partially mediated by DP (b = 1.139, t = 3.387, p<.05) and TMC (b = .782, t = 3.209, p<.05) as illustrated by significant indirect effects associated with these factors (see table M.1).

Figures M.1 – M.7 illustrate the mediating effect of coping between IPs and HRQoL.

Figure M.1

Mediation effect of coping on the relationship between consequences and HRQoL

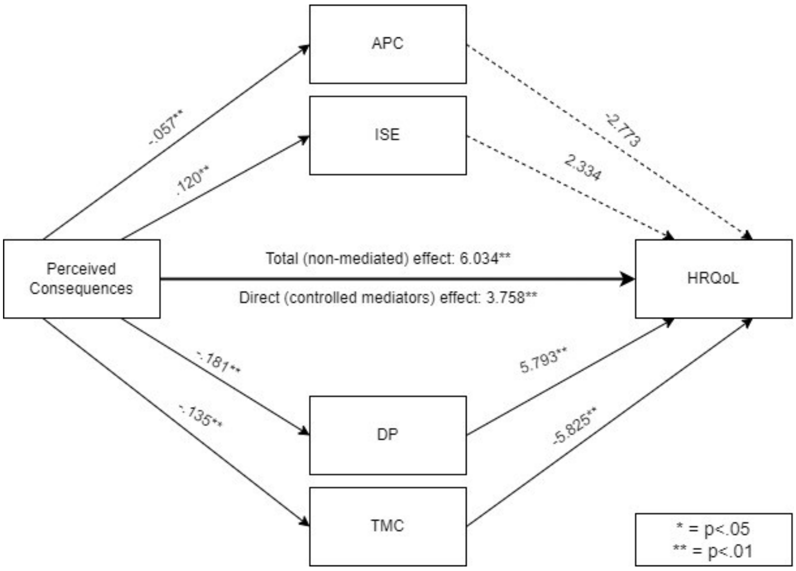


Figure M.2

Mediation effect of coping on the relationship between timeline and HRQoL

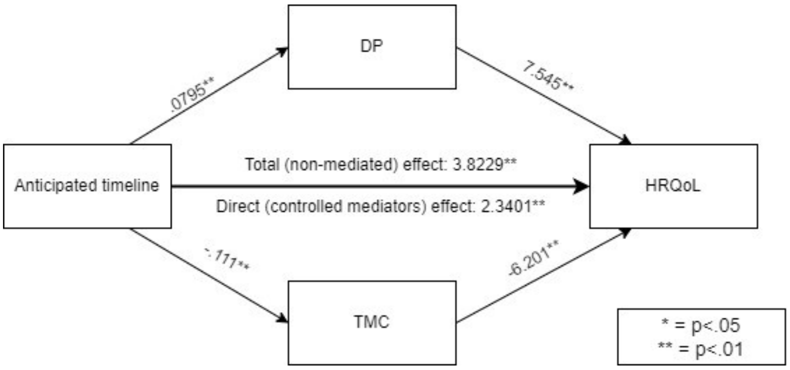


Figure M.3

Mediation effect of coping on the relationship between personal control and HRQoL

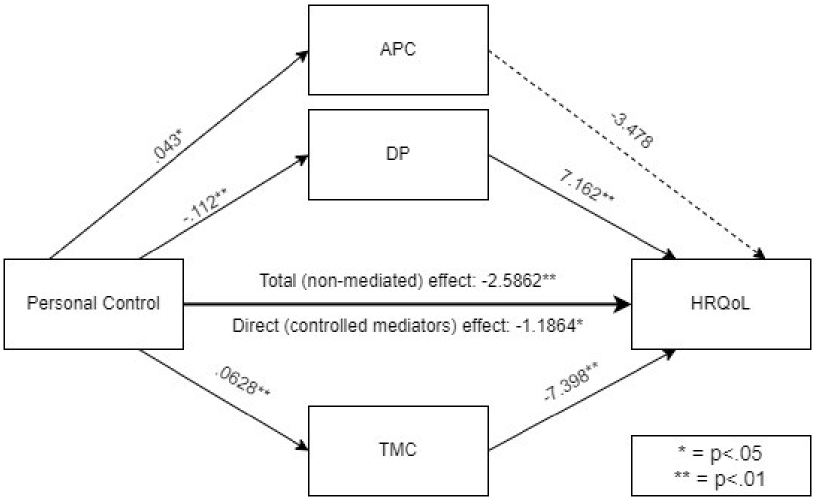


Figure M.4

Mediation effect of coping on the relationship between treatment control and HRQoL

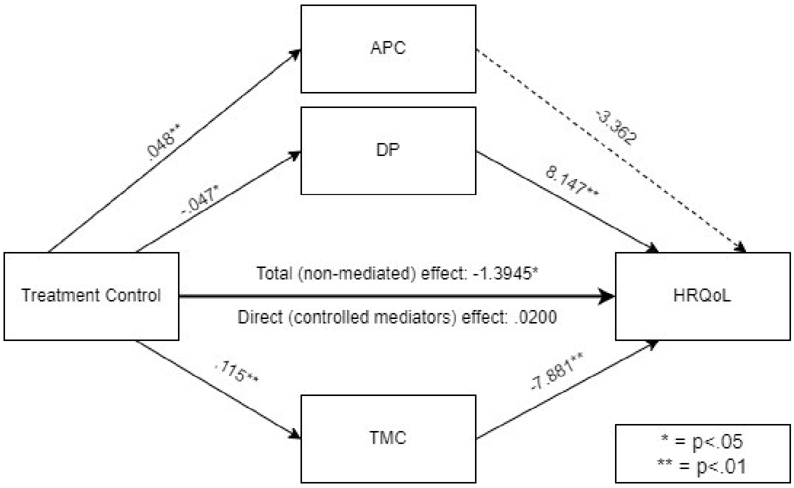


Figure M.5

Mediation effect of coping on the relationship between identity and HRQoL

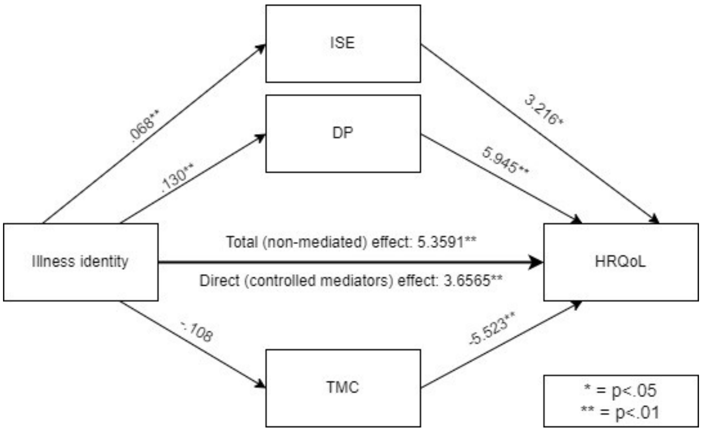


Figure M.6

Mediation effect of coping on the relationship between concern and HRQoL

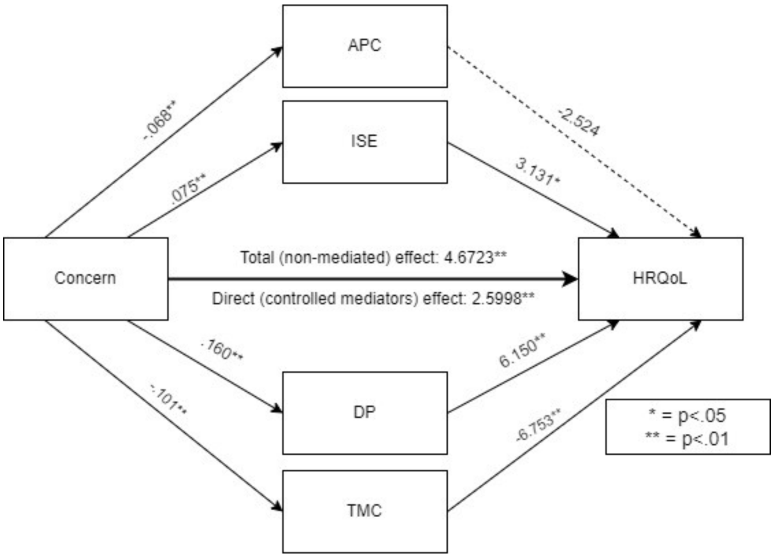
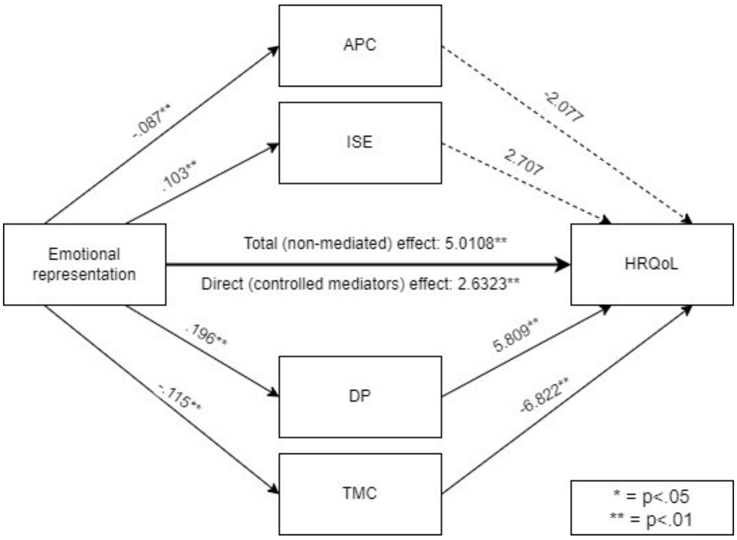


Figure M.7

Mediation effect of coping on the relationship between emotional representation and HRQoL



Anxiety

Table M.2

Results of mediation analyses performed to assess coping as a mediator between IPs and anxiety

Total effect (consequences – anxiety)	Direct effect (consequences – anxiety)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.2735**	.1247*	Consequences – APC – anxiety	.012	1.463	-.0002	.0517	No mediation
		Consequences – DP – anxiety	**.123***	**4.148**	**.0688**	**.1845**	**Partial mediation**
		Consequences – ASI – anxiety	.001	.174	-.0077	.0123	No mediation
		Consequences – TMC – anxiety	.005	.232	-.0388	.0445	No mediation

Total effect (timeline – anxiety)	Direct effect (timeline – anxiety)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.1534**	.0766	Timeline – APC – anxiety	.010	1.000	-.0055	.0351	No mediation
		Timeline – DP – anxiety	**.060***	**2.553**	**.0184**	**.1115**	**Full mediation**
		Timeline – ASI – anxiety	.001	.146	-.0080	.0126	No mediation
		Timeline – TMC – anxiety	.007	.372	-.0282	.0432	No mediation

Total effect (pers. control – anxiety)	Direct effect (pers. control – anxiety)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-.1640**	-.0613	Pers. control – APC – anxiety	-.015	-1.38	-.0410	.0012	No mediation
		Pers. control – DP – anxiety	**-.0812***	**-3.66**	**-.1297**	**-.0422**	**Full mediation**

		Pers. control – ASI – anxiety	-.001	-.171	-.0092	.0057	No mediation
		Pers. control – TMC – anxiety	-.006	-.596	-.0242	.0164	No mediation

Total effect (treat. control – anxiety)	Direct effect (treat. control – anxiety)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-.0991*	-.0362	**Treat. control – APC – anxiety**	**-.017***	**-1.49**	**-.0445**	**-.0001**	**Full mediation**
		Treat. control – DP – anxiety	**.036***	**-2.06**	**-.0722**	**-.0034**	**Full mediation**
		Treat. control – ASI – anxiety	-.001	-.164	-.0155	.0131	No mediation
		Treat. control – TMC – anxiety	-.008	.462	-.0439	.0291	No mediation

Total effect (identity – anxiety)	Direct effect (identity – anxiety)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.1892**	.0749	Identity – APC – anxiety	.013	1.24	-.0015	.0372	No mediation
		Identity – DP – anxiety	**.094***	**4.03**	**.0523**	**.1439**	**Full mediation**
		Identity – ASI – anxiety	.001	.170	-.0085	.0118	No mediation
		Identity – TMC – anxiety	.007	.405	-.0258	.0397	No mediation

Total effect (concern – anxiety)	Direct effect (concern – anxiety)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.2043**	.0529	**Concern – APC – anxiety**	**.024***	**1.69**	**.0003**	**.0560**	**Full mediation**
		Concern – DP – anxiety	**.117***	**4.39**	**.0679**	**.1714**	**Full mediation**

		Concern – ASI – anxiety	.002	.167	-.0160	.0213	No mediation
		Concern – TMC – anxiety	.009	.557	-.0235	.0392	No mediation

Total effect (emo. rep. – anxiety)	Direct effect (emo. rep. – anxiety)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.2809**	.1161	Emo. rep. – APC – anxiety	.028	1.60	-.0033	.0650	No mediation
		Emo. rep – DP – anxiety	**.129***	**4.248**	**.0701**	**.1914**	**Full mediation**
		Emo. rep – ASI – anxiety	.002	.172	-.0154	.0226	No mediation
		Emo. rep – TMC – anxiety	.007	.348	-.0332	.0411	No mediation

* = significant effect (p <.05)

** significant effect (p <.01)

Table M.2 illustrates a significant total effect of consequences on anxiety (b = .2735, t = 4.655, p <.001), as well as a significant direct effect of consequences when the mediators were added to the model (b = .1247, t(265) = 1.973, p = .049). There was a significant indirect effect of DP in this relationship (b = .1232, t = 4.162, p<.05) indicating a partial mediating effect.

Additionally, there was a significant total effect of anticipated timeline on anxiety (b = .1534, t = 2.608, p = .01). However, after the inclusion of the mediating variables, the direct effect of timeline of anxiety is non-significant (b = .077, t(265) = 1.336, p = .183). There was a significant indirect of DP on this relationship (b = .058, t = 2.509, p <.05), indicating a full mediation effect of DP. Thus, anticipated timeline affects anxiety indirectly, through influencing the use of DP as a coping style.

Next, table M.2 illustrates a significant total effect of personal control on anxiety (b = -.164, t = -3.425, p <.001). However, the direct effect of personal effect on anxiety was non-significant (b = -.061, t(265) = -1.289, p = .199). There was a significant indirect effect of DP on this relationship (b = -.081, t = -3.742, p<.05), indicating that DP fully mediated the relationship between personal control and anxiety.

There was a significant total effect of treatment control on anxiety (b = -.099, t = -2.032, p = .043), however the direct relationship between these variables was non-significant (b = -.036, t(265) = -.743, p = .458). There was a significant indirect effect of DP in this relationship (b = -.036, t = 2.040, p<.05), indicating that DP fully mediated the association between treatment control and anxiety.

There was also a significant total effect of illness identity on anxiety (b = .1892, t = 3.551, p<.001), however there was no significant direct effect (b = .075, t(265) = 1.38, p = .169). There was a significant indirect effect of DP in this relationship (b = .094, t = 3.996, p<.05), indicating a full mediation effect (see table M.2).

Furthermore, a significant total effect of concern on anxiety was also identified (b = .204, t = 3.878, p <.001), however this effect disappeared when the mediators were included in the model (b = .053, t(265) = .95, p = .343). DP had a significant indirect effect on this relationship (b = .117, t = 4.458, p<.05), indicating that it fully mediated the association between concern and anxiety.

Finally, table M.2 demonstrates a significant total effect of emotional representation on anxiety (b = .281, t = 5.352, p<.001). However, the direct effect of emotional representation is non-significant (b = .116, t(265) = 1.944, p = .053). There is a significant indirect effect of DP (b = .129, t = 4.38, p<.05), indicating a full mediation effect.

Figures M.8 – M.14 illustrate the mediating effect of coping between IPs and anxiety.

Figure M.8

Mediating effect of coping on the relationship between consequences and anxiety

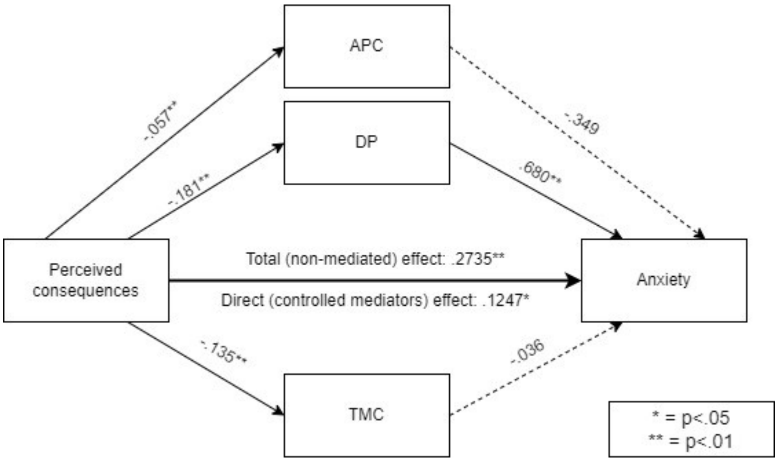


Figure M.9

Mediating effect of coping on the relationship between timeline and anxiety

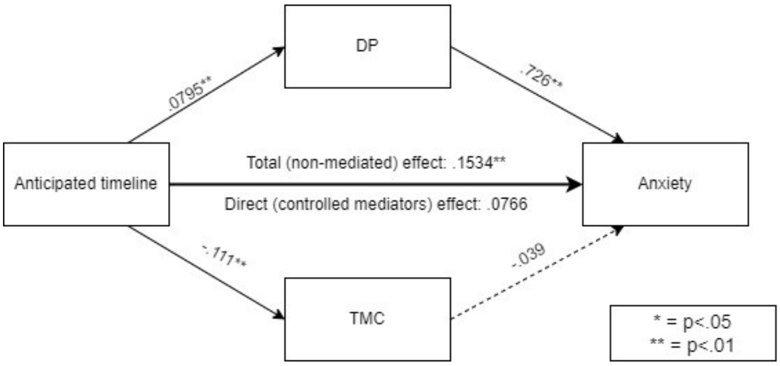


Figure M.10

Mediating effect of coping on the relationship between personal control and anxiety

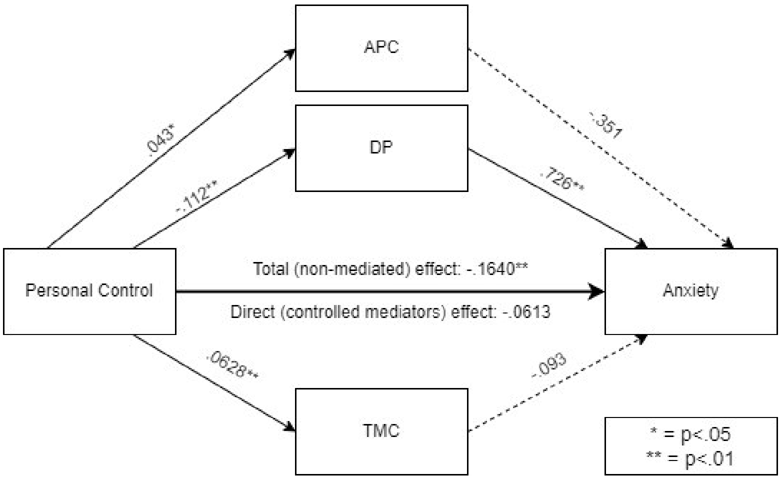


Figure M.11

Mediating effect of coping on the relationship between treatment control and anxiety

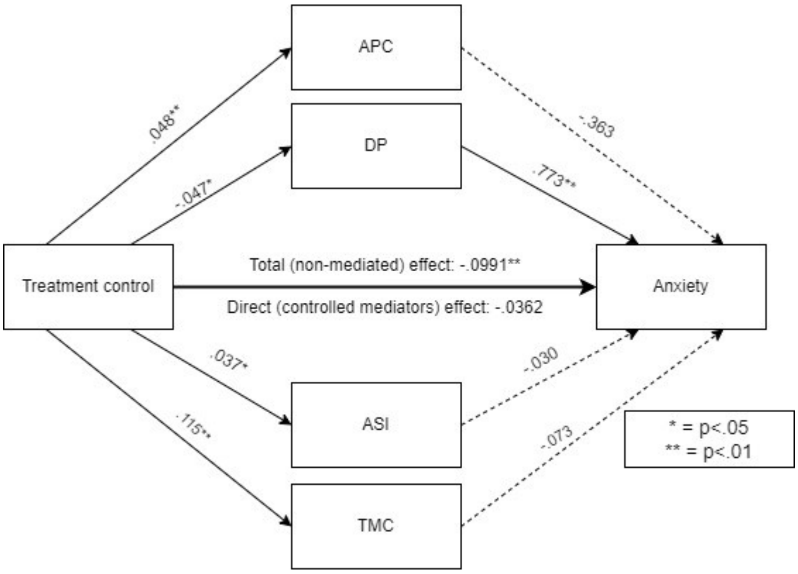


Figure M.12

Mediating effect of coping on the relationship between identity and anxiety

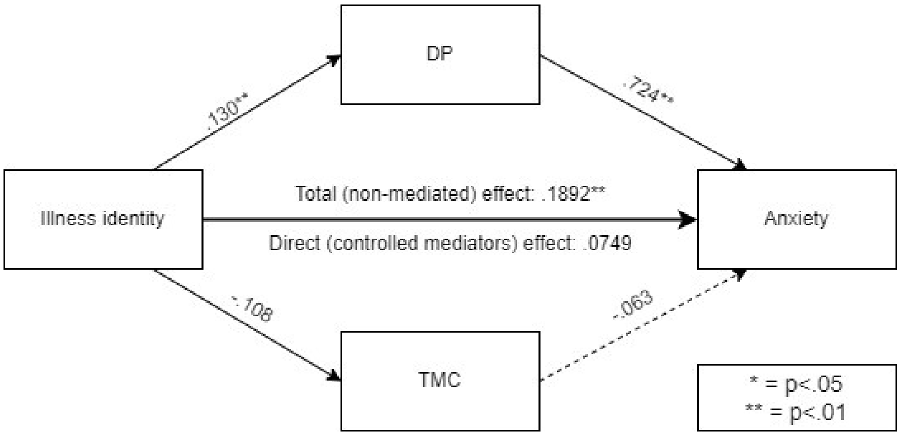


Figure M.13

Mediating effect of coping on the relationship between concern and anxiety

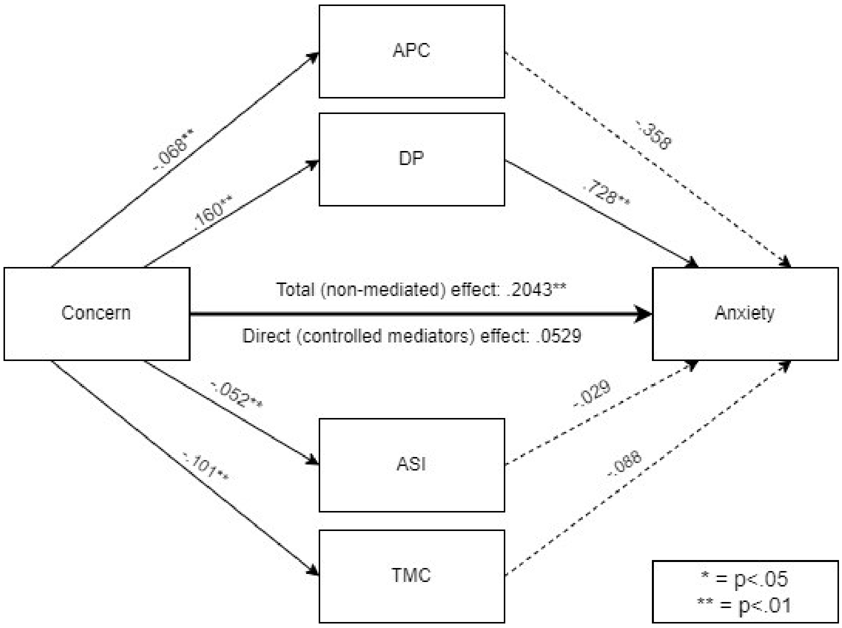
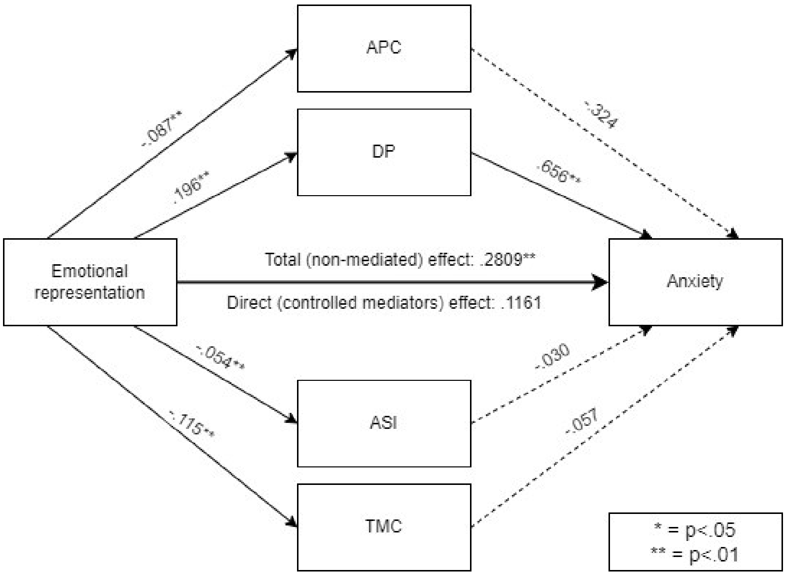


Figure M.14

Mediating effect of coping on the relationship between emotional representation and anxiety



Depression

Table M.3

Results of mediation analyses performed to assess coping as a mediator between IPs and depression

Total effect (consequences – depression)	Direct effect (consequences – depression)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.3197**	.1327*	**Consequences - APC - depression**	**.031***	**1.913**	**.0042**	**.0671**	**Partial mediation**
		Consequences – ISE – depression	.016	.908	-.0182	.0514	No mediation
		Consequences – DP – depression	**.127***	**4.199**	**.0715**	**.1912**	**Partial mediation**
		Consequences – ASI – depression	.001	.049	-.0083	.0092	No mediation
		Consequences – TMC – depression	.0135	.659	-.0268	.0543	No mediation

Total effect (timeline – depression)	Direct effect (timeline – depression)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.0927	-.0100						No relationship

Total effect (pers. control – depression)	Direct effect (pers. control – depression)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-.1948**	-.0831	**Pers. control – APC – depression**	**-.024***	**-1.77***	**-.0533**	**-.0019**	**Full mediation**
		Pers. control – ISE - depression	.001	.140	-.0094	.0124	No mediation
		Pers. control – DP – depression	**-.080***	**-3.69***	**-.1263**	**-.0414**	**Full mediation**
		Pers. control – ASI – depression	-.001	-.091	-.0082	.0055	No mediation

		Pers. control – TMC – depression	-.009	-.870	-.0303	.0102	No mediation

Total effect (treat. control – depression)	Direct effect (treat. control – depression)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-.1207*	-.0471	**Treat. control – APC – depression**	**-.027***	**-.206**	**-.0556**	**-.0046**	**Full mediation**
		Treat. Control – ISE – depression	.003	.585	-.0065	.0162	No mediation
		Treat. control – DP – depression	**-.036***	**-2.07**	**-.0743**	**-.0040**	**Full mediation**
		Treat. control – ASI – depression	-.001	.015	-.0131	.0149	No mediation
		Treat. control – TMC – depression	-.013	.074	-.0502	.0227	No mediation

Total effect (identity – depression)	Direct effect (identity – depression)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.2461**	.1119*	Identity – APC – depression	.019	1.48	-.0020	.0485	No mediation
		Identity – ISE – depression	.011	1.05	-.0075	.0345	No mediation
		Identity – DP – depression	**.096***	**3.88**	**.0500**	**.1442**	**Partial mediation**
		Identity – ASI – depression	-.001	-.043	-.0109	.0095	No mediation
		Identity – TMC – depression	.011	.651	-.0200	.0461	No mediation

Total effect (concern – depression)	Direct effect (concern – depression)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.2629**	.0529	**Identity – APC – depression**	**.037***	**2.32**	**.0097**	**.0713**	**Full mediation**
			.012	1.05	-.0099	.0354	

		Identity – ISE – depression					No mediation
		Identity – DP – depression	**.115***	**4.17**	**.0649**	**.1742**	**Full mediation**
		Identity – ASI – depression	-.001	-.129	-.0181	.0163	No mediation
		Identity – TMC – depression	.014	.862	-.0142	.0485	No mediation

Total effect (emo. rep. – depression)	Direct effect (emo. rep. – depression)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.3119**	.1025	**Emo. rep. – APC – depression**	**.045***	**2.34**	**.0126**	**.0877**	**Full mediation**
		Emo. rep – ISE – depression	.014	.958	-.0147	.0426	No mediation
		Emo. rep – DP – depression	**.136***	**4.38**	**.0766**	**.1993**	**Full mediation**
		Emo. rep – ASI – depression	.001	.115	-.0188	.0171	No mediation
		Emo. rep – TMC – depression	.015	.834	-.0182	.0531	No mediation

* = significant effect (p <.05)

** significant effect (p <.01)

There was a significant total effect of consequences on depression (b = .3197, t = 5.712, p <.001), and this relationship remained significant in the presence of the mediating variables (b = .1327, t(264) = 2.240, p = .026). A significant indirect effect of DP (b = .127, t = 4.269, p<.05) and APC (b = .0308, t = 1.925, p<.05) was identified, indicating that these coping styles partially mediate the relationship between perceived consequences and depression (see table M.3).

Additionally, table M.3 outlines a significant total effect of personal control on depression (b = -.195, t = 4.242, p<.001), however this relationship loses significance in the presence of the mediating variables (b = -.083, t(265) = -1.883, p = .061). DP has a significant indirect effect on this relationship (b = -.080, t = -3.627, p<.05), indicating that this coping style fully mediates the association between personal control and depression.

Furthermore, there was a significant total effect of treatment control on depression (b = -.121, t = -2.563, p = .011), but this relationship became non-significant in the presence of the mediators (b = -.047, t = -1.041, p = .299). There was a significant indirect effect of both APC (b = -.027, t = -2.093, p<.05) and DP (b = -.036, t = 2.08, p<.05), indicating that the relationship between treatment control and depression was fully mediated by APC and DP.

A significant total effect (b = .246, t = 4.855, p<.001) and direct effect (b = .112, t(265) = 2.239, p = .026) of illness identity on depression was identified. DP exerted a significant indirect effect on this relationship (b = .094, t = 3.848, p<.05) indicating a partial mediating role of DP in the relationship between illness identity and depression (see table M.3).

Table M.3 also illustrates a significant total effect of concern on depression (b = .263, t = 5.26, p<.001), however a non-significant direct effect was observed (b = .086, t(265) = 1.663, p = .097). There was an indirect effect of both APC (b = .037, t = 2.348, p<.05), and DP (b = .116, t = 4.246, p<.05), indicating that these coping styles fully mediate the relationship between concern and depression.

Additionally, there was a significant total effect of emotional representation on depression (b = .312, t = 6.231, p<.001), however this relationship lost significance in the presence of the mediating variables (b = .103, t(265) = 1.816, p = .071). There was a significant indirect effect of APC (b = .045, t = 2.342, p<.05) and DP (b = .136, t = 4.383, p<.05) in this relationship, indicating that these factors fully mediated the relationship between emotional representation and depression.

A mediation was performed to assess coping as a mediator in the relationship between anticipated timeline and depression, however no predictive relationship was observed between perceptions of the timeline of endometriosis and depressed mood.

Figures M.15 – M.20 illustrate the mediating effect of coping between IPs and depression.

Figure M.15

Mediating effect of coping on the relationship between consequences and depression

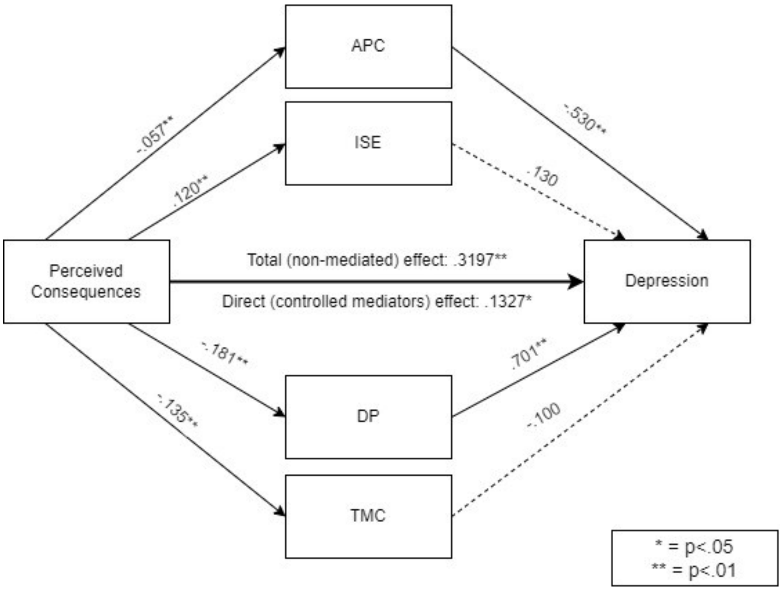


Figure M.16

Mediating effect of coping on the relationship between personal control and depression

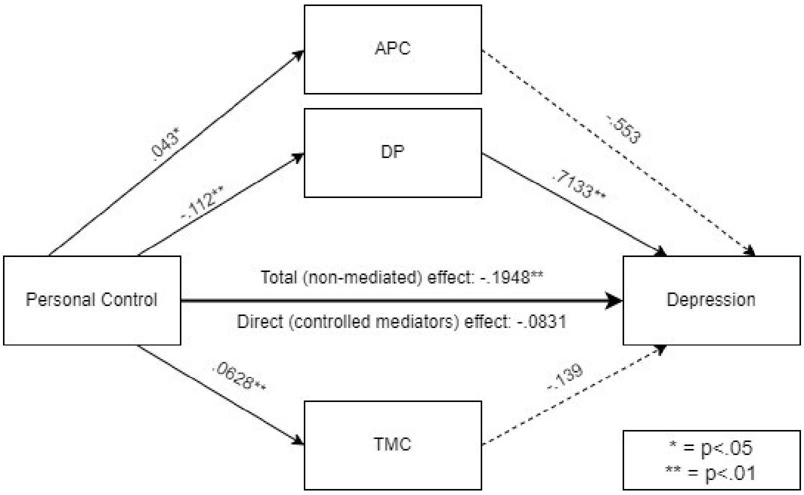


Figure M.17

Mediating effect of coping on the relationship between treatment control and depression

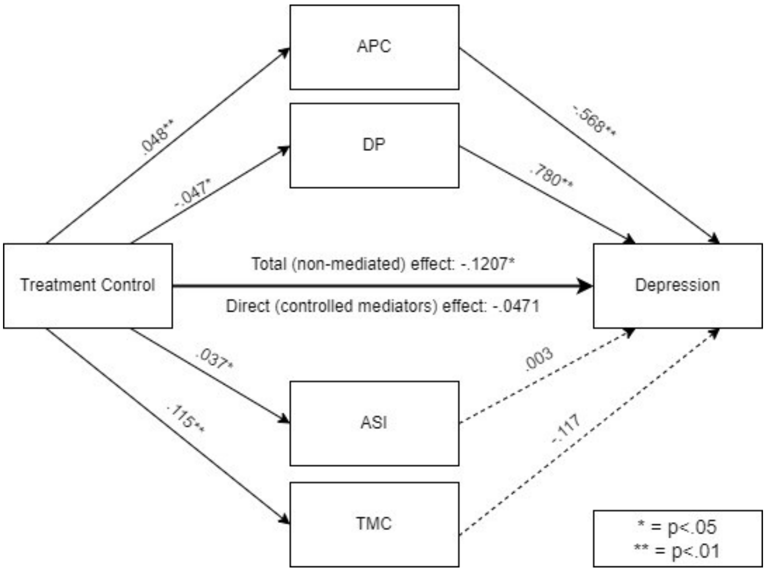


Figure M.18

Mediating effect of coping on the relationship between identity and depression

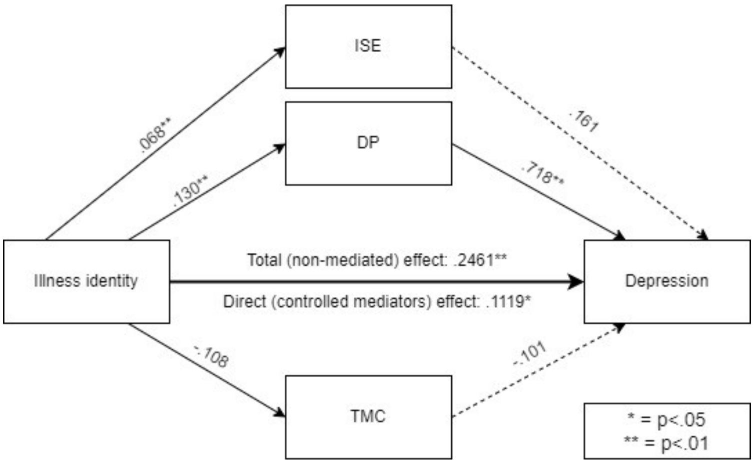


Figure M.19

Mediating effect of coping on the relationship between concern and depression

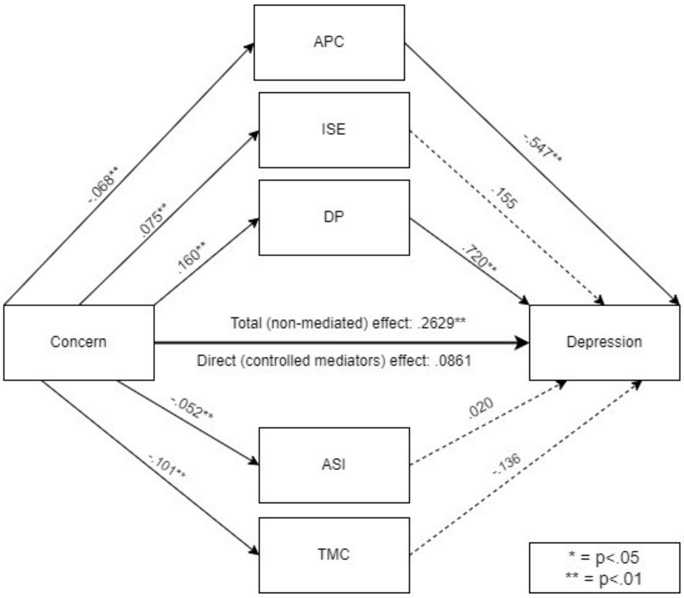
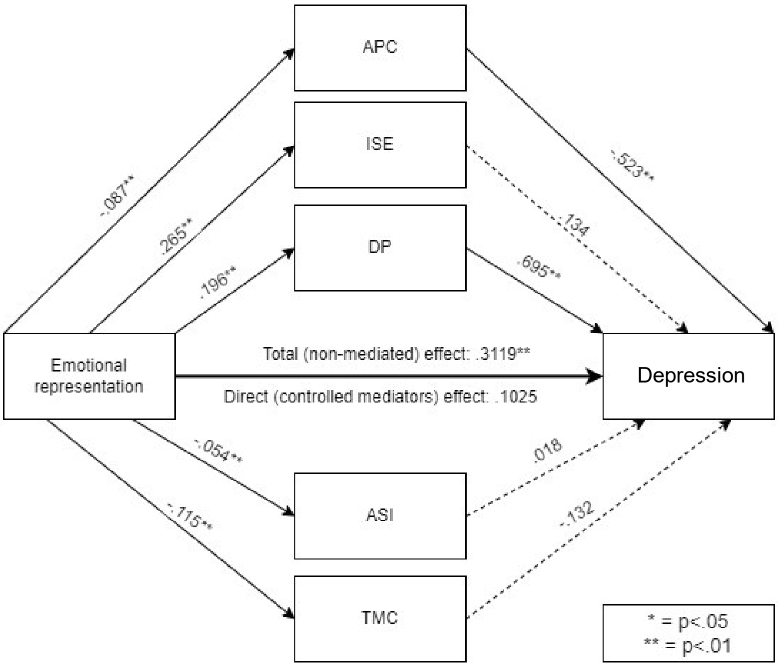


Figure M.20

Mediating effect of coping on the relationship between emotional representation and depression



Stress

Table M.4

Results of mediation analyses performed to assess coping as a mediator between IPs and stress

Total effect (consequences – stress)	Direct effect (consequences – stress)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.6411**	.3365**	**Consequences – APC – stress**	**.050***	**1.93**	**.0064**	**.1071**	**Partial mediation**
		Consequences – ISE – stress	.013	.438	-.0429	.0749	No mediation
		Consequences – DP – stress	**.193***	**3.81**	**.1057**	**.3086**	**Partial mediation**
		Consequences – ASI – stress	.004	.416	-.0099	.0310	No mediation
		Consequences – TMC – stress	.040	1.03	-.0391	.1158	No mediation

Total effect (timeline – stress)	Direct effect (timeline – stress)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.2717**	.0849	Timeline – APC – stress	.027	1.14	-.0108	.0829	No mediation
		Timeline – ISE – stress	.006	.496	-.0084	.0363	No mediation
		Timeline – DP – stress	**.102***	**2.55**	**.0331**	**.1857**	**Full mediation**
		Timeline – ASI – stress	.006	.552	-.0079	.0333	No mediation
		Timeline – TMC – stress	.047	1.40	-.0128	.1172	No mediation

Total effect (pers. control – stress)	Direct effect (pers. control – stress)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	

-.4019**	-.2101**	**Pers. control – APC – stress**	**-.039***	**-1.78**	**-.0873**	**-.0040**	**Partial mediation**
		Pers. control – ISE – stress	.001	.139	-.0152	.0186	No mediation
		Pers. control – DP – stress	**-.126***	**-3.56**	**-.2013**	**-.0639**	**Partial mediation**
		Pers. control – ASI – stress	-.004	-.437	-.0267	.0096	No mediation
		Pers. control – TMC – stress	-.0248	-1.29	-.0678	.0069	No mediation

Total effect (treat. control – stress)	Direct effect (treat. control – stress)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-.2787**	-.1313	**Treat. control – APC – stress**	**-.045***	**-2.03**	**-.0940**	**-.0073**	**Full mediation**
		Treat control – ISE – stress	.005	.549	-.0112	.0229	No mediation
		Treat. control – DP – stress	**.060***	**-2.03**	**-.1240**	**-.0080**	**Full mediation**
		Treat. control – ASI – stress	-.001	-.742	-.0388	.0128	No mediation
		Treat. control – TMC – stress	-.037	-1.14	-.1014	.0260	No mediation

Total effect (identity – stress)	Direct effect (identity – stress)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.4870**	.2517**	Identity – APC – anxiety	.032	1.48	-.0036	.0829	No mediation
		Identity – ISE - stress	.013	.769	-.0193	.0519	No mediation
		Identity – DP – stress	**.150***	**3.73**	**.0786**	**.2355**	**Partial mediation**
		Identity – ASI – stress	.006	.576	-.0084	.0311	No mediation

		Identity – TMC – stress	.034	1.13	-.0234	.0992	No mediation

Total effect (concern – stress)	Direct effect (concern – stress)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.4444**	.1153	**Concern – APC – stress**	**.063***	**2.25**	**.0158**	**.1242**	**Full mediation**
		Concern – ISE – stress	.015	.815	-.0209	.0556	No mediation
		Concern – DP – stress	**.195***	**4.12**	**.1111**	**.2948**	**Full mediation**
		Concern – ASI – stress	.013	.737	-.0168	.0524	No mediation
		Concern – TMC – stress	.044	1.49	-.0097	.1045	No mediation

Total effect (emo. rep. – stress)	Direct effect (emo. rep. – stress)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.6056**	.2537**	**Emo. rep. – APC – stress**	**.072***	**2.29**	**.0191**	**.1403**	**Partial mediation**
		Emo. rep. – ISE - stress	.012	.482	-.0383	.0632	No mediation
		Emo. rep – DP – stress	**.212**	**4.13***	**.1143**	**.3171**	**Partial mediation**
		Emo. rep – ASI – stress	.012	.690	-.0156	.0543	No mediation
		Emo. rep – TMC – stress	.044	1.32	-.0175	.1139	No mediation

* = significant effect (p <.05)

** significant effect (p <.01)

As illustrated by table M.4, there was a significant total effect of consequences on stress (b = .3365, t(364) = 3.34, p = .001), and this relationship remained significant when the mediators were entered into the model (b = .6411, t =

6.726, p <.001). APC (b = .0499, t = 1.912, p<.05) and DP (b = .1972, t = 3.780, p<.05) partially mediated this relationship, illustrated by the significant indirect effects attributable to the addition of these factors.

Additionally, there was a significant total effect of timeline on stress (b = .272, t = 2.742, p = .007), however this relationship lost significance in the presence of the mediators, as illustrated by the non-significant direct effect (b = .085, t(265) = .931, p = .353). There was a significant indirect effect of DP (b = .102, t = 2.501, p<.05), indicating that the relationship between perceived timeline and stress is fully mediated by DP.

Table M.4 also illustrates a significant total effect of personal control on stress (b = -.402, t = -5.102, p<.001), and this relationship remains significant with the inclusion of the mediating variables (b = -.210, t(265) = -2.791, p = .005). Both APC (b = -.039, t = -1.775, p<.05) and DP (b = -.126, t = 3.508, p<.05) had a significant indirect effect on this relationship, indicating a partial mediating effect of these coping styles.

There was also a significant total effect of treatment control on stress (b = -.279, t = -3.434, p <.001). However, this relationship lost significance with the inclusion of the mediators (b = -.131, t(265) = -1.692, p = .092). APC (b = -.045, t = 2.027, p<.05) and DP (b = -.06, t = -2.03, p<.05) both exerted significant indirect effects on this relationship, indicating that the relationship between treatment control and stress is fully mediated by APC and DP.

Also evident in table M.4 is a significant total effect (b = .487, t = 5.595, p<.001) and direct effect (b = .252, t(256) = 2.946, p = .004) of illness identity on stress. DP exerted a significant indirect effect on this relationship (b = .15, t = 3.652, p<.05), indicating a partial mediation effect.

Similarly, a significant total effect of concern on stress was observed (b = .444, t = 5.097, p<.001), however this relationship lost significance in the presence of the mediating variables (b = .115, t(265) = 1.293, p = .197). Both APC (b = .063, t = 2.22, p<.05) and DP (b = .195, t = 4.097, p<.05) had a significant indirect effect on this relationship, indicating that these factors fully mediated the relationship between concern and stress.

Finally, a significant total effect (b = .606, t = 7.082, p<.001) and direct effect (b = .254, t(265) = 2.632, p = .009) of emotional representation on stress was identified. There was a significant indirect effect of APC (b = .072, t = 2.338, p<.05) and DP (b = .212, t = 4.085, p<.05), indicating a partial mediation effect (see table M.4).

Figures M.21 – M.27 illustrate the mediating effect of coping between IPs and depression.

Figure M.21

Mediating effect of coping on the relationship between consequences and stress

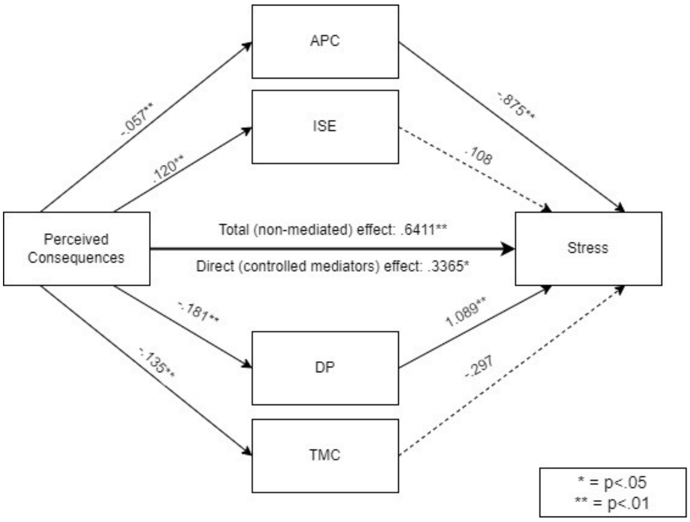


Figure M.22

Mediating effect of coping on the relationship between timeline and stress

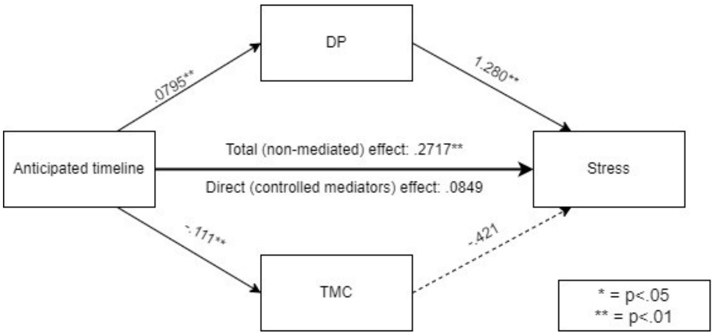


Figure M.23

Mediating effect of coping on the relationship between personal control and stress

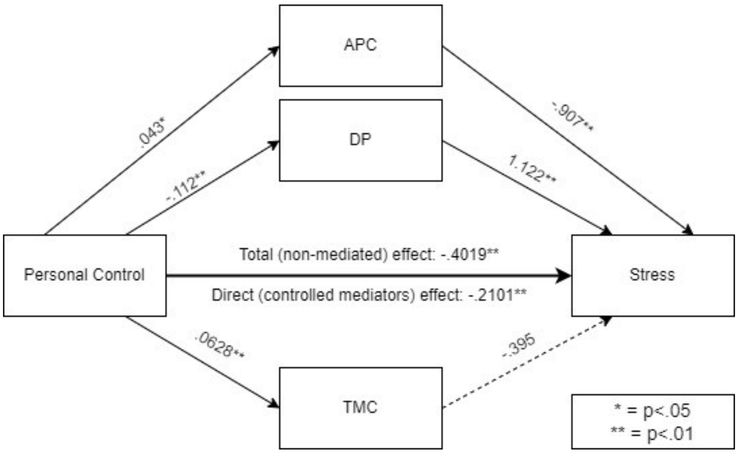


Figure M.24

Mediating effect of coping on the relationship between treatment control and stress

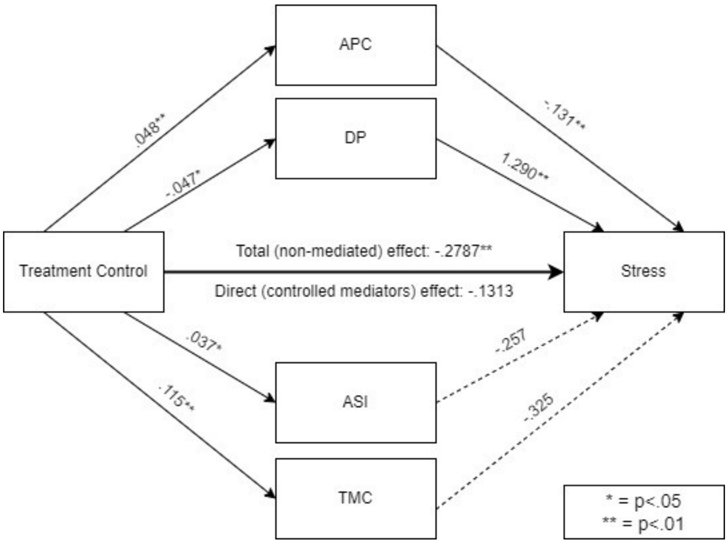


Figure M.25

Mediating effect of coping on the relationship between identity and stress

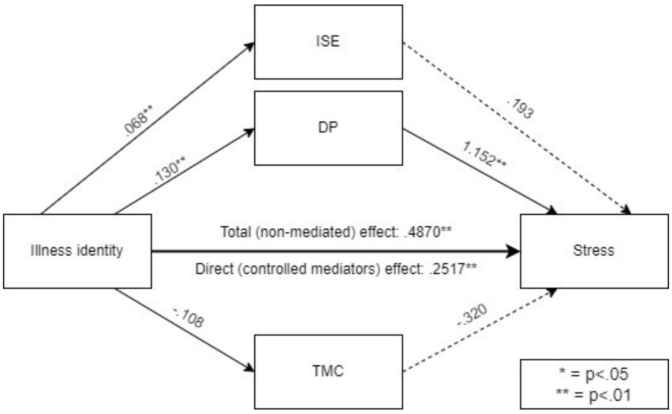


Figure M.26

Mediating effect of coping on the relationship between concern and stress

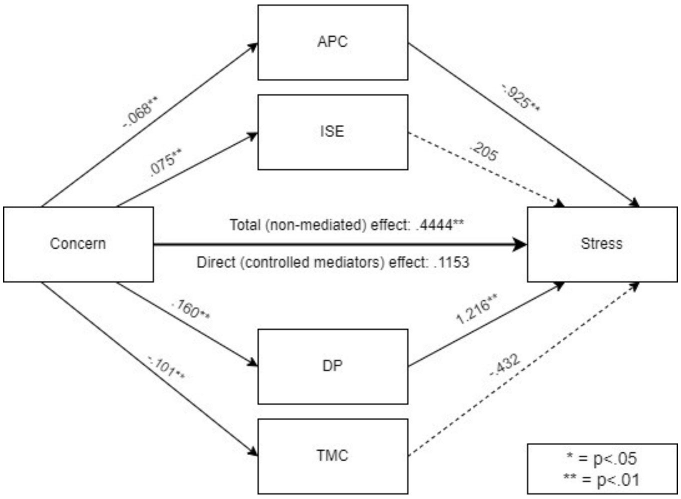
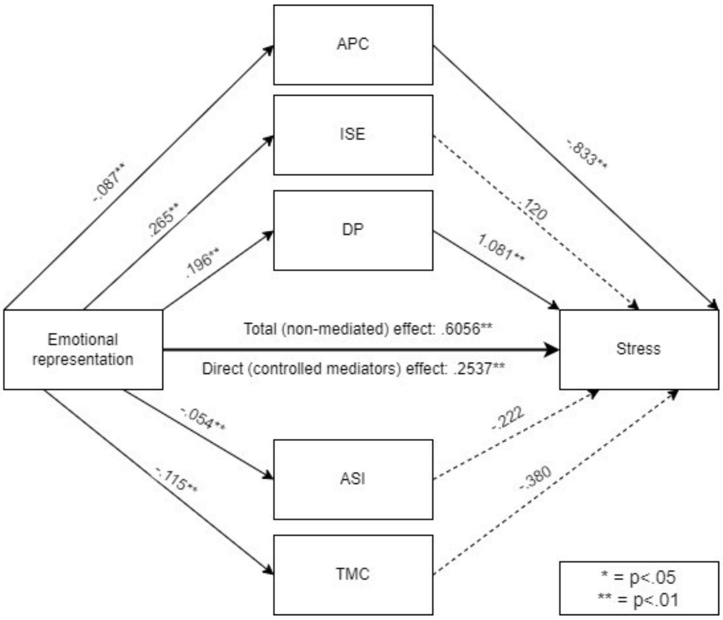


Figure M.26

Mediating effect of coping on the relationship between emotional representation and stress



Pain

Table M.5

Results of mediation analyses performed to assess coping as a mediator between IPs and pain

Total effect (consequences – pain)	Direct effect (consequences – pain)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
5.0872**	4.0733**	Consequences – APC – pain	.077	.056	-.1628	.3983	No mediation
		Consequences – ISE – pain	.184	.927	-.2008	.5871	No mediation
		Consequences – DP – pain	-.184	-.519	-.9118	.4812	No mediation
		Consequences – TMC – pain	**.936***	**3.20**	**.4101**	**1.545**	**Partial mediation**

Total effect (timeline – pain)	Direct effect (timeline – pain)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
3.8281**	2.8309**	Timeline – APC – pain	-.066	.691	-.0665	.3146	No mediation
		Timeline – ISE – pain	.077	.689	-.1022	.3519	No mediation
		Timeline – DP – pain	.064	.039	-.2397	.4318	No mediation
		Timeline – TMC – pain	**-.789***	**2.97**	**.3252**	**1.3657**	**Partial mediation**

Total effect (pers. control – pain)	Direct effect (pers. control – pain)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-1.8849**	-1.2025*	Pers. control – APC – pain	-.091	-.828	-.3284	.1141	No mediation
		Pers. control – ISE – pain	.012	.160	-.1540	.1735	No mediation

		Pers. control – DP – pain	-.060	-.262	-.5380	.3810	No mediation
		Pers. control – TMC – pain	**-.544***	**-2.71**	**-.9650**	**-.1829**	**Partial mediation**

Total effect (treat. control – pain)	Direct effect (treat. control – pain)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-1.6791**	-.5325	Treat. control – APC – pain	-.103	-.864	-.3612	.1266	No mediation
		Treat. control – ISE – pain	.054	.637	-.0964	.2527	No mediation
		Treat. control – DP – pain	-.069	-.068	-.3057	.1139	No mediation
		Treat. control – TMC – pain	**-.968***	**-3.56**	**-1.539**	**-.4948**	**Full mediation**

Total effect (identity – pain)	Direct effect (identity – pain)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
4.8365**	4.0051**	Identity – APC – pain	.071	.744	-.0616	.3121	No mediation
		Identity – ISE – pain	.168	1.37	-.0342	.4447	No mediation
		Identity – DP – pain	-.114	-.459	-.6159	.3699	No mediation
		Identity – TMC – pain	**.707***	**2.88**	**.2562**	**1.2205**	**Partial mediation**

Total effect (concern – pain)	Direct effect (concern – pain)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
3.4529**	2.4144**	Concern – APC – pain	.085	.542	-.2202	.4227	No mediation
		Concern – ISE – pain	.190	1.37	-.0508	.5030	No mediation

		Concern – DP – pain	-.051	-.158	-.6965	.5925	No mediation
		Concern – TMC – pain	**.815***	**3.28**	**.3742**	**1.349**	**Partial mediation**

Total effect (emo. rep. – pain)	Direct effect (emo. rep. – pain)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
3.7439**	2.7349**	Emo. rep. – APC – pain	.058	.292	-.3254	.4836	No mediation
		Emo. rep – ISE – pain	.205	1.17	-.1190	.5738	No mediation
		Emo. rep – DP – pain	-.175	.429	-1.002	.5946	No mediation
		Emo. rep – TMC – pain	**.922***	**3.29**	**.4392**	**1.5415**	**Partial mediation**

* = significant effect (p <.05)

** significant effect (p <.01)

As illustrated by table M.5, the total, non-mediated effect of consequences on pain was significant (b = 5.087, t = 7.558, p <.001), and this relationship remained significant following the inclusion of the mediating variables (b = 4.073, t(265) = 5.360, p <.001). TMC exerted a significant indirect effect on this relationship (b = .077, t = 3.222, p<.05) indicating a partial mediating effect.

Additionally, table M.5 outlines a significant total effect of anticipated timeline on pain (b = 3.828, t = 5.596, p <.001), and this relationship remains significant with the inclusion of the mediating variables (b = 2.8309, t(265) = 1.473, p<.001). There was also a significant indirect effect of TMC on this relationship (b = .789, t = 2.999, p<.05), indicating a partial mediating role of TMC.

Both a significant total effect of personal control on pain (b = -1.885, t = -3.237, p = .001), and a significant direct effect of personal control on pain (b = -

1.233, t(265) = -2.044, p = .042) are demonstrated by table M.5. There is a significant direct effect of TMC in this relationship (b = -.544, t = 2.665, p<.05), indicating a partial mediating effect.

Next, there was a significant total effect of treatment control on pain (b = -1.679, t = -2.858, p = .005). However, the direct effect of treatment control on pain was non-significant (b = -.593, t = -.978, p = .329). TMC exerted a significant direct effect on this relationship (b = -.968, t = -3.663, p<.05) indicating a full mediation effect.

There was a significant total effect (b = 4.837, t = 8.165, p<.001) and direct effect (b = 4.005, t(265) = 6.366, p<.001) of illness identity on pain. Only TMC exerted a significant direct effect on this relationship (b = -.707, t = 2.983, p<.05), suggesting that this coping style partially mediated the relationship between illness identity and pain.

As illustrated by table M.5, a significant total effect (b = 3.453, t = 5.55, p<.001) and a significant direct effect (b = 2.414, t(265) = 3.56, p<.001) of concern on depression was observed. A significant direct effect of TMC partially mediated this relationship (b = .815, t = 3.289, p<.05).

Finally, table M.5 outlines a significant total effect (b = 3.744, t = 5.943, p<.001) and significant direct effect (b = 2.735, t(265), p <.001) of emotional representation on pain. A significant indirect effect of TMC was observed (b = .084, t = 3.383, p<.05), indicating that the relationship between emotional representation and pain is partially mediated by this coping style.

Figures M.28 – M.34 illustrate the mediating effect of coping between IPs and depression.

Figure M.28

Mediating effect of coping on the relationship between consequences and pain

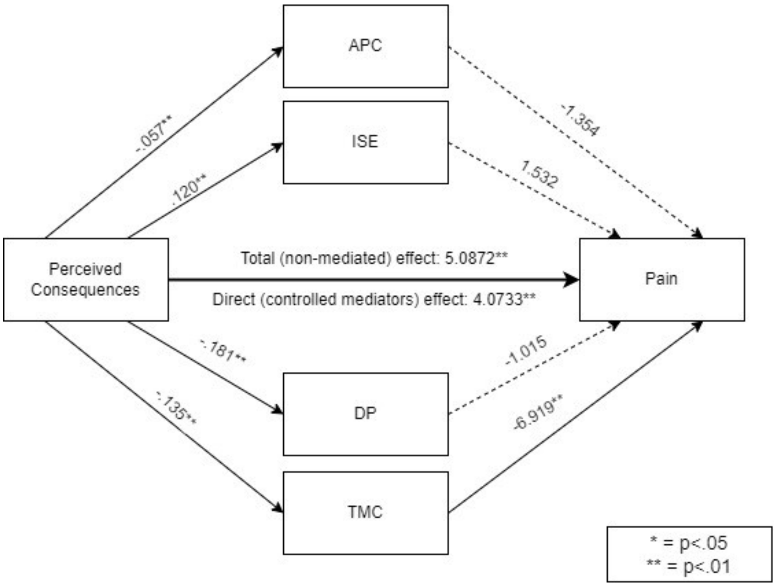


Figure M.29

Mediating effect of coping on the relationship between timeline and pain

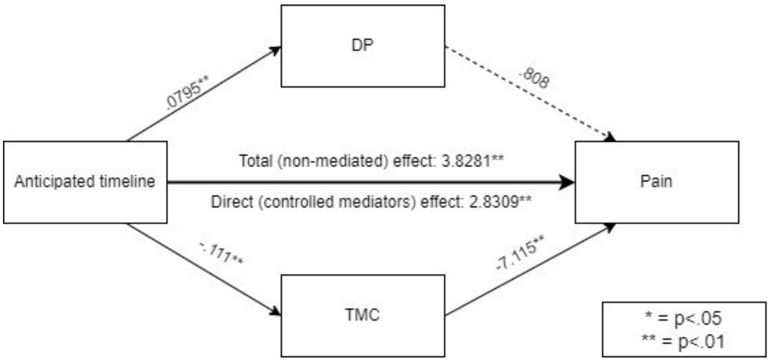


Figure M.30

Mediating effect of coping on the relationship between personal control and pain

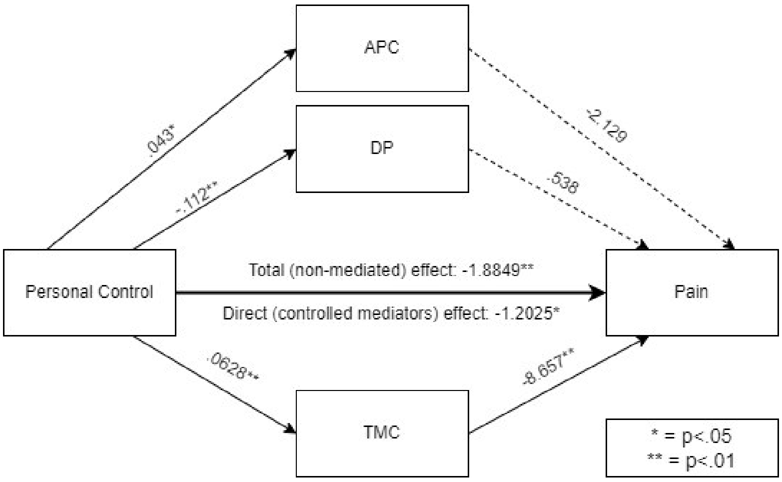


Figure M.31

Mediating effect of coping on the relationship between treatment control and pain

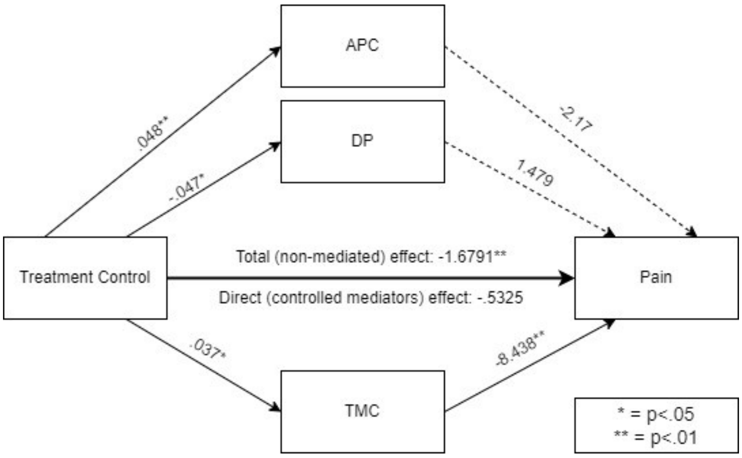


Figure M.32

Mediating effect of coping on the relationship between identity and pain

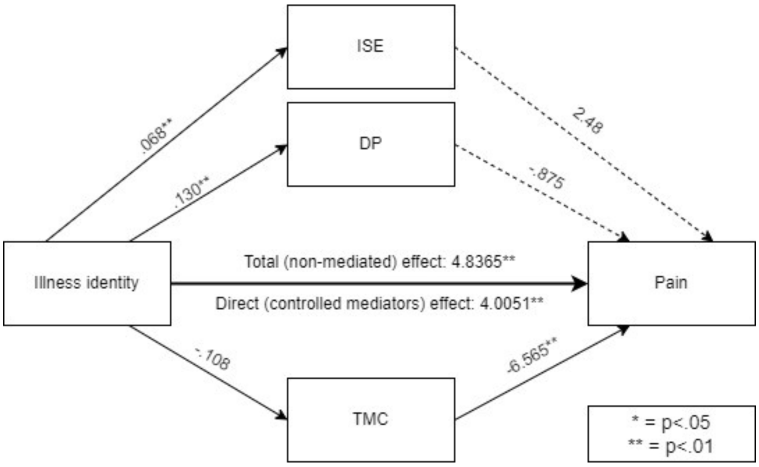


Figure M.33

Mediating effect of coping on the relationship between concern and pain

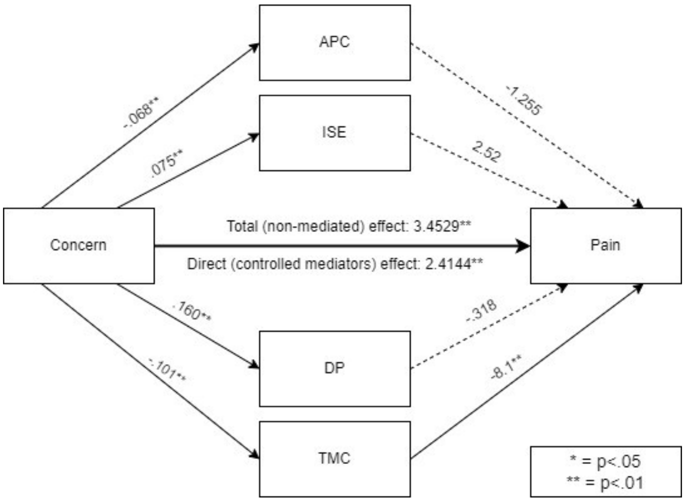
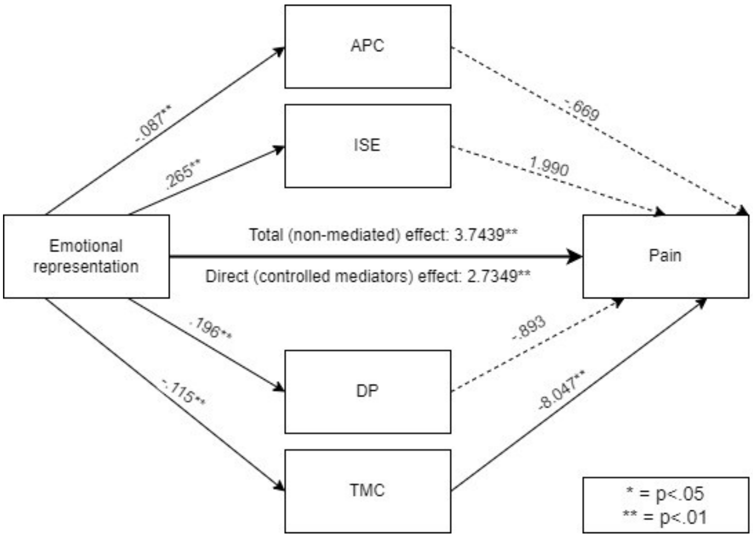


Figure M.34

Mediating effect of coping on the relationship between emotional representation and pain



Disability

Table M.6

Results of mediation analyses performed to assess coping as a mediator between IPs and disability

Total effect (consequences – disability)	Direct effect (consequences – disability)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.4899**	3474**	Consequences – APC – disability	.015	1.20	-.0060	.0442	No mediation
		Consequences – ISE – disability	**.039***	**1.90**	**-.0041**	**.0851**	**Partial mediation**
		Consequences – DP – disability	.021	.722	-.0373	.0778	No mediation
		Consequences – TMC – disability	**.069**	**2.51**	**.0177**	**.1218**	**Partial mediation**

Total effect (timeline – disability)	Direct effect (timeline – disability)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.2647**	.1573*	Timeline – APC – disability	.010	.951	-.0049	.0346	No mediation
		Timeline – ISE – disability	.011	.741	-.0138	.0451	No mediation
		Timeline – DP – disability	.023	1.42	-.0011	.0630	No mediation
		Timeline – TMC – disability	**.063***	**2.44**	**.0183**	**.1186**	**Partial mediation**

Total effect (pers. control – disability)	Direct effect (pers. control – disability)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-.1765**	-.0949	Pers. control – APC – disability	-.014	-1.31	-.0392	.0034	No mediation
		Pers. control – ISE – disability	.002	.163	-.0201	.0226	No mediation

		Pers. control – DP – disability	-.029	-.262	-.0708	.0081	No mediation
		Pers. control – TMC – disability	**-.041**	**-2.38**	**-.0768**	**-.0113**	**Full mediation**

Total effect (treat. control – disability)	Direct effect (treat. control – disability)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
-.1095*	-.0075	Treat. control – APC – disability	-.017	-1.45	-.0428	.0023	No mediation
		Treat. control – ISE – disability	.007	.661	-.0133	.0320	No mediation
		Treat. control – DP – disability	-.016	1.39	-.0423	.0005	No mediation
		Treat. control – TMC – disability	**-.077***	**-3.26**	**-.1257**	**-.0321**	**Full mediation**

Total effect (identity – disability)	Direct effect (identity – disability)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.4452**	.3396**	Identity – APC – disability	.011	1.16	-.0027	.0343	No mediation
		Identity – ISE – disability	**.028***	**1.88**	**.0041**	**.0625**	**Partial mediation**
		Identity – DP – disability	.017	.820	-.0219	.0589	No mediation
		Identity – TMC – disability	**.050***	**2.24**	**.0109**	**.0980**	**Partial mediation**

Total effect (concern – disability)	Direct effect (concern – disability)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.3253**	.1839**	Concern – APC – disability	.018	1.24	-.0095	.0503	No mediation
		Concern – ISE – disability	**.032***	**1.96**	**.0055**	**.0677**	**Partial mediation**

		Concern – DP – disability	-.031	1.15	-.0243	.0839	No mediation
		Concern – TMC – disability	**.061***	**2.70**	**.0221**	**.1101**	**Partial mediation**

Total effect (emo. rep. – disability)	Direct effect (emo. rep. – disability)	Relationship	Indirect effect		Confidence interval		Finding
b	*b*		*b*	*t*	Lower	Upper	
.3723**	.2198**	Emo. rep. – APC – disability	.019	1.06	-.0142	.0576	No mediation
		Emo. rep – ISE – disability	**.038***	**2.01**	**.0052**	**.0803**	**Partial mediation**
		Emo. rep – DP – disability	-.027	.821	-.0377	.0929	No mediation
		Emo. rep – TMC – disability	**.068***	**2.77**	**.0232**	**.1208**	**Partial mediation**

Finally, table M.6 illustrates a significant total effect of consequences on disability scores (b = .4899, t = 7.973, p <.001), and this relationship remained significant when the mediating variables were included in the model (b = .347, t(265) = 5.045, p <.001). Both TMC ((b = .0596, t = 2.453, p<.05) and ISE (b = .0352, t = 3.141) exerted a significant indirect effect on this relationship, indicating a partial regression.

Table M.6 also illustrates a significant total effect of anticipated timeline on disability (b = .265, t = 4.094, p<.001). This relationship remains significant in the presence of the mediators, demonstrating a significant direct effect of timeline on disability (b = .1573, t(265) = 2.484, p = .014). TMC exerted a significant indirect effect on this relationship (b = .063, t = 2.463, p<.05), indicating a partial mediating effect.

Next, a significant total effect of personal control on disability (b = -.176, t = -3.29, p = .001) is outlined in table M.6. However, the direct effect of personal control on disability was non-significant (b = -.095, t(265) = -1.786, p = .075). There was a significant direct effect of TMC (b = -.0405, t = 2.425, p<.05), indicating that TMC fully mediated the relationship between personal control and disability.

Additionally, there was a significant total effect of treatment control on disability (b = -.109, t = -2.007, p = .046), but no significant direct effect (b = -.008, t(265) = -.138, p = .89). TMC had a significant indirect effect on this relationship (b = -.077, t = -3.252, p<.05), indicating a full mediating effect of this coping style.

Table M.6 also illustrates a significant total effect of identity on disability (b = .445, t = 8.151, p<.001), which remains significant in the presence of the mediating variables (b = .34, t(265) = 5.94, p<.001). ISE (b = .028, t = 1.903, p<.05) and TMC (b = .05, t = 2.207, p<.05) exert a significant indirect effect on this relationship, indicating that these factors mediate the association between illness identity and disability.

There was a significant total effect (b = .325, t = 5.686, p<.001) and a significant direct effect of concern on disability (b = .184, t(265) = 2.989, p = .003). There were significant indirect effects of ISE (b = .032, t = 2.006, p<.05) and TMC (b = .061, t = 2.702, p<.05), indicating that these factors partially mediate this relationship.

Finally, table M.6 illustrates a significant total effect (b = .372, t = 6.481, p<.001) and a significant direct effect (b = .22, t = 3.282, p = .001) of emotional representation on disability. ISE (b = .038, t = 2.026, p<.05) and TMC (b = .068, t =

2.795, p<.05) each exerted a significant indirect effect on this relationship, indicating a partial mediating effect.

Figures M.35 – M.41 illustrate the mediating effect of coping between IPs and depression.

Figure M.35

Mediating effect of coping on the relationship between consequences and disability

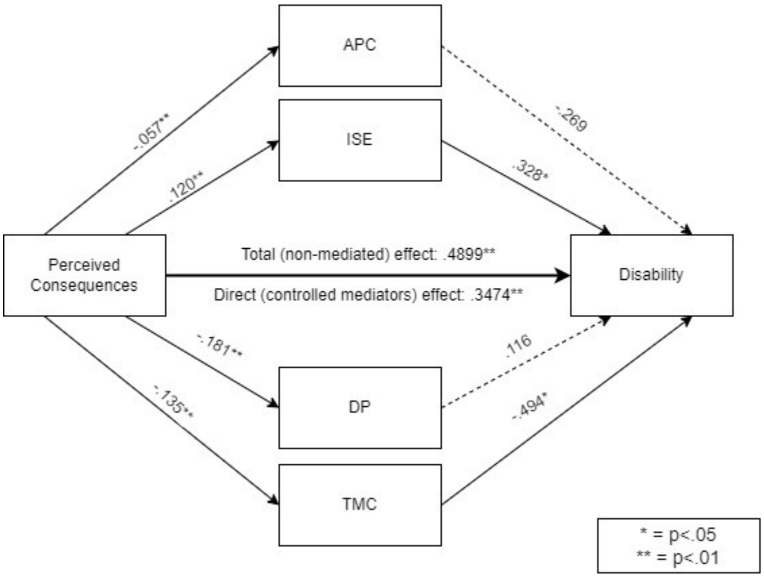


Figure M.36

Mediating effect of coping on the relationship between timeline and disability

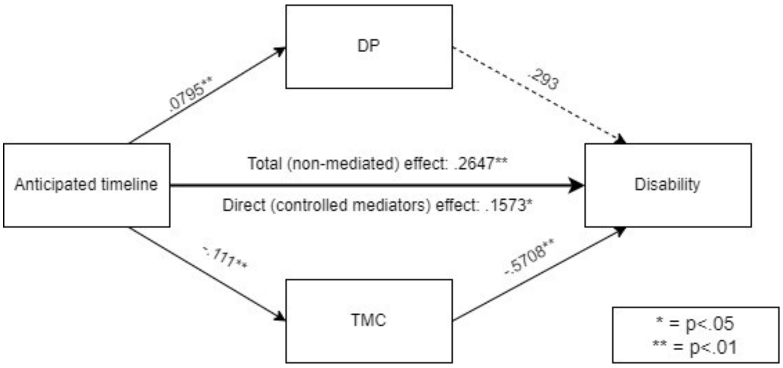


Figure M.37

Mediating effect of coping on the relationship between personal control and disability

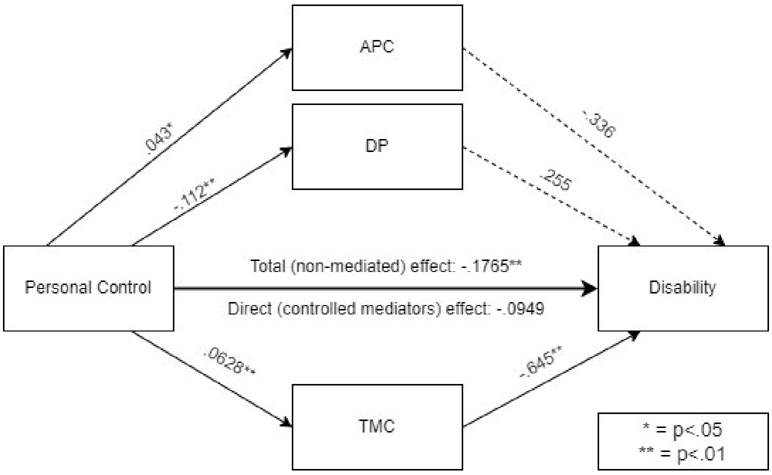


Figure M.38

Mediating effect of coping on the relationship between treatment control and disability

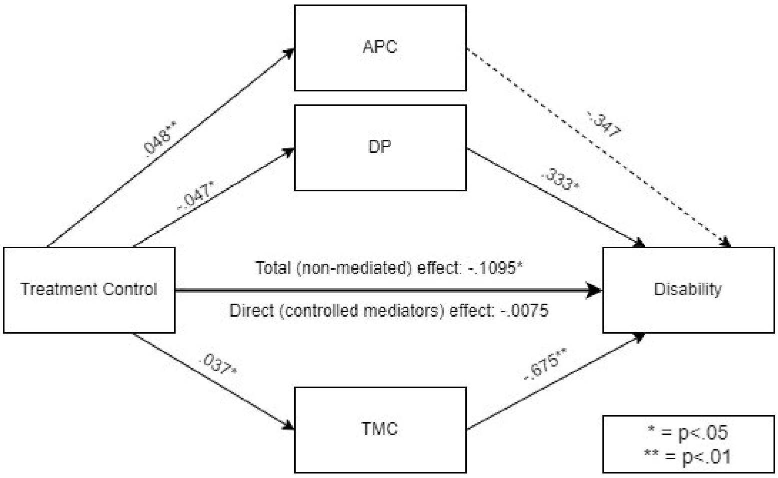


Figure M.39

Mediating effect of coping on the relationship between identity and disability

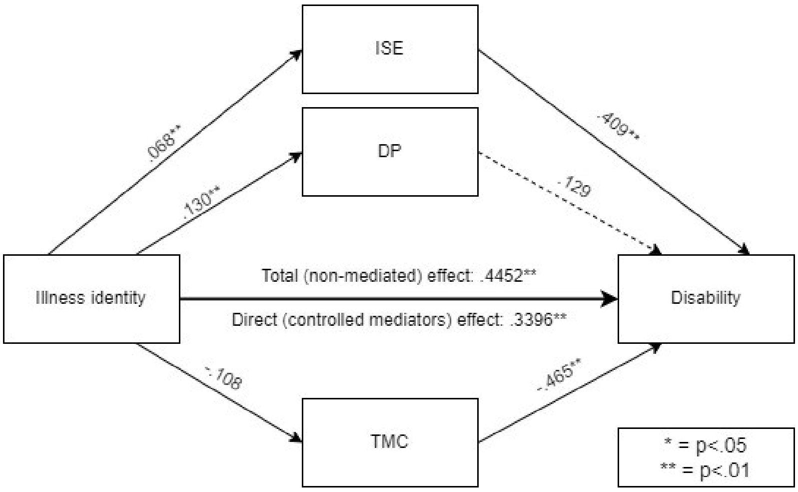


Figure M.40

Mediating effect of coping on the relationship between concern and disability

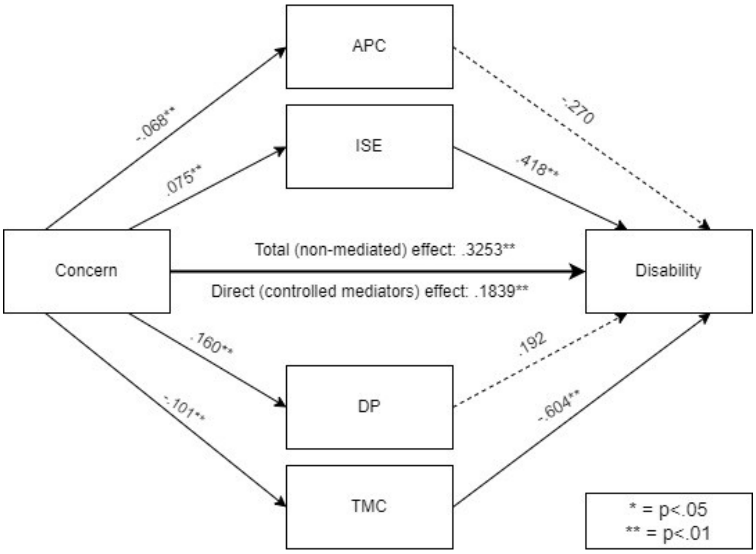


Figure M.41

Mediating effect of coping on the relationship between emotional representation and disability