

THE EFFECTS OF SYMPTOMATIC ENDOMETRIOSIS ON WOMANHOOD

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By

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Section C: Critique of research	4,434	4,694
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Abstract of thesis

THE EFFECTS OF SYMPTOMATIC ENDOMETRIOSIS ON WOMANHOOD

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Endometriosis is a common chronic gynaecological condition within women of reproductive age.

Section A

A literature review was conducted to evaluate the prevalence of depression in women with endometriosis and explain the development of depression using a diathesis-stress framework. A systematic search revealed twenty-one relevant studies. The evidence suggested that depression was more prevalent within women with endometriosis than women in the general population. The effects of chronic pelvic pain, dyspareunia, infertility and the psychosocial implications associated with these stressors were suggested to be involved in the development of depression in women with endometriosis, mediated by cognitive diatheses such as illness representations, perceived control, perceived self efficacy and coping style. In conclusion, the literature supported the application of the diathesis-stress model to explain the development of depression in women with endometriosis.

Section B

The research study investigated whether endometriosis affected womanhood through the qualitative exploration of identity as a woman, wellbeing, sexuality, fertility and relationships. Seven women with a laparoscopic diagnosis of endometriosis were interviewed. Four master themes were elicited from the data using Interpretative Phenomenology Analysis that represented women's experiences of endometriosis and its effect on womanhood, motherhood and emotional wellbeing. Womanhood remained relatively intact, although at times it affected identity as a woman, sexuality and self-esteem. The endometriosis journey was fluctuating and unpredictable, yet, women with endometriosis were able to regain control and normality, adjusting to the condition. The need for the availability of professional emotional support for women with endometriosis was highlighted.

Section C

The critique of research outlined my experiences and reflections of conducting research. It described the origin and development of the study, as well as the challenges met and learning points gained along the way. Furthermore, it detailed a critique of myself as a researcher and reflected on the personal impact of research on the self.

Section A**DEPRESSION IN WOMEN WITH ENDOMETRIOSIS:
A DIATHESIS-STRESS MODEL**

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(excluding references)

1. Abstract

Purpose: The current review aimed to evaluate the prevalence of depression in women with endometriosis and explain the development of depression within this population using a diathesis-stress framework.

Method: A systematic search for published, empirical studies dated post-1970 was conducted by searching six electronic databases and hand-searching relevant reference lists using key search terms.

Results: Twenty-one studies were identified and critically reviewed. The evidence suggested that depression was more prevalent within women with endometriosis than women in the general population. There was no evidence to support a link between depression and site or stage of endometriosis. The effects of chronic pelvic pain, dyspareunia, infertility and the psychosocial implications associated with these stressors were suggested to be involved in the development of depression in women with endometriosis, mediated by cognitive diatheses such as illness representations, perceived control, perceived self efficacy and coping style.

Conclusions: The findings in the current review suggested that depression is common in women with endometriosis and support the application of the diathesis-stress model to explain the causation of depression in women with endometriosis. Further research is needed to investigate suggested stressors and diatheses to validate the application of this model to this population.

2. Introduction

Psychological distress is common within gynaecological outpatient settings. Chaaya *et al.*, (2003) reviewed the literature examining the prevalence of psychological distress amongst women attending gynaecological settings. They found that prevalence rates of psychological distress world-wide ranged from 10-53%. More specifically, the literature investigating depression within gynaecology contexts demonstrated that current prevalence rates of depression world-wide, ranged from 10% (Sundstrom *et al.*, 2001) to 50% (Chaturvedi *et al.*, 1994), which demonstrated higher rates than would be expected within the general population¹. Variations within prevalence rates were attributed to differences in site of study, sample size and outcome measures used.

Glover *et al.*, (2002) explored the causation of psychological distress within gynaecological settings. They suggested that psychological distress was attributed to: the direct distress caused by gynaecologic symptoms; distress caused indirectly through reactions to diagnosis and treatment; distress caused by the impact of gynaecologic symptoms on relationships, social life and self identity; and distress caused by external factors unrelated to the gynaecologic symptoms. Socio-demographic factors such as age and marital status have also been associated with distress within gynaecological settings (Ballinger, 1977; Byrne, 1984).

Comorbidity between depression and chronic physical health conditions is well documented (Anderson *et al.*, 2001; Dersh *et al.*, 2002; Dickens, *et al.*, 2002; Strik *et*

¹ Current prevalence of major depression among women ranges from 3-14% (cited in Carr & McNulty, 2006, p.56). Lifetime prevalence of major depression among women is approximately 10% to 25% (APA, 2000a)

al., 2004), especially in chronic pain populations. For example, in a large scale cross-cultural study (N=5,438), it was found that participants who reported chronic pain were four times more likely to experience a comorbid depressive or anxiety disorder (Gureje *et al.*, 2001). In a review of studies investigating the prevalence of Major Depressive Disorder (MDD) within clinic-based chronic pain populations, rates ranged from 30-54% (Banks & Kerns, 1996). They indicated that MDD was more common in chronic pain than in other chronic conditions and the general population.

In respect of the literature highlighting the prevalence of depression within gynaecology and chronic conditions, the current review was an investigation of the prevalence and causation of depression within one of the most commonly occurring gynaecological conditions, endometriosis².

2.1. Background to endometriosis

Endometriosis is a chronic gynaecological disorder thought to affect around 5% - 15% of women of reproductive age (Damewood *et al.*, 1997), although, a recent review postulated that endometriosis is likely to be under-diagnosed and under-reported within the population (Gao *et al.*, 2006). It is found in women from all ethnic backgrounds and social groups (Royal College of Obstetricians and Gynaecologists; RCOG, 2006). Currently, a laparoscopy, an invasive surgical procedure, is the gold standard diagnostic test for endometriosis in clinical practice. Disease severity is

² Endometriosis is a condition where endometrial tissue develops outside the uterus, usually in the abdominal cavity but it can occur in other parts of the body. This tissue responds to ovarian stimulation in the same way as uterine endometrial tissue during the menstrual cycle. Therefore during menstruation, the ectopic endometrial tissue bleeds and the blood becomes trapped in the body, causing inflammation, pain, scarring, adhesions and cysts.

commonly assessed using the American Society for Reproductive Medicine (ASRM) classification of Endometriosis (previously known as the American Fertility Society (AFS) classification system) which rates endometriosis into four stages of severity (Stage I = low severity and Stage IV = high severity). No correlation has been found between stage and symptoms of endometriosis (Gao *et al.*, 2006). Currently, there is no guaranteed cure for endometriosis and treatment focuses on symptom relief and self-management. Generally, combinations of medical treatments (e.g. oral contraceptive, nonsteroidal anti-inflammatory agents, progestins and gonadotrophin-releasing hormone agonists) and surgical treatments (e.g. laparoscopic excision, laparotomy, or hysterectomy) are commonly used to treat women with endometriosis. However, no single treatment modality has been proven to prevent recurrence of symptoms post medical or surgical intervention (Gao *et al.*, 2006).

Endometriosis is associated with a range of symptoms: chronic pelvic pain (CPP), dyspareunia (deep pelvic pain experienced during or after sexual intercourse), fatigue, bowel and urinary problems and dysmenorrhea. In addition, endometriosis is a leading cause of female infertility, with infertility reported to occur in 30-40% of women with endometriosis (Low *et al.*, 1993). These symptoms are not specific to endometriosis and there is considerable overlap with other conditions such as irritable bowel syndrome and pelvic inflammatory disease. Furthermore, endometriosis can be asymptomatic only being discovered following investigations into fertility difficulties. As a result of these factors, there is often a large delay between symptom onset and a definitive diagnosis (Hadfield *et al.*, 1996; Denny, 2004a; Ballard *et al.*, 2006).

It is well documented that the symptoms associated with endometriosis can have a profound impact on general physical, mental and social wellbeing (RCOG, 2006), significantly negatively affecting quality of life, relationships, career, and social functioning (Huntington & Gilmour, 2005; Denny, 2004b; Jones *et al.*, 2004). Furthermore, the literature suggests that endometriosis can affect psychological wellbeing (Low & Edelmann, 1991; Gao *et al.*, 2006). A previous review (Low & Edelmann, 1991), which focused on the psychological aspects of endometriosis, considered the psychosocial factors that might be implicated in the aetiology of endometriosis and the psychological impact of the condition. They suggested that the emotional impact of endometriosis was likely to be related to a range of factors such as hormonal influences, severity of the condition and degree of disruption to life, mediated by the individual's personal coping resources, levels of support and interpretation of the condition. They concluded that endometriosis had the potential to be emotionally debilitating and that further research was required to investigate further the psychological impact of the condition. At the time of their review, Low and Edelmann commented on the dearth of population-based, longitudinal or other substantive studies and reflected that this had limited their conclusions. The review of psychological aspects within endometriosis by Low and Edelmann (1991) was the first of its kind and highlighted the potential psychological impact of endometriosis. However, it may have been flawed by its design as it was not conducted systematically and limited reference was made to psychological theory to explain its findings. Furthermore, their review is now almost 20 years out of date, and in light of the increasing awareness of endometriosis within health care and society demonstrated a gap in the scientific knowledge base.

2.2. Objectives

The current review had four main objectives:

- 1 To provide an up-to-date review of the literature investigating the prevalence of depression in women with endometriosis using a systematic literature search.
- 2 To critically analyse the studies included in the review to establish the quality of the study, methodological flaws and limitations.
- 3 To further the understanding of the development of depression within women with endometriosis by drawing on psychological theory and wider literature from chronic pain, infertility and chronic illness populations.
- 4 To consider the clinical implications and future research following the current review findings.

3. Methodology

3.1. Review criteria

Literature searches were conducted using clear review criteria. Studies included in the current review were selected using the following criteria:

- Population – Women with endometriosis. There were no limits on age of the population or site of study.
- Study design – Only empirical studies were included, incorporating both quantitative and qualitative studies. Therefore, literature review articles and non-empirical articles were excluded.
- Outcomes – Studies that examined psychological distress or depression within women with endometriosis were included. However, studies that measured psychological distress in relation to pre- and post-treatment interventions were excluded.
- Limiters – Only published peer reviewed studies in English that had been accepted since 1970 onwards were included.

3.2. Search methods for identification of studies

The search strategy used the following resources:

i) Electronic databases

The following databases were searched:

- PsychINFO (1970 - 2008)
- PsycARTICLES (1970-2008)
- Medline(1950-2008)
- Embase (1980-2008)
- Web of Science (1970-2008)
- Assia (1970-2008)

- CINAHL (1970-2008)
- The Cochrane Library

Key search terms included: ‘endometriosis’, ‘depression’, ‘psychological distress’, ‘distress’, ‘psychological impact’, ‘mood’, ‘mental health’, ‘psychological problems’, ‘psychiatric problems’, ‘Beck Depression Inventory’ and ‘General Health Questionnaire’. Synonyms and truncation of these key search terms were also searched.

ii) Reference lists

The references from relevant reviews and articles were examined for additional relevant studies.

3.3. Search results

All abstracts obtained by the initial search strategies were screened by the author for eligibility. Studies were excluded if they did not meet the inclusion criteria. The full texts of studies that met the basic criteria were then retrieved for critical evaluation. Appendix A provides further detail regarding the literature search and reasons for study exclusion. Overall, the literature search identified 21 studies to be critically evaluated and discussed within the current review. Included studies are tabulated in Appendix B.

4. Results

This section outlines the prevalence of psychological distress and more specifically, depression in women with endometriosis. It investigates multiple factors suggested to be linked to the development of depression in women with endometriosis from the studies reviewed.

4.1. Presence of psychological distress within women with endometriosis

The majority of studies reviewed indicated that endometriosis can have a negative effect on psychological wellbeing. Several studies (Marques *et al.*, 2004; Laursen *et al.*, 2005; Barnack & Chrisler, 2007) examined the effect of endometriosis on mental health using the SF-36 health survey (RAND SF-36; Hays, Sherbourne & Mazel, 1993) as part of a wider investigation into evaluating Health Related Quality of Life³ (HRQOL). A comparison of these studies indicated variation in scores on the mental health subscale. For example, Marques *et al.*, (2004) assessed HRQOL within 60 laparoscopically diagnosed Brazilian women with endometriosis from an outpatient endometriosis clinic. They found relatively poor mental health (mean score of 44 out of 100, lower scores indicate poorer mental health) within their sample. However, Laursen *et al.*, (2005) showed that Danish women with endometriosis (n=10) had relatively good mental health with an average score of 70 on the mental health subscale on the SF-36 health survey. It was thought that the difference in these findings was related to sample size and setting of the study, as Larsen *et al.*, (2005)

³ Health-related quality of life (HRQOL) is an individual's satisfaction or happiness with domains of life insofar as they affect or are affected by health (Wilson & Cleary, 1995).

used a very small sample and it was set in an affluent country. Therefore, the poorer mental health indicated by Marques *et al.*, (2004) could be related to socio-economic factors and standard of living.

Interestingly, Mathias *et al.*, (1996) in a large scale telephone survey examining the prevalence of chronic pelvic pain (CPP) in US women and its association with HRQOL found that women diagnosed with endometriosis (n=74) had moderate mental wellbeing scores (mean score 63 out of 100) on the Medical Outcomes Survey-Long form (Stewart & Ware, 1992). This was despite the endometriosis group having the most severely affected QOL, the greatest levels of pain, the greatest interference with activities because of pain, the most health distress and highest score for dyspareunia in comparison to other groups of women with CPP. Mathias *et al.*, (1996) also found that women with endometriosis accessed health care resources more frequently than CPP population. Therefore, this regular contact and support from services may have acted as a protective factor for mental health. This study was limited by its design because only women who could speak English and who had a telephone could participate in the study. Additionally, self-reported diagnosis could not be clinically confirmed, thereby women may have been mistakenly included in the study.

Mood disorders were found to be prevalent within women with endometriosis. For example, Lewis *et al.*, (1987) found a high prevalence (75%) of mood disorders, predominantly bipolar disorder and major depression within a small sample of women with endometriosis (N=16). However, Walker *et al.*, (1989) failed to find any association between endometriosis and mood disorders. In their study, they examined

the prevalence of mood disorder in women with endometriosis (n=14) in comparison to a group of women without endometriosis (n=55) and found no significant differences between groups. However, the comparison group used was a mixture of women with and without CPP, and so the presence of pain within both groups may explain why there were no differences in prevalence. Both these studies have methodological flaws such as small sample sizes and reliance on psychiatric interview to identify probable mood disorder rather than standardised psychometric tools.

Psychiatric 'caseness' within women with endometriosis was explored using the General Health Questionnaire (GHQ; Goldberg, 1972) by Low *et al.*, (1992). Low *et al.*, (1992; 1993) suggested that there were elevated levels of probable cases of psychiatric morbidity within a sample of women with endometriosis with CPP (n = 40), in comparison to normative data, regardless of stage of endometriosis as classified by AFS system. However, GHQ scores for the endometriosis group were not significantly different to the group of women with other gynaecological problems with CPP (n=41). Additionally, Peveler *et al.*, (1996) found that about 35% of women with endometriosis (n=40) were indicative of probable mood disorders measured on the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983). A similar level was also found in women with unexplained CPP (n=51). Overall, the presence of mood disorders has been evaluated using a variety of measures, however, the studies seem to indicate high probable levels of mood disorders within women with endometriosis.

4.2. Presence of depression within women with endometriosis

Specifically, depression was shown to be prevalent within the literature reviewed. Studies demonstrated that women with endometriosis frequently reported depressed

feelings (Mathias *et al.*, 1996; Hirsh *et al.*, 2001; Peveler *et al.*, 1995). For example, Lemaire (2004) indicated that 75.4% of a sample of women with a formal diagnosis of endometriosis (N=298) reported depressed feelings some or most of the time.

However, this sample may not have representative of women with endometriosis because participants were recruited from an Endometriosis Association Conference. Therefore, women who attend these sorts of conference may be women who are in more distress or in need of more support. Conversely, they might be women who are better informed, more aware and of higher educational attainment.

Difficulties regarding emotional wellbeing were commonly expressed within qualitative studies and provided a descriptive account of how women with endometriosis were feeling. For example, Jones *et al.*, (2004) conducted 24 individual semi-structured interviews within women formally diagnosed with endometriosis. Using grounded theory to elicit themes within the interviews, they reported that emotional wellbeing was affected by endometriosis and participants described feeling 'miserable' and 'depressed' and were frequently tearful. Another qualitative study by Cox *et al.*, (2003b) gained accounts of women's experiences of endometriosis using focus groups (N= 61). From a thematic analysis, 'depression' was identified as an important sub-theme for 'Living with endometriosis'. Within, this subtheme, Cox *et al.*, (2003) depicted the development of depression as a consequence of the psychosocial implications of endometriosis, infertility and negative experiences with health care services. They also highlighted a prevalence of suicidal ideation within women with endometriosis. However, without systematically measuring reported distress using standardised outcome measures, the severity or clinical significance of

the level of emotional distress is unknown. Furthermore, qualitative studies may be limited by the inherent subjective nature of the analysis and researcher bias within interviews.

Clinically significant levels of depression were shown in quantitative studies (Low *et al.*, 1992; Lorencatto *et al.*, 2006). For example, Lorencatto *et al.*, (2006) investigated the prevalence of depression in Brazilian women with laparoscopically diagnosed endometriosis with pain (n=50) and without pain (n=50). They found that depression scores on the Beck Depression Inventory (BDI; Beck, Steer & Brown, 1996) were significantly high in both groups. However, the proportion of women that met the cut off for clinically significant depression (score >13 on BDI) was higher in the symptomatic group at 86% in comparison to 38% in the asymptomatic group. Of the 86% in the symptomatic group, 52% met the criteria for moderate to severe levels of depression (20+ on the BDI). Conversely, Eriksen *et al.*, (2007) compared laparoscopically diagnosed symptomatic (n=43) and asymptomatic (n=20) endometriosis and found no significant differences in levels of depression between groups. Furthermore, the mean for both groups on BDI did not meet the cut off for clinical significance, indicating no evidence to support a high prevalence of depression within endometriosis populations.

Overall, the evidence suggests that psychological distress, in particular depression, was prevalent in women with endometriosis. However, as indicated there are inconsistencies within the literature, showing variation in levels of depression within this population.

4.3. The relationship between site and severity of endometriosis and the development of depression

The current review considered how depression might be associated with the site of endometriosis based on anatomical location or severity of endometriosis as classified using the American Society for Reproductive Medicine (ASRM) classification of Endometriosis system. The current study demonstrated that there was little evidence within the literature to support a relationship between psychological distress and either of these variables. The following studies failed to find any correlation between severity of endometriosis and mood (Low *et al.*, 1992; Peveler *et al.*, 1995; Hassa *et al.*, 2005). However, Marques *et al.*, (2004) found that women with moderate or severe endometriosis (Stages III and IV; n=31) demonstrated significantly better emotional wellbeing and mental health than women with minimal and mild endometriosis (Stages I and II, n=26). Marques *et al.*, (2004) suggested that women in advanced stage of endometriosis may be more aware of the importance of improving QOL and therefore take action to promote their wellbeing. Differences between these studies did not seem to be related to sample sizes but could be related to different outcome measures used or setting of the study.

Only one study explored the relationship between site of endometriosis and psychological distress. Hassa *et al.*, (2005) investigated the prevalence of depression in relation to the location of endometriosis: peritoneal, ovarian and combined peritoneal and ovarian endometriosis (N=68). They failed to find a significant correlation between depressed mood and the localisation of endometriosis. However,

this study did not define ‘depressed mood’ or how it was assessed, therefore, it was uncertain whether depressed mood was the same as major depression.

4.4. The relationship between endometriosis symptoms and the development of depression

4.4.1. Chronic Pelvic Pain (CPP)

As previously highlighted, an association between chronic pain and depression has been demonstrated in the wider chronic pain literature. Banks and Kerns (1996) supported the notion that depression was a sequela to the psychological experience of living with pain, as iterated by previous studies (Brown, 1990; Magni *et al.*, 1994). Although they acknowledged that in some cases, depression could be primary or develop simultaneously with the onset of pain. The current review considered how depression might develop secondary to chronic pelvic pain associated with endometriosis.

The experience of CPP is one of the most common themes presented in the literature on endometriosis, as supported by Denny and Khan (2006) in their review of qualitative studies. Pain is an adverse sensation, which typically produces an emotional reaction due to its association with harm. Within endometriosis, CPP is often severe and debilitating. The studies reviewed in the current review focused solely on CPP, however it was recognised that endometriosis is also associated with pain elsewhere in the body and hence also likely to adversely impact on the individual. Qualitative studies exploring the experience of CPP in women with endometriosis

recounted how women described their pain as ‘crippling’ and ‘gnawing’ (Huntington & Gilmour, 2005) and ‘overwhelming’ (Denny, 2004a).

In the studies reviewed, CPP was shown to have an integral role in the development of depression within women with endometriosis. Lorencatto *et al.*, (2006), demonstrated that depression was prevalent in both women with symptomatic and asymptomatic endometriosis, however, there were significantly higher rates of depression in women with endometriosis with pain. Similar findings linking depression to the presence of pain have been exhibited within other studies in the literature. For example, Low *et al.*, (1993) found no significant difference between mild levels of clinically significant depression exhibited amongst women diagnosed with endometriosis with CPP (n=40) and women with other gynaecological problems with CPP (n=41). This suggested that pain might be a necessary factor involved in the development of depression within women with endometriosis.

Waller and Shaw (1995) also found significantly higher proportions of depressive symptoms on the BDI within women with mild/minimal endometriosis (n=18) or unexplained CPP (n=30) than women who had been admitted for sterilisation with a normal pelvis (n=38) and women with mild/minimal endometriosis and infertility (n=31). However, it was noted that average total BDI scores for all of the groups were below the clinical cut-off for significant levels of depression (scores >13), although the mean BDI total scores for both women with mild/minimal endometriosis and women with unexplained CPP symptomatic groups were only slightly below the cut off.

Therefore, it was thought that larger sample sizes within each group might have indicated significant clinical levels of depression.

Eriksen *et al.*, (2007) found no significant correlation between degree of pain, as measured on Visual Analog Scales (VAS), and depression within women diagnosed with endometriosis, even though, significant positive correlations between pain severity and psychosocial impairment were demonstrated. Other studies have also suggested a lack of any correlation between pain and psychological distress (Christian *et al.*, 1993; Marques *et al.*, 2004). Furthermore, Low *et al.*, (1993) showed no significant relationship between pain duration and personality characteristics, depression, psychiatric morbidity, anxiety and marital state. Therefore, the literature indicated that the experience of pain alone might not directly lead to the development of depression.

Pain can have a debilitating effect on individuals, impairing and interfering with many aspects of their life such as daily activities, relationships, work and social life, as well as affecting self-esteem and personal identity (Jones *et al.*, 2004). Women with endometriosis and CPP described poorer health, greater interference with activities and greater pain during intercourse compared to women with no diagnosis or other non-gynaecological pain (Mathias *et al.*, 1996). Overall, pain associated with endometriosis reduced health related quality of life (Bodner *et al.*, 1997; Mathias *et al.*, 1998, Marques *et al.*, 2004). CPP can limit physical functioning and impede social and occupational activities and as a consequence, women may experience a loss of social and economic status. Peveler *et al.*, (1995) found that social dysfunction, as

measured on the modified Social Adjustment Scale (Cooper *et al.*, 1982) was increased in women with endometriosis in comparison to women with unexplained chronic pain. They posited that greater social dysfunction was related to greater severity of pain within women with endometriosis. However, a larger proportion of the endometriosis group was from higher socio-economic groups, which may also explain the demonstrated greater adverse effect on social functioning. The fear of pain may also contribute to impaired functioning, as the anticipation of pain may elicit pain avoidance behaviours such as not participating in activities or not wanting to go out, promoting inactivity and greater disability. Consequently, a reduction in social functioning may generate feelings of social isolation and loneliness (Jones *et al.*, 2004) which may contribute to the development of depression. Therefore, depression may develop in relation to the secondary adverse implications of CPP on a woman's life.

4.4.2. Dyspareunia

Dyspareunia was also considered to potentially be involved in the development of depression in women with endometriosis, due to its reported profound psychological consequences. It is a common symptom in women with endometriosis (Mathias *et al.*, 1996; Fauconnier *et al.*, 2002; Ferraro *et al.*, 2005). For example, Denny and Mann (2007) detected that 86% (N=30) of women with endometriosis sampled in their study experienced dyspareunia. Dyspareunia has been associated with a reduction in frequency of sexual intercourse and high levels of avoidance behaviour (Walker & Shaw, 1995; Denny & Mann, 2007). The fear-avoidance cycle described by Vlaeyen & Linton (2000) can be applied to the experience of dyspareunia, whereby multiple experiences of dyspareunia condition women to expect pain during or after intercourse,

which increases fear and anxiety about having sex. Therefore, the anticipation of pain leads to avoidance of sexual intercourse. If sexual intercourse is attempted, the anticipation of pain is likely to generate fear and tension, which in theory is likely to increase the experience of discomfort or pain when engaging in intercourse, perpetuating the cycle and leading to sexual dysfunction. Waller and Shaw (1995) found that women with symptomatic endometriosis exhibited mild disorders of sexual functioning as assessed by the Golombok Rust Inventory Sexual Satisfaction (GRISS; Rust & Golombok, 1986). However, this study only sampled women with mild or minimal endometriosis, therefore it was hypothesised that sexual functioning may be more greatly affected in women with moderate and severe endometriosis.

Common adverse consequences of sexual dysfunction described in the literature were feelings of guilt and inadequacy (Jones *et al.*, 2004; Denny & Mann, 2007). In their study, Denny and Mann (2007) explored the repercussions of dyspareunia with women with endometriosis using semi-structured interviews. They described that women reported the experience of dyspareunia as being extremely distressing and had deleterious effects on self-esteem with women describing feeling unfeminine and unattractive, as well as negatively effecting relationships with partners. In this study, the participants considered their partners to be very supportive, however they recounted that the lack of sexual intercourse sometimes caused tensions and arguments within relationships, with partners reported as often feeling rejected. Some participants thought that the effects of dyspareunia jeopardised their relationships. Alternatively, Low *et al.*, (1993) indicated that women diagnosed with endometriosis showed stable relationships and satisfactory marital state as measured by the

Golombok Rust Inventory Marital State (GRIMS; Rust *et al.*, 1986). However, this study was not specifically testing the relationship between the prevalence of dyspareunia and marital state and therefore it was unknown how many of the sample experienced dyspareunia. Additionally in terms of self-esteem, Christian (1993) examined the relationship between endometriosis symptoms and self-esteem using the Rosenberg Self-Esteem Scale (Rosenberg, 1965). In this study, no significant correlation was found between self-esteem and the number, frequency or severity of endometriosis symptoms (pelvic pain, dysmenorrhea and dyspareunia) or fertility. In fact, self-esteem scores were predominately high. However, this study used a small sample size (N=23) and participants were recruited from a private practice. Therefore, the sample may not be representative of the general population of women with endometriosis and it is possible that self-esteem may have been protected by other variables such as socio-economic status. Unfortunately, no other studies have empirically investigated self-esteem within endometriosis.

In summary, the experience of dyspareunia seemed to have detrimental implications on self-esteem⁴ and relationships⁵, which theoretically should contribute to the development of depression. However, this relationship has not been empirically tested within the literature and hence a direct causal relationship can not be validated.

⁴ Low self esteem suggested to be a vulnerability factor for depression (Fennell, 2004)

⁵ Stressful life events such as loss of a significant relationship as risk factor in the aetiology of depression (Carr & McNulty, 2006).

4.4.3. Infertility

A relationship between infertility and depression has been cited in the wider literature (Wright *et al.*, 1989; Greil, 1997; Anderson *et al.*, 2003). Link and Darling (1986) found that 40% of women and 16% of men undergoing treatment for infertility in the US had scores indicative of clinically significant depression. However, other studies revealed little evidence that global psychological functioning or marital satisfaction was impaired in infertile couples compared to fertile couples or normative data (Paulson *et al.*, 1988; Eugster & Vingerhoets, 1999). For example, Connolly *et al.*, (1992) found low depression scores amongst couples seeking treatment for infertility (N=130) at initial assessment and at follow up 7-9 months later. The literature reviewed in the current study suggested that infertility secondary to endometriosis might be a stressor involved in the development of depression. Similarly to the infertility literature, the evidence to support this association was mixed.

Qualitative data demonstrated that the experience of infertility secondary to endometriosis was extremely distressing. Cox *et al.*, (2003a) sent 465 formally diagnosed women a semi-structured questionnaire exploring the experience of endometriosis. The sample was recruited from a specialist endometriosis clinic and the Endometriosis Association membership. They found that women with infertility secondary to endometriosis described profound psychological repercussions including grieving, anger, guilt and lowered self-esteem, all of which may contribute to the development of depression. Similar findings have been shown in other qualitative studies (Jones *et al.*, 2004, Cox *et al.*, 2003b).

Very few studies were found to empirically investigate the relationship between infertility related to endometriosis and depression. However, the empirical studies reviewed have not supported an association between infertility and depression. For example, Hassa *et al.*, (2004) evaluated the prevalence of depression in relation to fertile and infertile women with endometriosis (N=68). They found that depressed mood did not differ significantly with fertility status, which suggested that women with infertility secondary to endometriosis were not more depressed than fertile women. Waller & Shaw (1995) also suggested that infertility may not lead to depression. They compared depression measured on the BDI for women with symptomatic mild endometriosis (patients complaining of at least one or more of the following symptoms; dysmennorrhea, dyspareunia or pelvic pain) (n=18) with women with asymptomatic mild endometriosis (patients complaining only of infertility) (n=31). They found that the symptomatic group had significantly higher BDI scores than the asymptomatic group, which suggested that women with infertility secondary to endometriosis were less depressed than women with symptomatic endometriosis. Therefore, this study failed to support an association between infertility and depression within endometriosis populations. Although, Waller & Shaw (1995) did not specify whether fertility was controlled for between groups and hence it is possible that some of the symptomatic group may also have been infertile. Currently, a causal relationship between infertility secondary to endometriosis and the development of depression is unclear and further research is needed to explore this relationship.

Infertility secondary to endometriosis can have implications on womanhood, impacting on self-esteem, femininity and self-image as a woman (Jones *et al.*, 2004). For

example, infertility was a theme elicited by Jones *et al.*, (2004) in their qualitative analysis of the impact of endometriosis on quality of life. They depicted the negative impact of infertility of participants, especially on female identity, with participants describing not feeling like a complete woman. Infertility may also disrupt a woman's life goals and planned life trajectory, as most women expect to become a mother (Ulrich & Weatherall, 2000). Therefore, the loss of motherhood may also threaten identity. Consequently, the impact that infertility secondary to endometriosis has on the self and the loss of motherhood may contribute to the development of depression.

4.4.4. Additional factors

Additional factors identified within the studies reviewed that theoretically may contribute to the development of depression in women with endometriosis were abnormal hormone levels (Lewis *et al.*, 1987); medication side effects (Bodner *et al.*, 1997); treatment experiences (Jones *et al.*, 2004); and negative experiences with health care services (Cox *et al.*, 2003b; Jones *et al.*, 2004). These factors were not discussed in detail in the current review because there was little empirical evidence to suggest that they had a substantial role in the development of depression within this population.

4.5. Potential mediating factors

As shown in the studies reviewed, there seemed to be some individual variability in the development of depression in response to endometriosis. Not everyone with endometriosis who experiences CPP, dyspareunia or infertility developed depression. This suggested that it was unlikely that these symptoms per se were

sufficient to lead to depression manifesting and that other individual factors may play an important intermediary role. Few studies reviewed had considered potential mediating factors, therefore, psychological theory was also referred to establish a greater understanding between endometriosis and the development of depression.

4.5.1. Illness representations

An individual's beliefs, attitudes and expectations about illness are important and will correspondingly affect how they perceive, respond and cope with an illness. In reference to the Self-Regulation Model (Leventhal *et al.*, 1980; 1984), an individual's experience of their illness will be influenced by their beliefs about its identity, perceived cause, time line, control and cure and the short and long term consequences of the illness. Therefore, it is likely that the relationship between endometriosis and depression may be mediated by an individual's cognitive representations of the condition. This hypothesis was supported by examining the chronic pain literature. For example, Turk *et al.*, (1995) suggested that an individual's appraisals of the effects of pain on their lives and their ability to exert control over the pain mediated the pain-depression relationship. They found that patients who thought they could function effectively and keep control were least depressed. Furthermore, Rudy *et al.*, (1988) tested a cognitive-behavioural mediation model of pain and depression and failed to find a direct link between pain and depression, however, measures of perceived life interference and self-control were found to be significant intervening variables between pain and depression. These findings advocated for the importance of cognitive mediators in the development of depression secondary to chronic pain.

4.5.2. Perceived control

In particular, perceived personal control⁶ may be a significant component in the development of depression. In reference to the locus of control theory (Rotter, 1966 as cited in Marks *et al.*, 2005), individuals may have an internal or external locus of control⁷. An internal locus of control would suggest that the individual believes that what happens to them is under their own control, whereas external locus of control would suggest that the individual believes that what happens to them is due to external influence such as fate or chance. When this theory is applied to health, it posits that individuals with an internal health locus of control adapt to illness better than individuals with an external health locus of control. For example in chronic pain populations, individuals with low perceived control over pain and its interference with desired activities can lead to depressed feelings (Maxwell, Gatchel & Mayer, 1998), whereas individuals with greater perceived personal control report lower levels of pain, disability and depression (Turner *et al.*, 2002; Covic *et al.*, 2003). Similar findings have been reported in other chronic conditions (Taylor *et al.*, 1991). Therefore, in relation to endometriosis, women with an external locus of control or low perceived personal control over the condition may be more likely to develop depression. Women with endometriosis may develop low feelings of perceived control due to the uncertain and enigmatic nature of the condition, as uncertainty can reduce a sense of personal mastery which in turn can increase stress and feelings of helplessness (Mishel & Sorenson, 1991).

⁶ Perceived control refers to the belief that one has the ability to make a difference in the course or the consequences of some event or experience; often helpful in dealing with stressors (Gerrig, & Zimbardo, 2002)

⁷ Locus of control refers to a person's belief about what causes the good or bad results in their life (Rotter, 1966).

In relation to learned helplessness model of depression (Seligman, 1975), feelings of helplessness may contribute to the development of depression. This hypothesis is supported by Lemaire (2004) who examined the relationship between illness uncertainty⁸ and emotional distress within women with endometriosis (N=298) and found a medium sized positive correlation between uncertainty and emotional distress and symptom distress. This demonstrated that illness uncertainty may also play a significant role in the development of depression.

4.5.3. Perceived self efficacy

An individual's perceived self-efficacy⁹ regarding the management of endometriosis may also play a role in the development of depression. Low self-efficacy beliefs are associated with higher levels of disability and depression (Arnstein *et al.*, 1999). Therefore, individuals who believe that they are able to cope with their pain are less likely to feel depressed. This suggests that women who feel able to effectively manage the endometriosis may be less likely to develop depression. A relationship between self-efficacy and depression within women with endometriosis had not been examined by the studies included in the current review, subsequently further research is needed to validate this association.

4.5.4. Coping styles

⁸ Illness uncertainty refers to an individual's inability to understand illness-related events and/or predict disease-related outcomes (Mishel, 1990).

⁹ Self-efficacy refers to people's beliefs about their capabilities to produce effects (Bandura, 1977).

Coping strategies used to deal with the effects of endometriosis could also impact on the development of depression, as they have been demonstrated to have an important mediating role within chronic pain populations. For example, Brown & Nicassio (1987) found that active coping such as physical exercise was associated with less pain, depression and functional disability in comparison to passive coping such as withdrawal. Additionally, chronic pain patients who used passive coping strategies were shown to have lower adaptive functioning, greater disability and depression (Scharloo *et al.*, 1998;Covic *et al.*, 2000). In relation to endometriosis, Eriksen *et al.*, (2007) investigated the effect coping style had on the prevalence of depression within women with endometriosis with and without pain (N=63).

Coping style was measured on the Coping Styles Questionnaire (CSQ; Roger, Jarvis & Najarian, 1993), which was made up of four subscales of rational, emotional, avoidance and detached coping; depression was measured on the BDI. They found moderate negative correlations between rational and detached coping and depression within the pain group and moderate positive correlations between emotional and avoidant coping and depression within the pain group. The correlational data for the pain-free group were not presented for comment. This suggested that coping style mediated the relationship between the experience of pain and the development of depression. However, only a small sample size was used within this sample, therefore conclusions are limited.

4.5.5. Summary

Depression could be perceived as an outcome of the experience of living with endometriosis, its symptoms, its psychosocial implications and secondary losses.

Although, the evidence found in the current review suggested that these factors alone may not have the potential to cause depression. Instead, depression may develop due to the interaction between these factors and individual factors such as illness representations; perceived control; perceived self-efficacy and coping style. Therefore, a diathesis-stress model may be the most appropriate framework to integrate the findings of the current study.

4.6. A diathesis-stress framework

A review of chronic pain literature highlighted the useful application of a diathesis-stress model to explain the development of depression within chronic pain populations (Banks & Kerns, 1996, Turk, 2002).

A diathesis-stress model was originally applied to explain the development of schizophrenia by Zubin and Spring (1977). However, its application has been widened to explain the development of other mental health problems such as depression (Monroe & Simons, 1991). The model proposes that for a disorder to develop, diatheses and a stressor are necessary. Diatheses refer to vulnerabilities or predispositions of an individual that render them susceptible to a stressor, such as low self-esteem or low social support, and increase their chance of developing a disorder. A stressor refers to environmental or life events perceived by the individual as threatening their physical or psychological wellbeing and exceeding their capacity to cope (Lazarus & Folkman, 1984), for example, bereavement, separation or illness. A stressor may increase the individual's vulnerability or

precipitate the disorder in vulnerable individuals. A diathesis-stress model posits that each individual has a unique susceptibility due to social, cognitive, and biological vulnerabilities that when activated by a stressor can lead to the emergence of a disorder. Hence, a diathesis-stress model offers an explanation for why some, but not all individuals exposed to the same stressor develop a disorder (Robins & Block, 1989).

Banks and Kerns (1996) applied a diathesis-stress model to explain the development of depression within chronic pain populations. They reflected upon cognitive and behavioural models of depression to identify potential diatheses that might render an individual vulnerable to chronic pain. They theorised that potential diatheses for the development of depression in relation to chronic pain could be: negative schemas and negative cognitions about the self, the world and the future (Cognitive distortions model; Beck, 1967, 1976); internal, stable, global attribution style when confronted with an uncontrollable negative event (reformulated learned helplessness model; Abramson *et al.*, 1978) and deficits in instrumental skills (Fordyce, 1976). Bank and Kerns (1996) expressed that the stressor was not only the aversive sensory aspects of pain, but also the accompanying emotional aspects of pain, impairment and disability and subsequent secondary losses. Therefore, Banks and Kerns (1996) argued that chronic pain patients might develop depression through the interaction of the experience of chronic pain with pre-morbid psychological predispositions to produce symptoms of depression.

In respect of this backdrop, it seemed appropriate to apply the diathesis-stress framework to conceptualise the development of depression in women with endometriosis. The diathesis-stress model posits that diatheses are necessary to moderate between the development of a disorder following a stressor. Potential stressors suggested in the current review were the experience of endometriosis-associated symptoms and their psychosocial repercussions, abnormal hormone levels, medication side effects, treatment experiences and negative experiences with health care services. Potential diatheses identified included an individual's illness representations, perceived control, perceived self-efficacy and coping style. Other potential diatheses suggested within the literature, which could be relevant to the application of the diathesis-stress model to endometriosis were premorbid episodes of depression, low self esteem, as well as the psychological predispositions proposed by Banks and Kerns (1996). Unfortunately, relatively few of the studies reviewed had investigated the relationship between these identified diatheses and the development of depression and therefore further research is needed to evidence their role in the development of depression in women with endometriosis.

In summary, depression in women with endometriosis may develop through the interaction of an individual's appraisal, beliefs and response to the multiple stressors experienced in relation to the condition. This would explain the variation seen within the studies reviewed regarding the prevalence and causation of depression in women with endometriosis, as every woman would have an individual susceptibility to depression. Further research is needed to evidence the application of a diathesis-stress model to endometriosis.

5. Discussion

5.1. Summary of findings

The current review explored the prevalence and development of depression within women with endometriosis. This was done by critically reviewing 21 relevant studies that explored the relationship between depression and endometriosis. Wider literature from gynaecology, chronic illness and chronic pain populations was also drawn on to reflect upon the development of depression within women with endometriosis and solidify conclusions.

The current review demonstrated that there was significant evidence to suggest that depression was prevalent within women with endometriosis at a level greater than women in the general population. However, it remains unclear whether levels of depression were significantly different from other chronic conditions. The association between depression and endometriosis found within this review supported the findings by Low & Edelman (1991) and also reflected the high level of psychological morbidity shown within gynaecological services and other chronic illnesses.

Uniquely, the current review applied a diathesis-stress framework to explain the development of depression within women with endometriosis. A range of potential diatheses and stressors were identified that might contribute to the development of depression within this population. There was no evidence to support a link between depression and site or stage of endometriosis. The effects of chronic pelvic pain, dyspareunia, infertility and the psychosocial implications associated with these stressors were suggested to be involved in the development of depression in women with endometriosis. However, the inconsistencies in findings and lack of firm evidence to support causal relationships between these stressors and depression suggested that these stressors alone do not facilitate the development of depression. Consequently, it was suggested that how a woman interprets and appraises the condition, their perceived ability to control and manage it and their individual coping style would mediate between the experience of endometriosis and the manifestation of depression. It is likely that a combination of diatheses and stressors are involved in the emergence of depression in women with this condition. Therefore, depression is likely to be the result of the experience of living with endometriosis in conjunction with a range of individual, biological, psychological and social vulnerabilities. Ultimately, the findings in the current review support the application of the diathesis-stress model to explain the causation of depression in women with endometriosis.

5.2. Critical appraisal of reviewed studies and current review

Considering the potential psychological ramifications of endometriosis, there is a paucity of studies that have focused upon systematically investigating the psychological impact of endometriosis. Furthermore, more methodological rigour is

needed be able to form firm conclusions of the association between depression and endometriosis. Methodological limitations identified within the studies reviewed have been highlighted throughout the current review and are outlined for each study in the inclusion study table in Appendix B.

Inconsistencies cited between studies regarding the prevalence of depression may have been related to limitations in study design, for example, differences in the definition of depression. Some studies defined depression in terms of psychiatric criteria for MDD (e.g. Lewis *et al.*, 1987; Walker *et al.*, 1989), other studies did not state how they defined depression at all (Hassa *et al.*, (2005). Therefore, individuals who do not meet clinical criteria for MDD may be included, inflating the depression rate. There were also differences in how depression was measured, which impaired comparisons of findings across studies. Studies used a mixture of screening tools such as the Beck Depression Inventory, unstandardised rating scales, self-report and diagnostic clinical interview. Furthermore, one study, (Hassa *et al.*, 2005) failed to state how they measured depression within their sample. Lastly, it was hypothesised that different rates of depression may relate to the point in time when it was assessed during the course of the condition. It may be that depression was more prevalent immediately after diagnosis or after living with endometriosis for a substantial amount of time. Few of the studies specified when depression was assessed in their sample.

Endometriosis comprises of a range of symptoms such as Chronic Pelvic Pain (CPP), dyspareunia, dysmenorrhea, menorrhagia and frequently, infertility. Therefore, the development of depression within endometriosis may be related to the experience of a

combination of these symptoms and their related difficulties. A main limitation seen within the literature reviewed was that studies mainly focused on the relationship between pain and the development of depression within endometriosis, without controlling for the potential impact of these other symptoms. Consequently, causal relationships suggested between pain and depression within women with endometriosis need to be interpreted with caution. Few studies have investigated the potential effect of other stressors and diatheses in the development of depression, leaving a gap in the knowledge base. Furthermore, another major shortcoming of the literature reviewed was that few studies had directly applied psychological theory to their findings to explain the causation of depression within endometriosis.

Within the current review, firm conclusions regarding the prevalence of depression within endometriosis was hindered by the dearth of literature specifically investigating the relationship between depression and endometriosis. The overall impact of endometriosis on mood or psychological wellbeing was more commonly assessed, using the GHQ or via the SF-36. Therefore, these studies were included in the current review to provide a stronger foundation of the prevalence of mental health problems with this population. Another consequence of the paucity in studies on the relevant subject area was that studies of questionable methodological rigour were included in the current review, however their flaws were clearly highlighted to notify the reader of the deficits in their study. It was speculated whether the search was too narrow and may have benefited from considering depression within a number of gynaecological conditions.

Both qualitative and quantitative empirical studies were included in the review, granted they met the inclusion criteria. It was thought that the inclusion of qualitative research enhanced the current review because it gave depth to the findings, providing data on the subjective experience of the emotional impact of endometriosis, enriching quantitative data. It also allowed a suitable number of studies to be reviewed. However, a weakness of including both methodologies was that they were difficult to critically appraise requiring separate quality criteria. Additionally, it was difficult to compare and assimilate both types of studies due to their differing intentions and aims, that is, quantitative studies focusing on hypothesis testing and qualitative studies focusing on hypothesis generating.

The current review was also limited by its search strategy. The search strategy identified a wide range of articles, many of which were irrelevant for the aims of the current review or did not meet the inclusion criteria and were therefore rejected. Due to the large number of false positives within the literature search, the number of excluded studies was not monitored. Even though, only published studies were included, the findings did not seem to show a publication bias towards only positive findings.

6. Future research and clinical implications

The current review conceptualised the aetiology of depression within endometriosis using a diathesis-stress framework. The application of this model to explain the development of depression within women with endometriosis needs to be validated by future research. Further research is also needed to investigate the relationship between endometriosis symptoms and depression to systematically identify or disprove potential variables that contribute to the development of depression. For example, whether there is a significant relationship between dyspareunia and depression or investigating the involvement of cognitive mediating factors such as perceived control. Additionally, further research is needed to clarify the relationship between infertility secondary to endometriosis and the emergence of depression. Longitudinal studies would also be useful to establish the occurrence of depression over the changing course of the condition. This might help health care services to predict when women with endometriosis may be most vulnerable to developing depression. The current review focused specifically on depression, however other psychological difficulties such as anxiety are also common within the literature. Further research into the prevalence and causation of other psychological difficulties may be useful.

Within clinical practice, the current review advocates that medical practitioners need to be attentive for signs of depression within women with endometriosis, so that it can be

assessed and treated effectively. Where depression has been identified, a diathesis-stress framework could be used in the formulation of the development of depression within women with endometriosis, which could then highlight possible areas for intervention. For example, negative schemas and thoughts could be modified through cognitive behavioural therapy.

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Section B

THE EFFECTS OF SYMPTOMATIC ENDOMETRIOSIS ON WOMANHOOD

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(excluding references)

1. Abstract

Purpose: To investigate whether symptomatic endometriosis affects womanhood through the qualitative exploration of identity as a woman, wellbeing, sexuality, fertility and relationships. Secondly, it aimed to explore women's experiences of received health care to determine whether their needs were being met by services.

Method: A qualitative design was used. Seven women with a laparoscopic diagnosis of endometriosis participated in the study. Individual, semi-structured interviews were conducted and data was analysed using Interpretative Phenomenology Analysis.

Results: Four master themes were elicited: The fluctuating and unpredictable experience of endometriosis; journey to motherhood; impact on womanhood; and emotional impact of endometriosis.

Conclusions: Womanhood remained relatively intact, although it was threatened by fertility concerns, sexual difficulties and experiences of discreditation, which at times affected identity as a woman, sexuality and self-esteem. Overall, the endometriosis journey was fluctuating and unpredictable, yet, women with endometriosis were able to regain control and retain normality, adjusting to the condition by incorporating it into personal identity. Lastly, the study found satisfactory experience of healthcare services, however there were still difficulties reported regarding delays in diagnosis, the lengthy treatment process and lack of information. Additionally, the emotional impact of the condition was highlighted, suggesting the requirement for the availability of professional emotional support for women with endometriosis.

2. Introduction

2.1. Background to Endometriosis

Endometriosis is a chronic condition where endometrial tissue develops outside the uterus, usually in the abdominal cavity but it can occur in other parts of the body. This tissue responds to ovarian stimulation in the same way as uterine endometrial tissue during the menstrual cycle. Therefore during menstruation, the ectopic endometrial tissue bleeds and the blood becomes trapped in the body, causing inflammation, pain, scarring, adhesions and cysts. It is associated with a range of symptoms: chronic pelvic pain (CPP), dyspareunia (deep pelvic pain experienced during or after sexual intercourse), fatigue, bowel and urinary problems and dysmenorrhea. However, endometriosis can be asymptomatic and may only be recognized following investigations into fertility difficulties. Endometriosis is a leading cause of female infertility, with infertility reported to occur in 30-40% of women with endometriosis (Low *et al.*, 1993).

Endometriosis is a common gynaecological disorder, thought to affect around 5% - 15% of women of reproductive age (Damewood *et al.*, 1997). Although, a recent review postulated that endometriosis is likely to be undiagnosed and under reported within the population (Gao *et al.*, 2006). It is predominantly found in women of reproductive age, from all ethnic backgrounds and social groups (Royal College of Obstetricians and Gynaecologist; RCOG, 2006). Although, it has an unclear aetiology, various hypotheses have been presented within the literature such as a genetic predisposition (Kennedy *et al.*, 1996), retrograde menstruation (Sampson, 1921), immune system dysfunctions (Simpson *et al.*, 1990) and environmental chemical

toxins (Rier, 1993). Ultimately, it is likely that there is a combination of factors involved in the development of endometriosis.

The pathway to a diagnosis of endometriosis can be long and difficult. Currently, a firm diagnosis can only be made through a laparoscopy, an invasive surgical procedure. The literature describes that it can be a battle to receive a diagnosis, usually incorporating multiple journeys to the general practitioner (GP) (Cox *et al.*, 2003) and misdiagnoses (Denny, 2004a). Consequently, endometriosis is commonly diagnosed a long time after initial onset of symptoms (Hadfield *et al.*, 1996). In a survey of 228 women with endometriosis, the average delay in diagnosis was 7.96 years in the UK (Hadfield *et al.*, 1996). Delays in diagnosis have been associated with the enigmatic nature of endometriosis, as symptoms vary between individuals, overlap with other conditions and the severity of symptoms does not necessarily correlate with the extent of endometriosis present, making diagnosis complicated. Additionally, the literature suggests a paucity in knowledge about endometriosis amongst GP's (Cox *et al.*, 2003; Denny 2004a). Furthermore, qualitative studies reported that women felt that their symptoms were not taken seriously by their GP and that their experiences were trivialised. Often women were told that symptoms such as heavy, painful periods were part of being a woman (Denny, 2004a; Jones *et al.*, 2004) or that CPP was normal (Denny, 2004a) or dyspareunia was psychological in aetiology (Ballweg, 1997; Denny, 2004b). All these factors seemed to have contributed to the delay in diagnosis. Generally, diagnosis brought relief and validation to women that they were not 'hypochochondriacs' and that their symptoms were real (Denny, 2004a; Huntington & Gilmour, 2005). Alternatively, some women felt angry that receiving a diagnosis had

taken so long (Denny, 2004a) and the diagnosis was perceived to play an important role in helping them make sense of their experiences (Denny, 2004a).

2.2. Current treatment for endometriosis

Currently, there is no guaranteed cure for endometriosis, therefore treatment focuses on symptom relief and self-management. Generally, combinations of medical and surgical treatments are commonly used to treat women with endometriosis. Choice of treatment depends on the age of the patient, severity of endometriosis and symptoms and wish to retain reproductive capacity.

Medical management uses hormonal treatments, which change hormone levels in the body. They work by either mimicking pregnancy by using contraceptive treatments and progestins, or by inducing a pseudo-menopause using gonadotrophin-releasing hormone agonists. Unfortunately, there can be significant adverse side effects to some of the medical treatments (Jones *et al.*, 2004; Denny, 2004b). Non-steroidal anti-inflammatory agents and analgesics are often used to control symptoms such as menstrual and pelvic pain. Surgical treatments include laparoscopic excision, where a laser ablates away the endometrial cells or laparotomy, if there are significant amount of adhesions. In more severe cases, a partial or full hysterectomy may be conducted.

A systematic review of medical and surgical treatments for endometriosis suggested that both treatment modalities led to improvements in patients' physical and psychological functioning, vitality, pain level and general health. However, it demonstrated that no single treatment modality has been proven to prevent recurrence

of symptoms post medical or surgical intervention (Gao *et al.*, 2006). This has been supported by reports of limited effectiveness of treatments (Denny, 2004b) and long term symptom relief (Lemaire, 2004). Therefore, it is not uncommon for women to feel that they are on a ‘treatment carousel’ (Cox *et al.*, 2003b), with the need for repeat surgery or changes in medication. Consequently, women were reported to be exploring other methods to manage and relieve their symptoms such as diet, exercise (Huntington & Gilmour, 2005) and complementary therapies (Cox *et al.*, 2003b).

2.3. Experiences of endometriosis

Pain is one of the most commonly described experiences of endometriosis (Denny, 2004b; Huntington & Gilmour, 2005, Denny & Khan, 2006), depicted as being ‘crippling’ and ‘gnawing’ (Huntington & Gilmour, 2005) and ‘overwhelming’ (Denny, 2004a). The pain can be severe and debilitating, interfering with many aspects of life (Mathias *et al.*, 1996) and emotional wellbeing (Peveler *et al.*, 1995; Lorencatto *et al.*, 2006). Additionally, dyspareunia is another common symptom of endometriosis (Jones *et al.*, 2002; Gao *et al.*, 2006; Denny & Mann, 2007). In a study investigating the prevalence and impact of endometriosis-associated dyspareunia on women’s lives, Denny and Mann (2007) detected that 86% of the women with endometriosis sampled (N=30) experienced dyspareunia. Similar, high prevalence rates (78.6%) were found by Fauconnier *et al.*, (2002). The occurrence of dyspareunia has been associated with the reduction and avoidance of sexual activity (Denny & Mann, 2007; Walker & Shaw, 1995), leading to deleterious effects on a woman’s self-esteem and their relationships with partners (Denny & Mann, 2007). Associated feelings of guilt,

inadequacy and unattractiveness related to dyspareunia are common (Jones *et al.*, 2004; Emad, 2004; Denny & Mann, 2007).

Systematic reviews of the literature have demonstrated consistent findings that endometriosis has a substantial impact on Health Related Quality of Life¹⁰ (HRQOL; Jones *et al.*, 2001; Gao *et al.*, 2006), with endometriosis significantly affecting multiple areas such as relationships, career, social functioning and emotional wellbeing. Interference caused by endometriosis-associated symptoms, such as pain, menorrhagia and fatigue, to daily life activities, social activities and work commitments is shown to have negative effects on psychosocial wellbeing, generating distress and a sense of loss and frustration (Weinstein, 1988; Cox *et al.*, 2004; Huntingdon & Gilmour, 2005). Curtailment of social activities fostered feelings of social isolation (Jones *et al.*, 2004; Denny, 2004b; Emad, 2006) and intrusion on work activities hindered performance and work productivity (Denny *et al.*, 2004b; Gao *et al.*, 2006). Therefore, the literature demonstrates that throughout their lifetime, women with endometriosis are likely to experience multiple losses such as losses of normalcy, independence, social roles, career, status, physical abilities and possibly relationships. Consequently, these losses may impact on self-esteem and identity (Weinstein, 1988; Jones *et al.*, 2004). However, Christian (1992) found that self-esteem, as measured by Rosenberg Self Esteem Scale, was not significantly affected by endometriosis symptoms. In particular, fertility difficulties can impact on identity as a woman, with some women describing ‘not feeling wholly a woman’ (Weinstein, 1988) or ‘not a complete woman’ (Jones *et al.*, 2004).

¹⁰ Health-related quality of life (HRQOL) is an individual's satisfaction or happiness with domains of life insofar as they affect or are affected by health (Wilson & Cleary, 1995).

Endometriosis has been described as an ‘emotional rollercoaster’, where women experience a wide range of emotions such as shock, denial, fear, anxiety, helplessness, lack of control and despair (Weinstein, 1988). Depression and anxiety are reported to be prevalent within the population of women with endometriosis (Low *et al.*, 1993; Walker & Shaw, 1995; Lemaire, 2004; Lorencatto *et al.*, 2006). For example, Lemaire (2004) found that 64.4% and 75.4% of women with endometriosis sampled (N=298) reported experiencing symptoms of anxiety or depression, respectively, some or most of the time. However, standardised measures were not used in this study. Although, Lorencatto *et al.*, (2006) measured the prevalence of depression using the Beck Depression Inventory and found that 86% of women with endometriosis with CPP (n=50) demonstrated clinically significant levels of depression, as well as 38% of the group of women with endometriosis without CPP (n=50). However, there are some inconsistencies within the literature regarding the prevalence of psychological problems within this population, with some studies suggesting that levels of depression and anxiety correspond to norms within the general population (Walker *et al.*, 1989; Eriksen *et al.*, 2007). Generally, psychological co-morbidity has been related to pain (Walker & Shaw, 1995; Peveler *et al.*, 1995), interference with quality of life (Jones *et al.*, 2004), illness uncertainty¹¹ (Lemaire, 2004; Gao *et al.*, 2006), infertility (Jones *et al.*, 2004) and side effects of medication (Bodner *et al.*, 1997).

2.4. The challenges and survival of endometriosis

There are many challenges along the journey of endometriosis such as battling through social taboos, searching for a diagnosis and riding on the treatment carousel.

¹¹ Illness uncertainty refers to an individual’s inability to understand illness-related events and/or predict disease-related outcomes (Mishel, 1990).

Additionally, the journey is full of uncertainty related to: prognosis (Lemaire, 2004); the changing and unpredictable nature of symptoms and symptom reoccurrence (Lemaire, 2004); the unpredictable outcomes of treatment (Jones *et al.*, 2004; Huntington & Gilmour, 2005) and general lack of information about the condition (Lemaire, 2004). Therefore, the future is unknown and often viewed with a mixture of optimism and pessimism (Denny, 2004b). Consequently, feelings of low perceived control¹² are common, leading to women with endometriosis feeling powerless, frustrated (Jones *et al.*, 2004) and hopeless (Weinstein, 1988).

The influences of medical and societal discourses of Western cultures on the conceptualisation of endometriosis have also been considered within the literature, particularly from a feminist perspective. For example, it was speculated that women may have become socialised to believe that menstrual cramps and pain are normal female experiences (Kennedy, 1991). Furthermore, it was hypothesised that endometriosis is stigmatised by its relationship to menstruation (Denny, 2004a), hence becoming encased in deep-seated taboos surrounding menstruation, sexuality and infertility (Ballweg, 1997). As a consequence, women may be deterred from accessing services and suffer in silence.

Responses to endometriosis by others e.g. work colleagues, friends and family can be mixed, ranging from being supportive to being labelled a hypochondriac or thought to be overreacting (Denny, 2004a). As previously indicated, these experiences of discreditation and invalidation are sometimes replicated by GPs and there is a vast quantity of literature describing that women feel that health care services had failed to

¹² Perceived control refers to the belief that one has the ability to make a difference in the course or the consequences of some event or experience; often helpful in dealing with stressors (Gerrig, & Zimbardo, 2002)

provide empathy, support and action to validate their experiences of endometriosis. Overall, these experiences leave women feeling frustrated, disillusioned and dissatisfied with the health care services (Cox *et al.*, 2003a; Denny, 2004a Jones *et al.*, 2004). Although, the literature does also report positive experiences of health care services, particularly at the specialist level (Montague and Wood, 1997; Cox *et al.*, 2003a; Denny, 2004a).

Studies investigating the needs of women with endometriosis suggest that women: want to be listened to and to be believed (Kennedy, 1991, Whitney, 1998); to be involved in the decision making process regarding their medical treatment (Kennedy, 1991); and to be given more information (Whitney, 1998). The growth of online internet communities has enabled the sharing of information and experiences about endometriosis amongst women with endometriosis, facilitating peer support (Whitney, 1998; Emad, 2006) and allowing women to feel more effectual (Huntington & Gilmour, 2005). Accordingly, the literature suggests that women with endometriosis have become assertive and more active in the management of their symptoms and treatment (Cox *et al.*, 2003a).

2.5. Aims and objectives

Endometriosis is a prevalent, chronic and at a times, debilitating condition, yet it is not commonly heard of or fully understood. Previous research into endometriosis has mainly been quantitative, measuring treatment outcomes or HRQOL (Denny & Khan, 2006). Although, with the increased notability of qualitative methodology within health research, particularly chronic illness, recent research on endometriosis has begun to explore how women with endometriosis make sense of their condition (e.g.

Denny, 2004; Jones *et al.*, 2004; Huntington & Gilmour, 2005). However, the literature has been criticised for the lack of rigorous qualitative research, with criticisms regarding issues around claims of generalisability, inappropriate designs and lack of validity testing (Denny & Khan, 2006). Nevertheless, an overview of women's experiences of endometriosis has been proficiently illustrated within the literature, providing a solid foundation for further research.

For the purpose of the current study, womanhood was defined as a sense of identity as a woman, incorporating themes of sexuality, physical appearance as a woman, femininity, fertility, motherhood and gender grouping. It was conceptualised to be an individual and subjective term, which was shaped by societal and cultural influences. A review of the literature identified the potential for endometriosis to impact on womanhood due to its implications on identity, sexuality and fertility. This has been demonstrated in other gynaecological conditions such as polycystic ovary syndrome (Kitzinger & Willmott, 2002) and within fertility literature (Whiteford & Gonzalez, 1995; Clarke *et al.*, 2006). Therefore, the current study intended to:

1. Explore women's experiences of symptomatic endometriosis to gain an insight into how the condition affected womanhood, focusing on identity as a woman and the impact of endometriosis on femininity, wellbeing, sexuality, relationships and motherhood.
2. Explore women's experiences of received health care to determine whether their needs were being met and to identify any areas for potential improvements or recommendations.

In conclusion, endometriosis is an under researched area, surrounded by tremendous uncertainty and ambiguity; more research is essential to enhance understanding and insight of the condition within clinical practice, as well as for women with the condition.

3. Methodology

3.1. Epistemology

The current study was designed and conducted from a stance of contextualist constructionism. Although a qualitative analysis is always partial and subjective, contextualism maintains that results can be justified to the extent that they are grounded in the data. Therefore, contextualism advocates a balance between a realist position, which claims that results emerge from the data, with the constructionist position, which suggests that the process of analysis is interpretative (Hammersley, 1989). Additionally, contextualism accepts the inevitability of bringing one's personal and cultural perspectives into the research. The impetus for the current study stemmed from personal, indirect experience of endometriosis. Therefore, the Principal Investigator was aware that prior knowledge and experiences of the condition and the associated emotional ties may influence the design and interpretation of the study. Awareness of one's own pre-existing assumptions and beliefs is important and reflexive practice is necessary throughout the research process. Consequently, the Principal Investigator kept a reflective journal to reflect on her own personal experience of endometriosis, emotional responses and views throughout the study. More information about the Principal Investigator's relationship with endometriosis is recounted in Appendix C.

3.2. Study Design

A qualitative design was used to explore the effects of endometriosis on womanhood. Qualitative methodology aims to 'make sense of, or interpret phenomena in terms of the meanings people bring to them' (Denkin & Lincoln, 1994). Accordingly, it was

considered the most appropriate methodology to use because the aim of the current study was exploratory rather than hypothesis-testing, such as is seen in quantitative methodology. Thus, a rich interpreted account of women's lived experiences of endometriosis was gained through the analysis of semi-structured interviews using Interpretative Phenomenological Analysis (IPA; Smith, Osborn & Jarman, 1999).

3.2.1. Participants

A small, purposive sample of women with symptomatic endometriosis was recruited from an Obstetric and Gynaecology outpatients clinic in a general hospital. To participate in the current study, all participants had to meet the following inclusion criteria: have a formal diagnosis of endometriosis made through laparoscopic surgery; be 16 years or over and have experienced some symptoms associated with endometriosis. The sample size achieved for the current study was seven, with a response rate of 50% (7/14). Small sample sizes are recommended when using IPA (Collins & Nicolson, 2002; Smith, 2004). Participants were recruited over four months, from January 2008 to April 2008.

Demographic information

Table 1 overleaf displays the demographic information of the participants interviewed. Their identities have been anonymised by the Principal Investigator using pseudonyms.

Table 1: Demographic information of participants

Pseudonym	Age	Ethnicity	Marital status	No. of children	Occupation	Member of National Endometriosis Society
Danielle	32	White/British	Single	None	F/T	No
Helen	32	White/British	Boyfriend	None	F/T	No
Rebecca	26	White/British	Living with partner	None	F/T	No
Olivia	39	White/British	Living with partner	None	F/T	No
Ana	35	Indian	Living with partner	None	F/T	No
Lisa	37	White/British	Living with partner	None	F/T	No
Amy	37	White/British	Married	None	P/T	No

The mean age of the sample was 34 years old, with age ranging from 26 years to 39 years. Participants were predominantly White British females (n=6), with only one participant from a different ethnic group. All but one of the women interviewed were in stable relationships (n=6) and none of the participants had children. All the women interviewed were employed, with six participants working full time. None of the women interviewed were members of the National Endometriosis Society (NES).

Endometriosis profile of participants

Table 2 overleaf displays a brief description of participants' endometriosis including information about their symptoms and medical treatment

Table 2: showing the endometriosis profile of participants

Pseudonym	Av. delay to diagnosis (yrs)	Main distressing symptoms	Fertility difficulties	Treatment	Level of satisfaction (out of 5)
Danielle	2	Pelvic pain, bloating, constipation	Don't know	Medical & Surgical	4
Helen	1	Dyspareunia	Don't know	Medical & Surgical	2
Rebecca	4	Pelvic pain, dyspareunia	Don't know	Medical & Surgical	4
Olivia	3	Pelvic pain, dyspareunia	Don't know	Medical & Surgical	2
Ana	18	Pelvic pain	Yes	No	1
Lisa	18	Pelvic pain, heavy bleeding	Don't know	Medical	2
Amy	24	Pelvic pain	Yes	Surgical	4

Information from the History of Endometriosis Form was used to build an endometriosis profile of the sample. It showed that the average delay of diagnosis from onset of symptoms to diagnosis was 10 years, ranging from 1 year to 24 years. The main distressing symptoms reported were pelvic pain (n=6), dyspareunia (n=3), heavy bleeding (n=1) and constipation (n=1). On average participants' had eight different symptoms associated with endometriosis; this ranged from 1 to 13 symptoms. The majority of the sample (n=5) were not sure whether or not they had fertility difficulties, as they had not started trying for a family. Two participants reported having fertility difficulties and were considering IVF treatment. Most participants reported having a combination of medical and surgical treatments, for example laser surgery and hormonal treatments. Only one participant had not begun any sort of treatment. Reoccurrence of symptoms requiring further treatment was common (n=4). Alternative therapies had been used by two participants to gain symptom relief and additional pain relief using over-the-counter painkillers was common (n=5).

Additionally, three of the participants had received counselling or psychological support due to difficulties related to endometriosis.

3.2.2. Materials used

For recruitment purposes, participants were sent a Participant Information Pack containing all the information pertinent to the study. An example of the participant information pack is displayed in Appendix D.

Development of measures

In order to form a profile of the sample, basic information regarding participant demographics and medical history related to endometriosis was collected through two short forms. The Personal Details Form gathered demographic information (Appendix E) and the History of Endometriosis Form was used to gain details of symptom presentation and treatment (Appendix F). Both forms were designed by the Principal Investigator and were based upon current knowledge within the literature on endometriosis and tailored to the requirements of the current study. Data from these forms was anonymised for confidentiality purposes.

Development of the interview schedule

Semi-structured interviews were used to access the meanings of women's lived experiences of the effects of endometriosis on womanhood. Semi-structured interviews encourage flexible exploration of an area of interest, allowing individuals to tell their story in their own words, with the use of open-ended questions and minimal prompts. Consequently, semi-structured interviews produce a rich, detailed account.

An interview schedule was constructed by the Principal Investigator to guide the interview. It was designed around broad topic areas relevant to the main research aim of exploring the effects of endometriosis on womanhood. Relevant topic areas were identified from the literature on endometriosis and from the direct narratives of women with endometriosis. Topic order was chosen with consideration of rapport building, sensitivity and logical transition from one topic to the next. Topic areas of interest were: women's experiences of endometriosis; their perceptions of how endometriosis has affected their womanhood in terms of their identity as a woman, self-esteem, femininity, sexuality, relationships and motherhood; their perceptions of how these effects have impacted on their lives and their perceptions of the relevance of these issues to health care services and associated implications for services. A copy of the interview schedule is presented in Appendix G.

3.3. Procedure

Following a peer review, ethical approval for the current study was obtained from local research (Appendix H) and ethic committees (Appendix I).

3.3.1. Recruitment

Participants were recruited through a local Obstetrics and Gynaecology clinic through a Consultant Gynaecologist. Participants were identified by the Consultant Gynaecologist from his current caseload using the inclusion criteria. Identified participants were either presented with a Participant Information Pack by the Consultant Gynaecologist during their clinic appointment or were sent a Participant

Information Pack by the Consultant Gynaecologist to their home address. Potential participants were asked to return the reply sheet in a stamped addressed envelope to the Principal Investigator if they were interested in taking part. If participants did not return the reply sheet, they were not contacted again. Interested participants were contacted by the Principal Investigator by telephone and were offered the opportunity to discuss the study further and ask questions. More time to consider participation was offered to potential participants if required. If they decided not to take part in the study, then they were not contacted again. If potential participants were still interested in taking part after receiving all the necessary information, then an interview was arranged.

3.3.2. Prior to interviews

Once recruited, participants were sent a Personal Details Form and History of Endometriosis Form to complete prior to interview. Completed forms were collected by the Principal Investigator at interview or if necessary, additional time was allocated for completion of the forms on the day of the interview.

3.3.3. At interview

Participants were invited to attend the research interview at the location of their choice. Interviews were either held at the participant's home or at the University of Leicester. Before the start of the interview, participants were reminded of the purpose of the study and the rights and responsibilities of the participant and the Principal Investigator. Further opportunity was allowed for questions or concerns. Participants were asked to give written informed consent immediately prior to the interview

commencing (Appendix J). Privacy was assured and efforts were made to help the participants feel at ease.

Research interviews were conducted by the Principal Investigator and were guided by an interview schedule. Areas of interest were explored further with follow-up questions. Interviews lasted between 21 minutes to 65 minutes, with the average duration of interviews being 44 minutes. All interviews were recorded using a digital recording device.

3.3.4. Post interview

After the interview, participants were thanked for their participation and were given a £10 gift voucher. Participants were not informed of this gift until after the interview had finished. Additionally, participants were invited to reflect and feed back how they had found the interview. Post interview, the participant's emotional wellbeing was reviewed and all participants were given a leaflet containing contact details of support agencies (Appendix K). Participants were also signposted to their GP or Consultant Gynaecologist if they had any queries or concerns. Participants were informed about the dissemination of the study findings and were asked whether they would like a summary of the findings.

After each interview, the Principal Investigator made reflective notes focusing on outstanding themes, emotional response to the content of the interview and general observations. Furthermore, a copy of the consent form was placed in participants' medical records.

3.4. Analysis

All interviews were transcribed by the Principal Investigator and transcripts were re-read whilst listening to the interview recording to achieve concordance of data.

Interpretative Phenomenological Analysis (IPA; Smith, Osborn & Jarman, 1999) was used to analyse the transcripts. IPA attempts to explore and make sense of the meanings individuals give to their experiences. The theoretical underpinnings of IPA are in line with the contextualist stance, as it appreciates the subjective nature of the account elicited through a dynamic, interactive process between the participant and researcher. Additionally, IPA has been described as being particularly relevant for understanding subjective responses to illness (Smith *et al.*, 1999), moving away from a biomedical model of illness to considering participants' perceptions and interpretation of their illness. Overall, it seemed the most appropriate method of analysis for the current study.

IPA involves the development of a systematic, rigorous and comprehensive account of hierarchical themes within the data (Clare, 2002). An idiographic approach was used where each transcript was analysed one at a time to identify emerging themes before incorporating other data. Final master themes were illustrated with verbatim extracts from participants' accounts to demonstrate that the analysis was grounded in the data. A detailed outline of how IPA was conducted is presented in Appendix L. Validity checks were conducted to ensure quality of the analysis. For example, emergent themes were discussed and validated by a clinician with clinical experience of

endometriosis and a woman with endometriosis external to the study. Further validity checks included discussions with other qualitative researchers, attendance at a qualitative methodology group and monitoring of endometriosis message boards on the internet to see whether similar themes were exhibited in vivo. It is important to recognise that in IPA the aim of the validity checks is not in an attempt to get a 'singular true account' but to ensure credibility of the final account (Osborn & Smith, 1998).

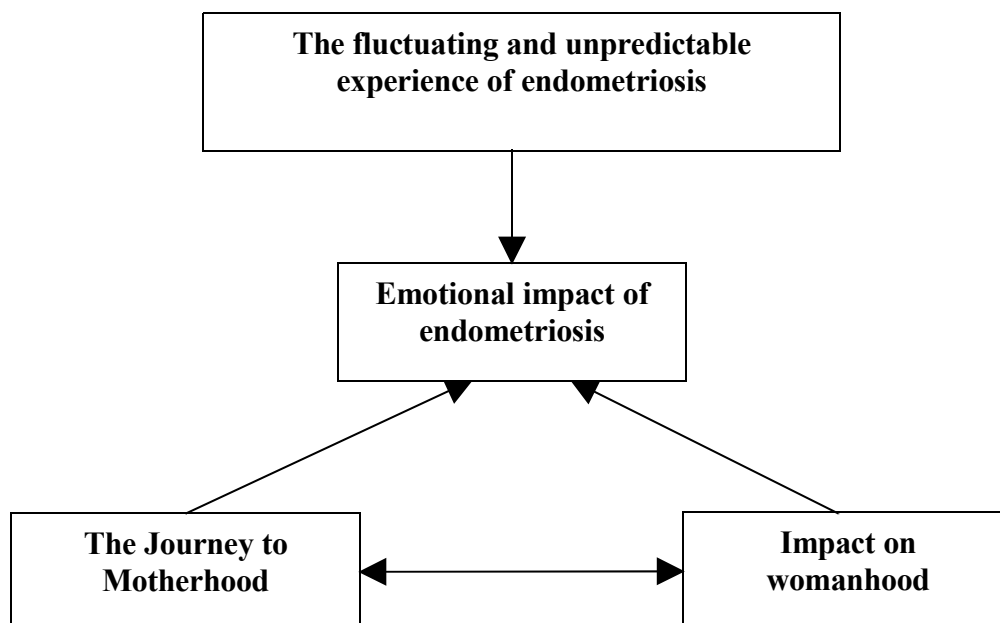
4. Results

Each of the transcripts were analysed by the Principal Investigator using Interpretative Phenomenological Analysis (IPA), which enabled the identification of themes that ran throughout participants' narratives.

Overall, four master themes were elicited as displayed in Figure 1 below. The development of these themes is transparently outlined in Appendix M and additional verbatim extracts are provided in Appendix N to illustrate themes in more detail.

Figure 1 demonstrates the interrelationships between master themes.

Figure 1: Themes elicited from the IPA analysis of seven transcripts of interviews with women with endometriosis

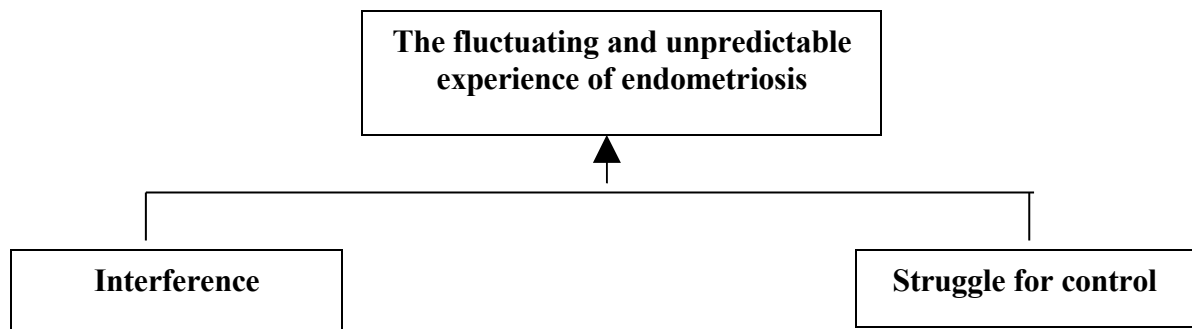


The endometriosis journey was described as being prolonged and complicated. It often incorporated repetitive experiences of being dismissed and discredited by GPs, culminating in a delay in diagnosis for some participants. In the current study, average delay from initial onset of symptoms to diagnosis was 10 years. Consequently, diagnosis was received with a mixture of relief, frustration, regret and bitterness. Even once diagnosed, there were many hurdles along the endometriosis trajectory. Treatment was described as a long and drawn out process, typically involving experimentation with medication and/or multiple surgeries. Furthermore, side effects related to treatment were common and distressing and symptom relief post-treatment was frequently short lived. Therefore, the experience of endometriosis was often cyclical with intermittent periods of relief when symptoms were under control or absent following treatment. Overall, the journey along the endometriosis trajectory was portrayed as being challenging, arduous and unpredictable, leaving many participants feeling like they were going round in circles.

4.1. The fluctuating and unpredictable experience of endometriosis

Endometriosis was presented as a dynamic fluctuating condition due to symptom reoccurrence and the cyclical nature of symptoms in relation to the menstrual cycle. Consequently, oscillations were seen in participants' descriptions of its interference and their perceived control of it.

Figure 2: The fluctuating and unpredictable experience of endometriosis



4.1.1. Interference

Endometriosis interfered with many aspects of a woman's life, thus reducing quality of life. The current study found that endometriosis impacted on adolescence, daily activities, sleep, work, social activities, relationships and for some participants, motherhood, as illustrated by the excerpts below:

"It really interfered with my life as a teenager because I was being sick at school and passing out and stuff." (Amy: 11: 272-273)

"You don't want to go out with your friends, you kinda miss, I feel I missed out on a big chunk of my life." (Danielle: 2: 35-37)

As shown in Danielle's quote above, some of the participants felt a sense of loss and resentment towards endometriosis due to its interference on their lives. Most participants stated that they wished they did not have the condition. Endometriosis associated symptoms were cited as being distressing and annoying and at times, participants described feeling overwhelmed. Pain was cited as the main cause of

interference on life and participants gave vivid descriptions of the severe and debilitating nature of their pain:

“I have a pain in my stomach that feels like somebody has just been battering me with a truncheon or someone has made me do a 100 sit ups, you know, every hour on the hour.” (Olivia: 1: 23-26)

“the main symptoms are severe pelvic pain to the point where sometimes I have to have time off work and painkillers just don’t really seem to touch it.” (Rebecca: 3: 57-59)

The fluctuating nature of endometriosis produced an intermittent rather than continuous interference on life. Therefore, when symptoms were absent or being successfully managed by medication, participants described minimal interference and consequently less distress. This was evidenced by Olivia, who highlighted how the impact of endometriosis on her life had changed over time:

“At this point of my life it doesn’t have a huge impact a couple of years ago it seemed to be, you know, the only thing in my life I did just seem to be, just dominated everything cos I just felt so bad all the time.” (Olivia: 12: 275-278)

4.1.2. Struggle for control

The fluctuating nature of endometriosis also impacted on participants’ ability to control and cope with endometriosis. Feelings of control varied along the

endometriosis trajectory, with the amount of perceived control and power over endometriosis fluctuating in synergy with symptom presentation, as described by Lisa:

“You probably have two or three days and you feel alright and then it comes back with a vengeance and it’s got you again.” (Lisa: 2: 48-49)

Generally, the more severe and intense the symptoms, the more power and control the endometriosis had over the participant. Where symptoms were problematic, participants seemed to be in a tug of war for control with the endometriosis in an attempt to retain a sense of normality. For example, Ana described how she needed an abundance of analgesics to carry on working as normal:

“I sort of dose myself up with paracetamol, aspirin, Ponstan and sort of hope that it will get me through the day.” (Ana: 4: 90-92)

Therefore, participants tried to persevere with their lives despite the endometriosis, with determination to not to let it dominate them as shown by Lisa;

“It really does take over your life sometimes but I try and push myself.” (Lisa: 12: 276-277)

These attempts to maintain a sense of power and control was interpreted as an endeavour to preserve identity and desired lifestyle.

At times endometriosis was restrictive over participants' lives, dictating what they could or could not do. For example, Amy described how endometriosis severely restricted her activities and prevented her from doing the things she had planned:

"I was virtually a recluse I never left the house. There was so many... like, family gatherings or things we'd planned to do that I had to cancel and sometimes at the last minute letting everybody down." (Amy: 4: 83-85).

Consequently, at times participants felt taken over by the endometriosis and ruled by its presence. When this occurred they portrayed a sense of defeat, resignation and powerlessness:

"I've got what I've got and there's nothing I can really do about so what's the point in me researching it on the internet" (Ana: 22: 526-527)

Hope and social support were important coping strategies used by participants to manage the emotional impact of endometriosis and maintain control. Many participants used downward social comparisons to prevent themselves from dwelling upon depressed feelings, as demonstrated by Danielle:

"There always someone worse off and there always someone better off and that is true but sometimes just you need reminding of it don't you but you know there are much worse things that could happen to you." (Danielle: 13: 322-324)

However, the uncertainty surrounding endometriosis seemed to undermine participants' perceived control of the condition and their future. The unpredictable and unknown prognosis of endometriosis fostered high levels of anxiety and apprehension about the future, as shown by the excerpt below:

"I do worry about will it affect fertility, will I have to keep going through surgery, will I still get this pain all the time and have time off work and things but unfortunately there's no way of, they can reassure you against that because it's still fairly unknown"
(Rebecca: 3: 78-82)

This uncertainty was further compounded by the lack of understanding about endometriosis by participants and the wider medical community. Consequently, many of the participants had unanswered questions about the aetiology and prognosis of endometriosis. Participants also recognised that the paucity in knowledge about endometriosis also limited the management of the condition, with few treatment options available to them. However, few participants demonstrated trying to take control of their own treatment using self-management techniques.

Generally post-treatment, participants described feeling more in control of the endometriosis. For example, Olivia demonstrated how the power and importance of endometriosis faded following successful treatment management:

"I think now I've got it all sorted and that I'm on the medication and I feel in control of it, it doesn't really mean an awful lot now." (Olivia: 11: 265-266)

Consequently, symptom relief made participants feel more powerful and in control of the endometriosis. When in control, participants were more positive about managing endometriosis and demonstrated a feeling of acceptance that endometriosis was part of their lives, as shown by participants below:

“I think I’ve learnt to adapt to it, it’s almost become part of my life and I’ve just accepted it as the norm for me.” (Ana: 2: 26-27)

“I just live with it now, I’ve just got use to it.” (Olivia: 1: 8-9)

“It can actually not been that bad, you can have it and yes it’s painful and yes it’s awful but you can live with it and it’s not necessarily going to affect you in the way that you automatically think.” (Rebecca: 18: 432-435)

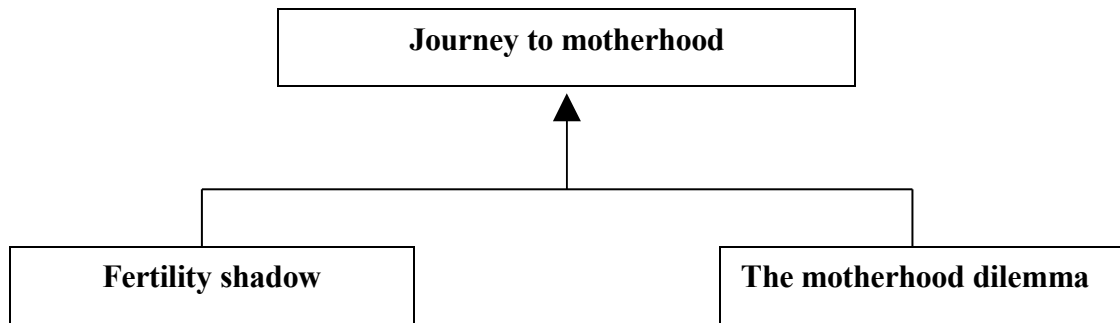
This suggested that some participants felt they had adapted to endometriosis and were able to live with the condition. However, Rebecca’s quote above was interpreted to suggest that this positive message of adaptation may get overshadowed by a general negative portrayal of endometriosis.

Overall, the fluctuating nature of endometriosis created two different stories within participants’ narratives: a story of pain and suffering when symptoms were present; and a story of adaptation when symptoms were being managed. Participants transitioned between each story as they described their experiences at different stages along the endometriosis trajectory.

4.2. Journey to motherhood

Fertility was a very important issue that arose unprompted, early on in interviews and seemed to have direct implications on womanhood. The theme ‘Journey to motherhood’ described the uncertainty surrounding fertility and the dilemmas faced along the endometriosis trajectory.

Figure 3: Journey to motherhood



4.2.1. Fertility shadow

The current analysis revealed a high amount of uncertainty related to fertility status in women with endometriosis. Two participants knew that they had fertility difficulties, however the majority were unsure about whether or not they were able to have children. This uncertain fertility status generated immense anxiety and haunted them, lingering in the back of their minds:

“Yeah it’s a constant thing it’s always in your head whether you can have children or not.”(Danielle: 9: 211-212)

“It does make you question oh would I have a problem if I did want to have a child, you know, so I don’t know how easily that would happen when I want it to happen and I do actually worry that I would have problems, I don’t know why but there’s something in my head that that from all of this makes me think I’m gonna really struggle.” (Rebecca: 6: 137-142)

Some participants perceived that their fertility was in the hands of fate and other participants attributed their fertility difficulties to the delay in diagnosis, blaming health care services. The externalisation of locus of control away from self could function as a way of coping with their fertility difficulties. Generally, participants oscillated between feeling hopeful and hopeless about their fertility chances. Participants who had confirmed fertility problems were considering IVF.

4.2.2. The motherhood dilemma

Participants who were uncertain about their fertility but wanted to have children in the future described being placed in a difficult dilemma. On one hand, they felt a sense of pressure and urgency to conceive because of the known fertility difficulties associated with endometriosis and increasing age. However, on the other hand some of the participants did not feel ready for motherhood because of their age or stage in relationship with partner:

“They’ve told me at the minute if I was going to have children to have them now... and myself I’m not in the frame of mind to say I want to have children now so, I was put in a bit of a predicament when I went because I know its hard to get pregnant with this problem.” (Lisa: 3: 72-76)

Therefore, some of the participants interviewed were caught between the desire for motherhood and not feeling it was the right time in their lives to have children. It seemed that having endometriosis pushed participants into having to think and make choices about motherhood far earlier than for women generally.

For the participants with confirmed fertility problems, endometriosis had taken away the option of conceiving, leaving a sense of loss. Ana described feeling angry about her fertility difficulties and envious of other mothers. It seemed that she tried to avoid thinking about her fertility as a way of coping:

“It’s something I’d rather not think about because I probably will find it very upsetting.” (Ana: 6: 146-147).

Overall, participants reported the uncertainty surrounding fertility and confirmed fertility problems as being extremely distressing.

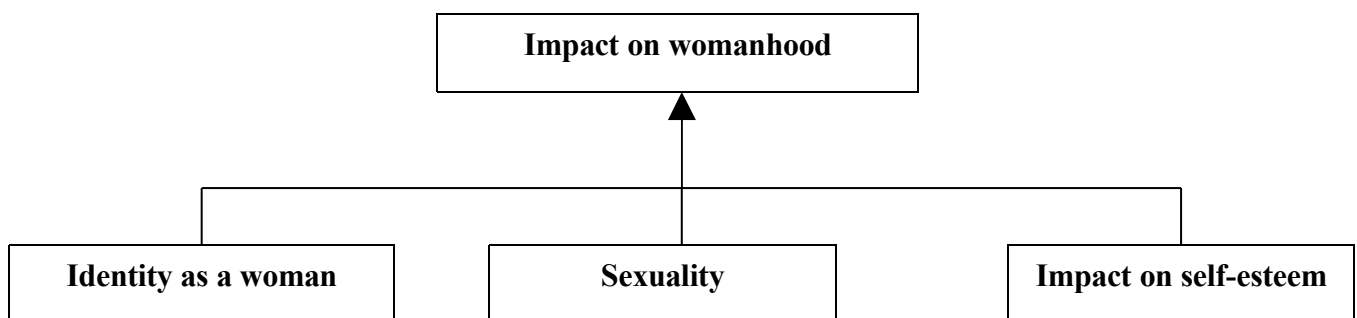
The pursuit of motherhood was described as an anticipated route for most participants and it was viewed as an expected, subscribed role for women within society and hence an important part of identity as a woman. It was hypothesised that some of the anxiety

surrounding threats to fertility was related to fears of not meeting societal conventions. Therefore, the journey to motherhood for participants seemed to be influenced by the strong discourse of motherhood within society.

4.3. Impact on womanhood

This theme showed how endometriosis impacted on womanhood, particularly identity as a woman, sexuality and self-esteem.

Figure 4: Impact on womanhood



4.3.1. Identity as a woman

The most prominent threats to womanhood were concerns about fertility and loss of motherhood. This study showed how strongly womanhood was intertwined with motherhood, where the ability to have a child was seen as an important and expected role of being a woman, as illustrated below:

“Womanhood to me is someone who is able to conceive I think that’s what I would perceive as womanhood.” (Ana: 7: 167-168)

“I think it does impact on how you feel about yourself cos women are obviously born put on the earth to reproduce well that’s the reason so and if you want children and you can’t have them then obviously you’d be pretty gutted.” (Helen: 10: 247-250)

Consequently, Helen, thought that her womanhood would be affected if she could not have children:

“My concern is the possibility of being infertile, I mean the consultant said... better start thinking about having children before your 35 otherwise you’ve got no chance basically so that’s the way its affecting my womanhood, in with regards to the fact that I might not be able to have children because of it.” (Helen: 5: 101-106)

Therefore, loss of motherhood was seen as a threat to womanhood. Furthermore, participants reported how fertility difficulties had affected their sense of identity as a woman, making them feel incomplete and useless as illustrated by the following extracts:

“It just makes me feel less of a woman, the fact that I can’t have children. I don’t feel whole. It almost feels like my insides are missing but there not they’re there but I just can’t do anything with them so I just feel like I’ve got no womb a lot of the time or something. It’s probably a strange thing to think but it just feels like there’s something missing inside of me, the fact that I can’t conceive naturally.” (Ana: 19: 474-479)

“You feel a bit like a barren cow (laughs) I’m from a farm you see and as I look at it if you have an animal on the farm, what was barren, a barren cow you get rid of it, you

know what I mean and that's how I feel about myself at the minute. I think, oh, what a waste." (Lisa: 6: 141-144)

The analogy of being like a 'barren cow' was interpreted as demonstrating how dehumanising, self-deprecating and worthless fertility difficulties can make a woman feel. Furthermore, participants reported that endometriosis made them feel abnormal and different from other women because their bodies did not working in the way that they should:

"I think I just feel abnormal, different to other women because all of my friends have children, all my relations have children; I am the only one now that doesn't. I remember when I came home from my operation, I just burst into tears and said to my husband, you know I can grow this huge cyst thing inside me but I can't grow a baby and you just feel freakish almost that you have these things growing inside you and... blood going where it shouldn't be going." (Amy: 3: 69-73)

Participants described feeling quite negative about themselves and their identity as a woman. In particular, threat or loss of being a mother was especially distressing, as most women had planned to have a family. Therefore for some participants, endometriosis had prevented them from achieving their life goals, desired identity as a mother and overall, identity as a woman, which for some participants was difficult to accept:

"I suppose you have a normal, an idea in your head of what a normal woman is supposed to be like and the major one is being able to have children, being a mother

and I think well perhaps I'll never know what its going, what it feels like to be a mother and that sometimes if anything is going to make me cry it's that thought. I think well what on earth am I going to do with the rest of my life, if I don't have children. So in a in a sense, its not just my identity as a woman its my whole identity, because I'd always thought I would have children so now I've got to completely rethink, well what am I going to do now?." (Amy: 18: 443-451)

For other participants, motherhood was not part of their planned life trajectory. Therefore, the effect of fertility on their identity and self-esteem was less pronounced. For example, Olivia did not plan to have children and therefore, endometriosis did not have a negative impact on how she felt about herself as a woman:

"I feel fairly good about myself.... But I've not set out to achieve what a lot of woman would, which is to have children. If endometriosis stopped me from having children when I wanted to have children, I think I could feel very very negative about myself." (Olivia: 16: 383- 386)

Consequently, the importance of motherhood to participants and its priority in their lives had an effect on how they felt about themselves and level of distress experienced.

4.3.2. Sexuality

Issues regarding sexuality were commonly described by participants. Most of the participants described experiencing dyspareunia, which interfered with sexual activity and consequently, their relationship with their partner and own sexuality:

“Every time that we have sex it hurts me and it hurts me and it makes me cry because it hurts me you know and I get upset because I know that he’s trying to be careful and he’s aware that he’s hurting me so the whole thing has actually become a very unpleasant experience, it’s not something that that I look forward to or want to do basically and that seems to be getting worse, you know, the amount of time between our sessions just gets longer and longer and longer to the point where I suppose eventually we won’t actually be having it at all.” (Olivia: 4: 84-91)

The experience of dyspareunia made sexual intercourse extremely unpleasant and participants described the development of a fear- avoidance cycle where previous experiences of pain caused participants to become anxious and fearful in the anticipation of pain causing their bodies to tense up. Subsequently, sexual activity was more difficult and painful, reinforcing the cycle.

“It was so painful when the endometriosis was there I think I’m thinking its going to be painful which is obviously causing my body to respond like no tightening up, tense up.” (Helen: 6: 143-145)

Generally, the experience of dyspareunia led to the avoidance of sexual activity and loss of interest or desire in sex. Amy described that losing her sex drive made her feel like she had lost part of her identity:

“I just lost my sex drive completely so you kind of start to feel a bit sort of... part of your identity goes I suppose.” (Amy: 18: 441-443)

This was interpreted as suggesting that sexuality was viewed as an important part of a woman's identity and therefore, the restrictive nature of endometriosis on sexuality also interfered with identity. Additionally, diminished sexual intercourse had deleterious effects on relationships with partners. Participants perceived that their partners felt rejected, pushed away and powerless.

"It has caused problems between myself and [partner] cos he feels that I'm pushing him away at times" (Helen: 3: 67-68)

Not being able to fulfil their role as a sexual partner was described by some of the participants as upsetting and generated feelings of guilt, as shown by Olivia;

"I feel like I'm denying you, you know, this is all part of what you deserve really in our relationship and it really really did used to upset me." (Olivia: 24: 572-574)

Having a solid relationship with partners was acknowledged to be a very important factor in helping participants manage endometriosis. Participants in relationships acknowledged how difficult they thought it must be for their partners and felt lucky to be so supported by them. For the participants where dyspareunia was not a problem, sexuality and sexual relationships appeared unaffected by endometriosis.

4.3.3. Impact on self-esteem

Participants' sense of personal identity and self-esteem was also affected by how other people responded to them. For instance, some participants felt objectified by medical practitioners, being viewed as a medical case rather than a person:

"I think they forget that you're a person and not something out of a text book" (Amy: 23: 558-559)

Additionally, a few participants commented upon the medicalised and clinical language used by medical practitioners. For example, one participant recalled how being told that she was 'grossly abnormal' by her doctor had made her feel:

"The doctor telling you that you're grossly abnormal (laughs).... That's obviously made an impression with me because I've remembered it. I think well, I wonder what I do look like inside then if I'm grossly abnormal. I'm not quite sure what that means but I don't like the sound of it much." (Amy: 18: 426-430)

Therefore, it seemed that at times the professional demeanour of medical practitioners promoted an insensitive manner towards their patients, potentially creating emotional distress and impacting on self-esteem.

Participants described that they had encountered a mixed response to the experience of endometriosis from others. Generally, participants denoted receiving support and empathy from their social and familial network and work colleagues, however some participants had also experienced negative responses. They recounted that some

people, men and women, did not understand the implications of endometriosis or how it affected them, leading to a lack of empathy regarding symptoms such as symptoms being trivialised as bad period pain. These experiences were distressing for participants, but also frustrating and infuriating, as highlighted by Ana,

“I wish there was something (laughs) some robot that could stand there and pick at their insides and slap them about and make them feel like they’re giving birth or something you know, I would love people to feel what I what I go through each month for them to really understand.” (Ana: 32: 799-803)

Frequent experiences of being discredited and invalidated by others were reported. These experiences adversely affected participants making them feel bad about themselves and lowering their self-esteem. For example, Ana seemed to have taken on the label of being “a wimp” pre-diagnosis. It was interpreted that she adopted this label after being exposed to repetitive experiences of perceiving that other people thought she was being ‘a wimp’:

“Quite often I have to go to occy health and they say you know you really need to buck up your ideas and I’m thinking it’s not me, I’m not doing it on purpose but the GP and everybody says I’m just being a wimp, just to get on with it, it’s the norm so I thought right fine.” (Ana: 2: 35-39)

Diagnosis of endometriosis, even though upsetting, seemed to bring a sense of relief and validation for participants that their experiences were real and that there was a problem. For Ana, diagnosis legitimised her experiences and helped her shed the label of being ‘a wimp’:

“Saw him (Consultant) and he went ‘No, your not a wimp’ and I thought thank you (laughs) and it was almost relieving to think that it wasn’t me that was being a wimp and there was something wrong with me.” (Ana: 3: 51-53)

The current study showed that endometriosis had the ability to affect womanhood, threatening identity as a woman, sexuality and self-esteem. However, participants’ accounts suggested that womanhood was damaged rather than lost. Overall, most participants kept hold of their sense of womanhood.

4.4. Emotional Impact of endometriosis

Endometriosis can have a profound emotional impact as depicted throughout the preceding master themes. Emotional impact was a commonality seen running through all of the other master themes presented (See Figure 1). All participants had felt distressed at some point along the endometriosis trajectory, whether due to the fluctuating and uncertain nature of the condition, the experience of symptoms and their interference, the impact of diagnosis, fertility issues, and difficult experiences with health care services or negative responses by others. The experience of pain and fertility issues were the most commonly cited causes of distress. A few of the participants (three out of seven) reported significant psychological difficulties such as

depression, anxiety and sexual dysfunction for which they had accessed counselling or mental health services for additional support. However, it was difficult for participants to tease out whether their psychological problems were the result of the endometriosis or other factors. Overall, most of the participants thought that it would be beneficial for women with endometriosis to receive additional emotional support, particularly after diagnosis or related to fertility difficulties.

“Perhaps offering emotional support whether if that’s through counselling or clinical psychologist, if you need it.” (Helen: 14: 328-329)

This implied that there may be a role for clinical psychologists within gynaecological services and highlighted the need for multidisciplinary working and thorough assessment for psychological and sexual problems within this population.

5. Discussion

The current study set out to identify how endometriosis may effect womanhood. By means of qualitative interview and IPA, a rich description of seven women’s experiences of endometriosis and it’s effect on womanhood was obtained through exploring identity as a woman, wellbeing, sexuality, fertility, and relationships.

Furthermore, participants described their experiences of health care services and highlighted areas for improvements.

As depicted by Huntington & Gilmour (2005), there was no single ‘true’ static representation of endometriosis but rather it comprised of cyclical, variable and fluctuating experiences over time. Each woman experienced endometriosis differently and this changed at different stages along the endometriosis trajectory, making narratives context specific. In some respect, the narratives could be considered as unfinished as the endometriosis journey for participants was ongoing and prognosis unclear, with a mixture of fear and hope for the future, as described in other studies (Denny, 2004b).

The current study highlighted that ‘womanhood’ was a socially constructed concept, which was threatened or damaged by endometriosis due to it interfering with a woman’s ability to meet cultural and societal expectations and norms. For participants, ‘Womanhood’ incorporated feelings of femininity, sexuality, self-esteem and predominantly, the ability to conceive. Consequently, fertility issues can jeopardise womanhood. The interrelationship between motherhood and womanhood has been shown in studies on infertility (Whiteford & Gonzalez, 1995; Ulrich & Weatherall, 2000). Threats to womanhood related to fertility status found in the current study validated previous studies exploring endometriosis (Jones *et al.*, 2004), as well as infertility literature (Whiteford & Gonzalez, 1995; Clarke *et al.*, 2006).

Motherhood is still seen as the primary role of a woman and there are strong cultural expectations that women will become mothers (Letherby, 2002, Ulrich & Weatherall, 2000). Therefore, damage to womanhood due to fertility difficulties related to endometriosis could be explained by the perceived importance of motherhood in Western societies. Women with fertility difficulties may feel stigmatised for failing to fulfil a social norm, fostering feelings of worthlessness, inadequacy, abnormality and incompleteness (Whiteford & Gonzalez, 1995; Clarke *et al.*, 2006). Consequently, infertility may threaten a sense of being a woman, leading to a devalued sense of self and spoilt identity (Whiteford & Gonzalez, 1995; Clarke *et al.*, 2006). In light of these dominant societal discourses surrounding motherhood in Western societies, it may be unsurprising that infertility secondary to endometriosis or an ambiguous fertility status caused distress, anxiety and adversely affected identity as a woman in the current study. Interestingly, for participants who were voluntarily childless, concerns regarding stigma were not exhibited. This was contrary to findings by Letherby (2002) and therefore may reflect a growing acceptance of voluntary childlessness with Western Societies.

Sexuality was reportedly affected by endometriosis due to the experience of dyspareunia and associated loss of libido. The association between dyspareunia, sexuality, lowered self-esteem and relationship difficulties seen within the current study were resonant with previous literature on endometriosis (Weinstein, 1988; Denny, 2004; Jones *et al.*, 2004; Denny & Mann, 2007). Feelings of inadequacy, guilt and subsequent impact on self-esteem may be fostered by perceived failure to meet

societal expectations of the role of a sexual partner. Furthermore, loss of this role may also impact on identity as a woman.

Interestingly, the current study suggested that womanhood was less affected by endometriosis in comparison to other similar conditions e.g. a mastectomy following breast cancer (Bredin, 1999) or the development of hirsutism in polycystic ovarian syndrome (Kitzinger & Willmott, 2002). Perhaps the invisible nature of endometriosis helped to preserve a sense of womanhood: their physical appearance met the stereotypical image of a woman in Western society and hence did not affect their external identity. Regardless, participants still highlighted feeling ‘different’ and ‘abnormal’ in comparison to other women due to menstrual irregularities and fertility issues. This suggested that they felt that they did not fit the stereotypical representation of a woman. Carpenter & Johnson (2001) found that women derived a significant portion of self-esteem from their gender group membership. They suggested that a decrease in gender group identification lead to pejorative self-evaluations. Therefore, self-esteem and identity as a woman may be adversely affected because women with endometriosis felt segregated from their gender group. In the current study, participants seemingly used downward social comparisons, such as comparing themselves to people with a terminal condition, as a mechanism to increase self-esteem.

Endometriosis impacted on personal identity as well as womanhood. Charmaz (1983) outlined that the experience of chronic illness could be detrimental to an individual’s identity, leading to a loss of self. She identified four areas that contributed to the loss of self: living a restricted life; existing in social isolation; experiencing discredited

definitions of self; and becoming a burden. Although these were common themes within participants' narratives of endometriosis, the analysis did not show a loss of self. Endometriosis' impact on identity was variable. For example, on good days when participants felt more in control of their symptoms, the endometriosis was a small part of their identity; however when symptoms were severe and perceived control was low, participants assumed an illness identity. This fluctuating pattern resembled the 'Shifting Perspectives Model of Chronic Illness' (Paterson, 2001), which ascertains that within chronic illness an individual constantly shifts between presenting either illness or wellness is on the foreground. Thereby, when illness is in the foreground, the individual is more focused on the condition and its negative outcomes and has a low sense of perceived control of the condition. When wellness is in the forefront however, the individual focuses on the self and presents as being optimistic despite the chronic condition. Shifts between perspectives were suggested to be triggered by identified threats to control such as symptom reoccurrence, discrediting experiences and external factors (Telford, Kralik & Koch, 2006). This model helped to make sense of the shifting perspectives identified within participants' narratives.

Generally, the current participants maintained a valued sense of self. Participants' reportedly strong social support networks and relationships may have protected this. Furthermore, all participants were in employment, which may have also served boosted self-esteem and may have afforded opportunities for validation. Charmaz (1983) suggested that the underlying determinants of loss of self were losses of control and action. In the current study, loss of self may not have been experienced because

participants were active agents in their environment, striving to maintain a sense of normality, optimism and retain control over their lives.

Overall, participants showed resilience, despite the high levels of uncertainty and stress along the endometriosis trajectory. Research on resilience suggests that resilience in the face of loss or potential trauma is more common than often believed (Bonanno, 2004). Resilience refers to the transitional process of adapting to stressful life events (Kralik, van Loon & Visentin, 2006), whereby people rebound from crisis and adversity and move on with their lives (Polk, 1997). Resilience was seen within the current study. Participants did not appear as being passive, pessimistic or ‘sick’ patients but instead presented as a group of strong-minded, resourceful women who had accepted the condition and its consequences. Consequently, they were progressing with their lives, as shown by the language used within interviews e.g. ‘deal with it’ and ‘get on with it’. This mantra of ‘dealing with it’ may reflect a societal expectation that women should cope with menstrual pain or more widely a discourse from British culture of soldiering on and not complaining. Regardless, it seemed that identity was reconstructed to incorporate endometriosis, indicated by endometriosis being embodied rather than distanced from the self. This contrasts with findings by Osborn and Smith (2006) who found that individuals experiencing chronic low back pain consciously excluded painful parts of the body from self. Additionally, endometriosis may become incorporated into personal identity because initial onset of symptoms was common during adolescence, an important phase of identity formation and development of a sense of womanhood following puberty. Therefore, symptoms may become internalised and viewed as part of being a woman.

Emotional distress within women with endometriosis is commonly reported (Weinstein, 1988; Jones *et al.*, 2004; Lorencatto *et al.*, 2006). The current study's findings concurred with these studies. Within the current study, endometriosis caused emotional distress both directly through the experience of symptoms, fertility and treatment and indirectly through its impact on quality of life, relationships and how other people responded to it. Degree of distress was variable for each participant and fluctuated along the endometriosis trajectory, seemingly greater immediately post-diagnosis or related to fertility concerns.

The rollercoaster ride of emotions for women with endometriosis was portrayed within their interviews and shown by the changing tone of the narratives e.g. from anger about the delays in diagnosis to sadness about losses and positivity about symptom reduction. The rawness of emotion displayed in some interviews suggested that for some participants, the interview might have been the first opportunity to talk with someone in depth about their experiences of endometriosis and its emotional impact. This suggested that healthcare services might not be meeting the emotional needs of some patients. Participants highlighted a need for the provision of emotional support from outside agencies, perhaps not necessarily for themselves but for others with the condition. Although, three out of seven participants reported experiencing psychological problems secondary to endometriosis, significant enough to require psychological services or counselling. The refutation of emotional distress was perhaps because it was being perceived as a weakness of character or stigmatising, as suggested by Pollock (1993). This may also indicate a reluctance for women with

endometriosis to discuss emotional or sexual issues with medical practitioners as highlighted by Denny (2004) who observed that women would not volunteer personal information to medical practitioners and medical practitioners rarely asked. Therefore, the current study showed that the psychological needs of women with endometriosis are important and need to be addressed.

Participants used a variety of coping strategies for reducing emotional distress and effectively managing the condition such as: taking back control using medication and through being involved in treatment decisions; decreasing illness uncertainty through information-seeking via the internet, other women with endometriosis and their consultant; and using self management strategies such as hot baths and hot water bottles. However, unlike other studies (Cox *et al.*, 2003) few participants described using complementary therapies, diet, relaxation or exercise. Even though, initial studies investigating the use of self-management training for endometriosis have shown positive results (Wright *et al.*, 2005; Barlow *et al.*, 2005). The limited use of self-management strategies may reflect the effectiveness of current treatment or a lack of awareness of these additional self-management and their potential value. Support groups and internet web-forums have been set up for women with endometriosis to reduce social isolation and allow the sharing of experiences (Whitney, 1998; Emad, 2006). Not one of the participants in the current study had accessed these resources, suggesting that they may have maintained supported through work and social relationships and did not need to form bonds with other women with endometriosis. Another reason was for fear of other women dwelling on their problems and being

negative, which would be counter to their objective of taking control, being positive and trying to be as normal as possible.

Resonant with existing literature on endometriosis, the current study showed that: endometriosis is still a relatively unknown condition within general society; there are still lengthy delays in diagnosis (10 years) and difficulties at GP level such as experiences of discreditation. All of which caused participants frustration and emotional distress. Overall, participants were fairly satisfied with healthcare services received and they described positive doctor-patient relationships, particularly with their consultant. Factors that were identified as creating a good doctor- patient relationship were related to being treated as a person, such as being valued and validated, being shown empathy and being listened to. When compared with previous literature (Weinstein, 1988; Kennedy, 1991), what women with endometriosis wanted from their doctors had not changed.

In the current study, it was clear that endometriosis was painful, frustrating and at times a hindrance. However, the positive message that women can adapt and live with endometriosis also came out of the analysis. This positive message is not often portrayed in the literature or on the Internet. For example, the tone of the stories displayed on the endometriosis message board (Endometriosis in the UK – You are not alone forum) generally tended to be quite sad and negative. This discrepancy may indicate that the current participants felt more in control of the condition and were less distressed and hence felt able to volunteer to take part in the current study. Overall, the current study emphasised a more balanced view of endometriosis demonstrating

the difficulties and the distress but also their experiences of actively managing the condition and successfully incorporating it into their lives.

5.1. Summary of findings

The current study demonstrated that the endometriosis journey could be difficult and distressing. It was made harder by the fluctuating and unpredictable nature of the condition, creating high levels of uncertainty and at times, interference. Yet, it showed how women with endometriosis were able to regain control and normality and adjust to the condition by incorporating it into their personal identity. Ultimately, womanhood remained relatively intact, although it was threatened by fertility concerns, sexual difficulties and experiences of discreditation, which at times affected identity as a woman, sexuality and self-esteem. Generally, participants' experiences of health care services were fairly satisfactory. However delays in diagnosis, the lengthy treatment process and lack of information were common criticisms. Women with endometriosis experience a multitude of emotions throughout living with the condition and it can have a significant psychological impact on mood. The current study highlighted the need for the availability of professional emotional support for women with endometriosis who are emotionally distressed.

5.2. Limitations of the study

The current study presented some interesting findings for further research to build on regarding the experience of endometriosis and its impact on womanhood and identity. However, there were a number of methodological flaws and practical constraints within the study that need addressing.

It is important to recognise that the findings of the current study depicted a detailed final account from a small, homogeneous group of women with endometriosis who were based within the same locality and under the same Consultant Gynaecologist. Therefore, the findings are not claiming to be representative of all women with endometriosis. Sample size and homogeneity of the sample were suitable for the chosen method of analysis, IPA (Smith & Osborn, 2003). However, the sample was constrained by recruiting through one Consultant Gynaecologist who had to generate interest in the study and identify who would be suitable to take part, possibly leading to some sampling bias. Recruiting from a wider range of settings may have been beneficial, for example through other consultants, the National Endometriosis Society (NES), support groups or via the Internet.

Emotional distress was a common theme within the current study with participants reporting 'feeling down' or 'feeling low'. However, it was not possible to determine if levels of emotional distress were clinically significant. Therefore, a standardised quantitative measure such as the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) may have been appropriate to measure emotional distress within this sample. Additionally, it is likely that participant's mood effected their interview account, for example participants who felt distressed depicted a more negative experience of endometriosis. Consequently, by not controlling for mood there was the possibility of gaining a skewed impression of endometriosis from participants. However, mood would have been difficult to control for, as it seemed to

fluctuate in accordance with the experience of endometriosis. Therefore, a single measurement of mood taken on one day may not be representative of mood generally.

IPA was considered to be an appropriate method of analysis for the current study.

Although, IPA has been criticised for failing to meet conventional scientific standards i.e. whether findings are scientifically valid (Smith, 1996). Various measures were taken to increase validity and credibility of the findings in the current study such as: illustrating themes with verbatim quotes; keeping a 'audit paper trail' to demonstrate the development of themes from raw data; and using independent analysis of transcript extracts. However, other methods that could have been used to further enhance methodological rigour were participant validation through focus group discussion and triangulation of findings by interviewing a significant other or asking participants to keep a diary. These methods were not used due to time restraints.

It is important to consider the influence of the Principal Investigator on the interview and analysis and the context of the study. An inherent bias is created by the existence of the Principal Investigator within the research process (Greenhalgh & Taylor, 1997). The Principal Investigator attempted to minimise researcher bias through making reflective summary notes immediately post interview and by keeping a reflective diary throughout the research study. An example extract from the reflective diary is displayed in Appendix O. Factors that may have shaped the interview due to the presence of the Principal Investigator included: age, gender, socio-economic background, education and professional background. In reflection of the Shifting Perspective Model for Chronic illness, most participants presented with 'wellness' in

the foreground. This may not necessarily reflect their general experience of endometriosis but may be the perspective that they want to give the Principal Investigator or perceives that this perspective is what the Principal Investigator is looking for. Triangulation of findings might have resolved this limitation.

5.3. Future research

There are numerous avenues for future research:

1. Future research may find it useful to use a grounded theory methodology as this promotes theoretical sampling and therefore explicitly looks for exceptions. In particular, it would be interesting to examine whether the effects of endometriosis on womanhood would be different for women who had children or greater variations in age or ethnic diversity.
2. The current study suggested the application of the Shifting Perspective Model of Chronic Illness (Paterson, 2001), further research is needed to validate the utilisation of this model in relation to endometriosis.
3. Further investigation into the impact of endometriosis on partners would be informative to gain a better understanding of their feelings and needs.
4. Further exploration into examining who does and who does not access support groups and internet web forums for endometriosis to examine whether these resources are meeting the needs of women with endometriosis.
5. Further work investigating the application of self-management training for women with endometriosis and its effectiveness would be beneficial.

5.4. Clinical implications and recommendations

The current study highlighted the following clinical implications and recommendations for healthcare services and medical practitioners:

1. Healthcare services need to play an active role in raising awareness of endometriosis and educating society via disseminating more widely information about the condition. For example, it was suggested that endometriosis should be highlighted within schools to provide adolescents with information about the condition.
2. The need for more information given to women with endometriosis about the condition and prognosis. Participants suggested that it would have been useful for information to be presented in a written format e.g. a leaflet or to be able to contact a dedicated individual who had expert knowledge of the condition and flexibility and times to talk e.g. a specialist nurse. However, in practice creating a new role would have resource and funding implications.
3. Emotional distress is common in women with endometriosis and therefore it is important for medical practitioners to bear in mind the psychological and emotional repercussions of endometriosis. Consequently, it may be beneficial to incorporate routine screening for mental health difficulties, emotional difficulties and sexual dysfunction within clinical practice. Although, the fluctuations in distress seen within the current study may cause difficulties for the identification of significant psychological difficulties.
4. Additionally, the development of multidisciplinary teams or specialist endometriosis clinics where women can visit and access a range of different

professionals might be advantageous. For example, Wingfield et al., (1997) demonstrated a high demand for a specialist endometriosis centre.

5. The need for responsive and proactive healthcare was highlighted by participants, as most criticisms of services related to difficulties with diagnosis and lengthy treatment process. However, healthcare services are hindered by the enigmatic nature of the condition.
6. There is a clear role for the application of self-management training and Expert Patients Programme to women with endometriosis. Therefore, healthcare services need to promote the use of self-management strategies to empower patients to use their own skills and information to improve their wellbeing and effectively take control of living with the condition, alongside accessing professional services.

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Internet web forum

Endometriosis in the UK – You are not alone: www.endometriosis.org.uk

Section C

CRITIQUE OF RESEARCH

Word Count : 4,434

(excluding references)

Critique of Research

This section outlines my experiences and reflections of conducting this research and demonstrates learning points throughout the research process. It describes the origin and development of the study, challenges met along the way and the experience of conducting research. Finally, it details a critique of myself as a researcher and reflects upon the personal impact of this research on the self.

1. The conceptualisation and preparation of research

1.1. Origin of the study

My interest in endometriosis began when my sister was diagnosed with the condition and listening to her experiences of endometriosis made me aware of the major impact it has on women. My curiosity with the condition developed through talking to other professionals with an interest and knowledge of endometriosis and reading around the subject. One of the main sources of information that I used to gain a basic insight into the experience of living with endometriosis was through Internet web forums especially 'Endometriosis in the UK-You are not alone' site. This allowed me to read a range of women's stories, gaining an insight into their experiences, difficulties, needs and the emotional and psychological impact of the condition. These sources demonstrated the high prevalence of women with endometriosis in the population in spite of its low profile in society and medical communities. Furthermore, it highlighted the paucity of research in this area.

Initially, I had aimed to focus on exploring psychological distress and coping in women with endometriosis using a mixed design. However, this focus was discontinued after reviewing the literature and through discussion with others, as it was felt that there was already a substantial volume of knowledge on this topic due to its association with chronic pelvic pain. Subsequently, the focus changed to explore the effects of endometriosis on womanhood. This idea stemmed from discussions with my researcher supervisor about the nature of endometriosis and its implications for a woman. As well as, through observations and conversations with my sister regarding how endometriosis had affected her sense of femininity and by reviewing women's stories on the web forum message boards, which highlighted its potential impact on womanhood.

1.2. Research design and development

Various methods were used to develop ideas around womanhood and endometriosis. A review of the literature related to endometriosis was conducted as well as additional relevant articles related to gynaecology (e.g. Nicholls, Glover & Pistrang, 2004), fertility (e.g. Ulrich & Weatherall, 2000), and womanhood (e.g. Kitzinger & Willmott, 2002). Additionally, I posted a message on the message board on the website 'Endometriosis in the UK-You are not alone', asking members of the site generally how endometriosis had affected their womanhood. One woman responded to the message. She described that endometriosis made her feel 'undesirable' and like an 'unattractive heffalump'. She stated that she did not feel like a woman anymore but a medical condition and a burden. Her response validated the need for research within this area. However, the low response rate to the message was disappointing. I had

anticipated a greater response, in light of the acknowledged need for more research on condition (Cox *et al.*, 2003b; Denny 2004b). I think the low response might have been because my research was not a medical study and therefore was not going to provide answers about the aetiology of the condition or improve treatment interventions.

I was also aware that the concept of womanhood was abstract and difficult to define and I wondered how participants would interpret the term. For me womanhood was an individually conceptualised sense of identity as a woman, incorporating themes of sexuality, physical appearance as a woman, femininity, fertility and motherhood. However, I also acknowledged that societal and cultural influences play a significant role in shaping the term. To help gain a greater understanding of how other people understood the term, I asked my cohort (mixed gender) to feedback their ideas about the meaning of womanhood. Overall, they found it a difficult task. Throughout the length of the research process, I have found it useful to keep referring back to all these resources (my academic and field supervisors, my sister, the Consultant Gynaecologist, Internet, media and knowledge base) to develop, discuss and validate my ideas for this research study.

1.3. Choice of methodology and design

A qualitative design was chosen because it seemed the most appropriate method for the exploratory purposes of the research study, as the study did not intend to objectively assess specific variables to answer specific research hypotheses. I found Interpretative Phenomenological Analysis (IPA; Smith, Osborn & Jarman, 1999) to be an effective, systematic method of analysis. It endeavours to understand the

participant's view of the world and to adopt an 'insider perspective' (Conrad, 1987). IPA permitted me to obtain a deep understanding of how participants made sense of their meanings of their experiences of endometriosis. The theoretical underpinnings of IPA are also in line with my epistemological position, in that it acknowledges the subjective nature of participants' narratives and subsequent interpretation. Consequently, it emphasises that the data arises out of a dynamic interaction between the participant and researcher within that given context (Smith, 1996). The investigation of the effects of endometriosis on womanhood was a unique area of research and hence the purpose of the study was to gain a firmer understanding and insight. Therefore, I felt that IPA was the most appropriate methodology for this study because it has been suggested to be useful for exploring under researched areas (Smith, Osborn & Jarman, 1999). Additionally, IPA was also chosen because it had been effectively applied to similar research studies and had a strong foundation within research in health settings (Smith, 1996; Smith, Flowers & Osborn, 1997).

The current study has been development in conjunction with support and guidance from academic and field supervisors and liaison with a Consultant Gynaecologist. There were some differences in opinion regarding research design with the Consultant Gynaecologist with whom I was liaising with to recruit participants. These difficulties seemed to be related to our different epistemological positions and research experience. For example, he was well acquainted with quantitative methods of research coming from a Positivist epistemology whereas I preferred qualitative methodology, in line with my own epistemological position of a contextualist constructionism stance. Another difference of opinion was related to the focus of the

study. The Consultant Gynaecologist thought it would be better to focus on specific symptoms rather than the generic diagnosis of endometriosis. However, I wanted to keep to a diagnosis because it clearly defined participants forming a homogenous sample, which is necessary for IPA (Smith, Osborn & Jarman, 1999). In hindsight, I can understand his concerns because investigating endometriosis was limited by the constellation of symptoms, not solely specific to the condition.

Some changes were made to the design of the study following a research panel and peer review. The inclusion criterion was modified to allow participation to women from the age of 16. This was done because the literature highlighted that this age group often got overlooked (Gao *et al.*, 2006). A query regarding the clinical application of the study was highlighted at peer review. Consequently, a secondary aim of the study was to investigate women's experiences of services to identify possible recommendations for service improvements.

A pilot interview was used to test the appropriateness of the interview schedule. Consequently, minor amendments were made to the wording of the interview schedule. The pilot also reminded me of the importance of having the appropriate recording equipment and interview setting to facilitate the interview process. The findings from the pilot highlighted that I had predominately focused on the negative aspects of endometriosis and had neglected to think about whether it had any positive effects on women and consequently, it slightly altered my conceptualisation of endometriosis and its impact.

2. Conducting the research

2.1. Liaison with external agencies

The current study recruited from an outpatient hospital population and hence had to meet the requirements of the Trust Research and Development (R&D) department. Liaison with the R&D office was often problematic due to staff shortages and current transition in sponsorship arrangements between the hospital and the university R&D departments. My study was significantly delayed by the latter difficulty, as the hospital R&D department declined to sponsor my study on the grounds that the university R&D department had agreed to take on small low risk projects. However, the university R&D department had only just taken on research governance sponsor status and was hesitant about taking on a study which incorporated hospital populations. In the end the hospital R&D department accepted responsibility of sponsorship. This experience highlighted the difficulty and time required in getting a research project off the ground. Furthermore, there were many additional steps to take that I had not anticipated such as mandatory consent training and research governance training through the hospital R&D department before they would grant approval. Conversely, my experience obtaining ethical approval through the local ethic committee was much more straightforward.

2.2. Sampling and recruitment difficulties

Recruitment of participants was more difficult than anticipated. Overall, I had aimed to recruit between 10-12 participants, but my final sample size was 7. However, this was verified to be appropriate for the method of analysis by the IPA guidelines by Smith & Osborn, (2003). Possible reasons why approached women did not take part in the

study could have included: time pressures, losing study information, concerns regarding the emotional and sensitive aspects of the study or lack of interest. All participants were recruited via a single Consultant Gynaecologist. Therefore, the study was dependent on him to promote and sell the study to participants. Originally, I had planned to additionally recruit through a support group; however the local support group had disbanded at the time of recruitment. Furthermore, a sample of women with endometriosis was not specifically recruited through the National Endometriosis Society because of worries that this sample might not be representative of women with endometriosis. Other ways of recruiting could have been through targeting multiple Consultant Gynaecologists, advertising on Internet web forums or snowballing sampling.

On a few occasions, the Consultant Gynaecologist suggested women that were willing to take part in my study, however subsequently, I never heard from them or upon contact they later declined. I wondered whether this phenomenon was related to the power dynamics between the doctor and patient, in that they felt under pressure or obliged to take part when really they did not want to. Sometimes this power dynamic was felt between the Consultant Gynaecologist and myself. In reflection of the participants who did volunteer, it may be that women who took part felt less distressed and were effectively managing the condition and so felt more able to participate. Coincidentally, the first three participants I interviewed had accessed counselling or psychological input. Initially, I wondered whether the Consultant Gynaecologist was purposive sampling due to my professional background. However, this was not the case. Therefore, it might reflect that women who had received additional support felt

more able to talk about their experiences and hence volunteered for the study.

Additionally, some participants described that they had taken part because they wanted to help other women and raise awareness of the condition.

Ultimately, a homogeneous sample was collected, with limited variation in age and ethnic diversity. Furthermore, none of the participants had children. It could be argued that because the sample was recruited through a specialist gynaecology clinic, it might represent the more severe cases of endometriosis. However, I thought that the sample represented a range of symptoms and severity of endometriosis across the continuum.

2.3. Reflections on the process of interviewing

I enjoyed conducting the interviews and felt privileged to hear participants' narratives and learn about their experiences of endometriosis. However through the process of interviews and IPA, I felt that I got to know some participants more than others, in particular Amy, Ana, and Olivia. The reason for this may be because these were the longer, richer interviews. Some participants may have been more cautious about disclosing such personal information. Although, all efforts were made to make participants feel as comfortable as possible and all participants gave informed consent so they knew beforehand what the interview would cover.

I used the interview schedule as a guide; however, I frequently follow up on points that were of interest, which made the interview feel like more of a conversation rather than a barrage of questions. Therefore, my interview style was flexible and participant led.

At times, I did feel a tension between letting participants talk freely and keeping them focused on the topic of the interview, as I had certain topics that I wanted to cover. Reflecting back on the interviews, I think, sometimes, I repeated questions by saying them in a different way. I think I did this not only because I wanted to obtain a clear understanding of what participants were saying but also because I was anxious about missing important details. However, at times I think I was wary of pushing topics which touched on sensitive topics for fear of upsetting participants. By the final few interviews I think I had become more confident in my interviewing style and role as a researcher.

At times, some participants' narratives seem a little contradictory and I wondered whether these participants were still trying to make sense of their diagnosis and their experiences. This was indicated by participants making connections within the interview and taking a long time to respond to questions, suggesting that they were still processing their experiences. The interviews demonstrated that there were numerous variables that influenced participant's experience of endometriosis such as symptom presentation, age of onset of symptoms, treatment received, length of time since diagnosis, fertility status and personality. All of which led to variations within participants' narratives, indicating that there was not one static true representation of the experience of endometriosis. The fluctuating nature of endometriosis and shifts in time frame within narratives suggested that if I had interviewed participants on a different day or at a different point along the endometriosis trajectory, I would have probably heard a very different account. This emphasised the subjective, dynamic and

context specific nature of participants' narratives, which was in accordance to IPA and my epistemological position.

3. Reflections of the analysis and presentation of findings

I wanted the final written document to accurately portray the narratives of the women that I interviewed and hence, my analysis was firmly grounded within the data.

However, the analysis will have been affected by my own interpretations of participants' experiences, which will be inherently influenced by my own identity, beliefs and experiences. The analysis required a lot of time and I found it difficult to develop the analysis into deeper levels of interpretation as well as maintaining the detail obtained within the word limit set. However, the analysis endeavoured to be interpretative as well as descriptive by considering contradictions, rhetoric, semantics, prosodic features and changes in temporal location (e.g. retrospective, prospective).

The pressure of having word limits was also beneficial in that it made me prioritise and concisely construct the most important details of my study and stay focused on the main research aims. The richness of interviews created a wealth of interesting data, which could not be fully discussed in detail. Therefore, it may be possible for further points to be written up as a second part to the current study. The limitations generated by having a word limit made me reflect on published work. I became more aware that published studies may only present a proportion of their findings in order to keep to word limits, highlighting the subjective nature of the portrayal of findings in accordance to what the researcher feels is information that needs to be disseminated. Another difficulty identified when writing up the study was evidencing findings within previous literature because the findings could be related to a wide range of the

literature, not just on endometriosis but also fertility, chronic illness and other gynaecology problems. I found it difficult to refer to all these relevant areas of literature in any depth. Therefore, it may have been better to adhere to literature specifically on endometriosis and gynaecology.

Regular research supervision was an important element of the research process. It helped me reflect on the meanings coming out interviews as well as offering practical guidance on structuring and conducting a piece of research. Furthermore, it was a vital source of support and an opportunity to debrief. Additionally, it was useful to discuss the study with my field supervisor who had practical clinical experience of working with women with endometriosis to validate findings.

4. Reflections on being a researcher

I found the role as a researcher at times quite difficult. Occasionally, I felt a tension between being a researcher and being a psychologist and had to consciously remind myself of my role to prevent slipping into a therapeutic interaction, particularly if participants became distressed.

From the start of the interview, I was clear to participants that I had no medical training or medical knowledge of endometriosis and therefore I was not an expert and could not give advice about treatment. At times, I was shocked by the limited amount of information given to participants and their lack of basic knowledge about endometriosis. I found it frustrating that it was not part of my role to give advice or information to participants, especially to those who had a lot of questions about the

condition. Instead, I referred participants to talk to their Consultant or GP and gave all participants a leaflet outlining contact details of various relevant organisations where they could find out more information if necessary.

It was hypothesised that my presence within interviews would in some way effect participants' narratives. This was an inherent bias, which will have affected what participants chose to say and how they wanted to appear. Primarily, I think participants would have identified with me as a woman, which on one hand could have helped them feel more comfortable about talking about gynaecological issues and menstruation. However, on the over hand it could have created feelings of resentment, as they may have perceived me as being a healthy, fertile woman. Participants' narratives may have been different if a man had conducted the interview. Secondly, I had introduced myself as a Trainee Clinical Psychologist; this may alter how participants responded in the interview. They might have felt obliged to mention psychological or emotional issues or suggested the need for further emotional support by psychological services/counselling due to my professional background. Other potential influential factors could have been related to my ethnicity, socio-economic background or age.

Additionally, I had been worried that I would be seen by participants as an outsider because I did not have endometriosis and that this might affect participants' narratives e.g. they might not open up as much. Alternatively, I was also wary that participants might assume that I had the condition. Consequently, I decided to disclose that a family member had endometriosis which had been the impetus for the study. This was

done to establish an alliance with participants as well as demonstrate transparency within the research process.

5. Impact on self

I found it really useful to keep a reflective diary from the start of the research process to note down ideas, reflections and monitoring of self. After every interview, I made reflection in my reflective diary about how I thought the interviews went, the context surrounding the interview and the feelings it evoked. Reflexivity was essential, particularly due to my own experience of endometriosis within my family, which would have constructed preconceived beliefs and assumptions. These became more apparent as the research process progressed. By being reflective, I realised that I had entered into this research study was a preconceived belief about the experience of endometriosis being negative. Consequently, evidence to the contrary took me by pleasant surprise. For example, I was astonished that all participants were in employment with 6 out of 7 working full time, highlighting that I had presumed that endometriosis would have interfered more with occupational functioning. Again, I noted that the women I interviewed rarely referred to themselves as ‘sufferers’, which again surprised me, as it is a descriptive term used so often in the literature. Lastly, I was surprised that overall the majority of participants portrayed a positive perspective of endometriosis and their lives. However, I wondered whether women had timed the interviews so that it landed on a ‘good day’ such as avoiding times when menstruating. I think my perspective of endometriosis was not only influence by my personal experience of the condition, but also related to the published literature and women’s accounts on web forums regarding the condition that I reviewed during the

development of the study. These latter sources seemed to amplify the negative aspects of endometriosis, depicting how devastating and debilitating it could be. I hypothesised whether the literature did this to make an impact in order to raise awareness of the condition and boost empathy within medical community and society. Through conducting this piece of research, my perspective of endometriosis has changed to become more positive.

This research study made me more conscious of my own experiences of menstruation. It made me reflect on how menstrual pain made me feel and the effects it had on my functioning such as not able to concentrate on work, feeling nauseous and fatigued from disrupted sleep. However after hearing about my participants' experience of menstrual pain, I felt guilty if I complained about my menstrual pain because I knew I was not suffering as much these women. It amazed me how they tolerated such excruciating pain and managed to get on with lives. Therefore, I think being a woman helped me empathise with participants. Additionally, I noticed that since starting this research project I have become more alert for signs of endometriosis in other people such as my friends. The study also made me reflect on my fertility and made me realise that like most women, I probably take my fertility for granted. Therefore, listening to participants' worries regarding their fertility status made me question my own fertility, especially in light of the connection of endometriosis within my own family. Alternatively after interviewing women with confirmed infertility secondary to endometriosis, I felt a mixture of feeling lucky and guilty that I still had the opportunity to have children.

Endometriosis was an emotive topic and at times, readings about or listening to women's experiences of the condition made me feel a little sombre. I found that similar to participants, I also experienced a roller-coaster of emotions throughout the research process ranging from awe, compassion, sadness, anger and frustration. Some of the feelings evoked during interviews may have been generated through counter-transference. In particular, I felt a strong sense of sadness and powerlessness following speaking to women with infertility secondary to endometriosis, which elicited rescuer feelings of wanting to make everything alright. Additionally, at times I was shocked and angered by the severity of some of women's past experiences of pain and the inadequate response by healthcare services. The emotional context of the study was anticipated; therefore structures were put in place to reduce any emotional distress, such as the use of research supervision to debrief and planning enjoyable activities after interviews. Furthermore, the emotive nature of endometriosis made me motivated to portray how awful endometriosis can be to the reader, however this would not have been an accurate portrayal as it would have ignored the positives and the important message coming out of the analysis that women with endometriosis can adapt and live with the condition.

The nature of this study made me more aware of the strong influence society has on our judgements and beliefs e.g. stigma and taboo associated with menstruation, infertility and gynaecology. Interestingly, a male radio presenter queried why as a society do we find it difficult to talk openly about menstruation even though half the population is female. This highlighted the nonsensical nature of society to dismiss a natural common occurrence due to its perceived taboo nature. In reflection, I

recognised that I found it difficult and embarrassing to explain to lay people, especially men, the content of my study because it inevitable involved a description of endometriosis and discussion of menstruation and the female reproductive system. Generally, disclosure of my study topic was met with an uncomfortable response, which in turn made me reticent to discuss it further. Consequently, it demonstrated the difficulty of disclosure for women with endometriosis and the taboo nature of the condition. I feel from conducting this study I have become more critical and reflective about societal conventions, taboos and stigma, especially attached to women.

6. Learning points

This experience has highlighted the challenges and rewards of conducting research. It involved encountering new research experiences and learning new skills such as conducting a systemic search and review of the literature, applying to ethics, recruiting participants and learning how to analyse qualitative data using IPA. After conducting this research I feel more confident about conducting qualitative research. However, in the future I would like to develop my quantitative research skills. Furthermore, it has developed my reflexivity and encouraged me to be more critical about myself as a researcher as well as an interviewer. The research skills developed throughout this study will not only be useful for future research but can also be applied to my clinical practice such as interviewing clients, being reflective and critically appraising psychology literature and theory. At times, I have found it difficult to conduct this research alongside continuing my clinical duties on my training placement in relation to: time management, prioritising and the separation of the two commitments in my mind. This gave an insight into the challenges Clinical Psychologists face when endeavouring to conduct a piece of research within the role of a clinician.

7. Summary

I feel that this research experience has encouraged personal development as well as developed my skills as a researcher. At times, I have found it frustrating but challenging, enjoyable and poignant. By using qualitative methodology, the lived experiences of women with endometriosis and its effects on womanhood were portrayed. I hope that this research study accurately reflected their experiences, needs and recommendations for healthcare services. Furthermore, I hope that the findings

resonate with other women with endometriosis and can be utilised by healthcare services and other researchers to continue to improve services and ameliorate the experiences of living with the condition. Ultimately, endometriosis is surrounded by a lack of awareness and paucity in knowledge; I hope that this research study will make a useful contribution to the knowledge base.

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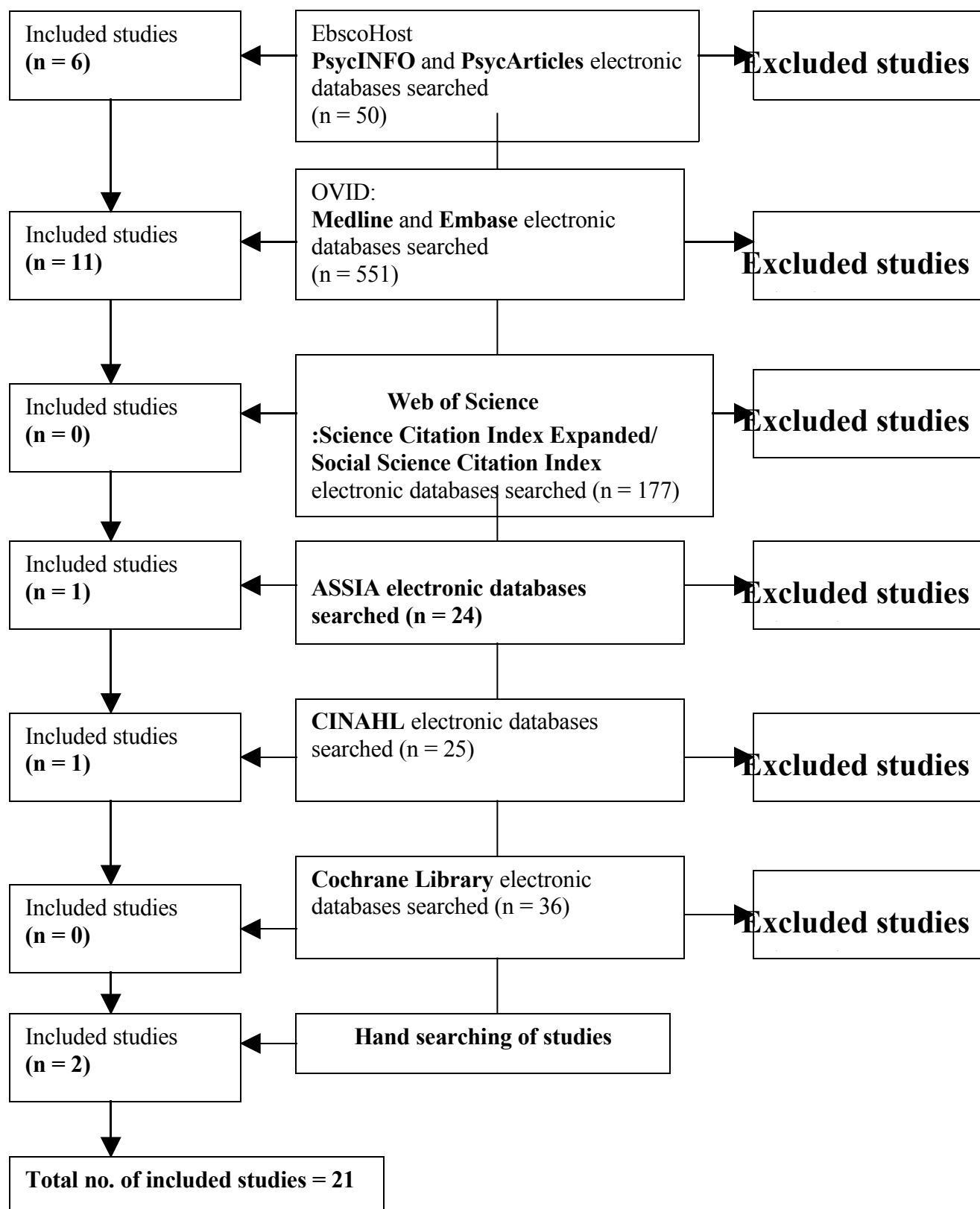
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Internet web forum

Endometriosis in the UK – You are not alone: www.endometriosis.org.uk

Appendix A

Literature Search Results



EBSCOhost**Databases searched:** PsycINFO/ PsycArticles**Limiters:** 1970-2008, journal articles, peer reviewed, English

			No. found	No. kept	No. excluded
1	Endometriosis		40		
2	AND	Depression	10	1	9
3	AND	Psychological distress	1		1
4	AND	Distress	5		5
5	AND	Psychological impact	0		0
6	AND	Mood	11	1	10
7	AND	Mental health	4	1	3
8	AND	Psychological problems	0		0
9	AND	Psychiatric problems	0		0
10	AND	Beck Depression Inventory / BDI	0		0
11	AND	General Health Inventory / GHQ	0		0
12	AND	Psychol*	12	2	10
13	AND	Psychiatr*	7	1	6

OVID

Databases searched: Medline/Embase

Limiters: 1970-2008, journal articles, peer reviewed, English

			No. found	No. kept	No. excluded
1	Endometriosis		19,778		
2	AND	Depression	196	5	191
3	AND	Psychological distress	2		2
4	AND	Distress	36	2	34
5	AND	Psychological impact	2		2
6	AND	Mood	90		90
7	AND	Mental health	22	1	21
8	AND	Psychological problems	1		1
9	AND	Psychiatric problems	0		0
10	AND	Beck Depression Inventory / BDI	10		10
11	AND	General Health Inventory / GHQ	2		2
12	AND	Psychol*	155	3	152
13	AND	Psychiatr*	35		35

Web of Science

Databases searched: Science Citation Index Expanded/ Social Science Citation Index

Limiters: 1970-2008, journal articles, peer reviewed, English

			No. found	No. kept	No. excluded
1	Endometriosis		6,734		
2	AND	Depression	40		40
3	AND	Psychological distress	4		4
4	AND	Distress	16		16
5	AND	Psychological impact	3		3
6	AND	Mood	14		14
7	AND	Mental health	9		9
8	AND	Psychological problems	8		8
9	AND	Psychiatric problems	3		3
10	AND	Beck Depression Inventory / BDI	6		6
11	AND	General Health Inventory / GHQ	5		5
12	AND	Psychol*	49		49
13	AND	Psychiatr*	20		20

ASSIA

Limiters: 1970-2008, journal articles, peer reviewed, English

		No. found	No. kept	No. excluded
1	Endometriosis	24	1	23

CINAHL					
Limiters: 1970-2008, journal articles, peer reviewed, English					
			No. found	No. kept	No. excluded
1	Endometriosis		442		
2	AND	Depression	2		2
3	AND	Psychological distress	1		1
4	AND	Distress	4		4
5	AND	Psychological impact	0		0
6	AND	Mood	4		0
7	AND	Mental health	3		3
8	AND	Psychological problems	0		0
9	AND	Psychiatric problems	1		1
10	AND	Beck Depression Inventory / BDI	0		0
11	AND	General Health Inventory / GHQ	2	1	1
12	AND	Psychol*	7		7
13	AND	Psychiatr*	1		1

Cochrane Library					
Limiters: 1970-2008, journal articles, peer reviewed, English					
			No. found	No. kept	No. excluded
1	Endometriosis				
2	AND	Cochrane reviews	25		0
3	AND	Other reviews	11		0

There was substantial overlap across databases, duplicates were removed.

Reasons for exclusion

Many studies were elicited in the search but were later excluded from the study because they did not meet the inclusion criteria. Reasons for exclusion included:

- Studies were excluded if they did not sample women with a diagnosis of endometriosis. For example, some studies focused on women with unexplained chronic pelvic pain, hysterectomy or other gynaecological disorders.
- Studies were excluded if they did not examine endometriosis in relation to depression or psychological distress. For example, studies that focused exclusively on investigating treatment options or assessing pre-treatment and post-treatment outcomes following an intervention, such as pharmacological treatment, surgery or self-management training.

Appendix B

Table of studies for literature review

ID	Study	Participants	Aim	Design	Findings related to depression	Cited cause of depression	Limitations
1	Barnack et al., (2007) USA	*N= 73 *Endometriosis group n= 41 *Migraine group n= 32 *Recruited through Endometriosis Association support groups and internet listservs *Sample from USA, Canada and Australia	*To compare the experience of pain, physical and psychological wellbeing, stress, pt satisfaction, social support and attitudes towards menstruation of women who suffer from endometriosis and migraines.	*Quantitative *Cross sectional *Internet study *Demographic & illness history section Outcome measures used: *West Haven Yale Multidimensional pain inventory *Index of Clinical Stress (ICS) *Patient reaction assessment (PRA) *SF-36 health survey *Beliefs about and Attitudes towards menstruation questionnaire *Quality of Social Support Scale (QSSS)	*In comparison to the migraine group, the endometriosis group reported: - sig. more pain - poorer social, physical and emotional functioning - more role limitations due to emotional problems - greater life interference. - sig. more negative attitude than women with migraines - more social support - sig. less control - more solicitous and distracting reactions *Sig. lower SF-36 health survey emotional wellbeing score = 55.54 compared to 68.20 *No between group differences on ICS, QSSS and PRA.	*Societal response *Pain *Life interference *Control *NOT stress	*Does not specify laparoscopic diagnosis of endometriosis *Not representative sampling *Recruitment online therefore only included women with internet access. *Possibility that some women had both endometriosis and migraines or another chronic illness which could affect findings *Use of incentives may have led to some participants taking part multiple times *No pain free control group *SF-36 is a generic questionnaire and may lack sensitivity

2	Bodner et al., (1997) Scotland	<ul style="list-style-type: none"> *N=273 *Newly diagnosed with endometriosis. *Primary presenting problems were: <ul style="list-style-type: none"> -pain (n=145) -infertility (n=62) -other (n=66) *recruited from hospital population * 72% response rate 	<ul style="list-style-type: none"> *To evaluate the impact of endometriosis and its treatment of women's HRQOL * To examine the measurement properties of both a condition specific questionnaire and the SF-36 	<ul style="list-style-type: none"> * Quantitative *Longitudinal *self administered postal questionnaires at diagnosis & 6mths follow up <p>Outcome measures used:</p> <ul style="list-style-type: none"> *SF-36 health survey *Condition specific questionnaire developed by authors 	<ul style="list-style-type: none"> *Pain associated with endometriosis led to poorer outcome on QOL measures. *Women with more treatment side effects had lower scores on SF-36 *Larger improvements in pain dimensions for the treated group of women *Little change in mental health scores over time post treatment. 	<ul style="list-style-type: none"> *Pain *Treatment side effects *Severity of endometriosis 	<ul style="list-style-type: none"> *Does not specify laparoscopic diagnosis of endometriosis *Does not give full SF-36 scores for comparison *Predominately focuses on the second aim *SF-36 is a generic questionnaire and may lack sensitivity
3	Christian (1993) USA	<ul style="list-style-type: none"> *N= 23 *Formal diagnosis of endometriosis *Convenience sampling *Recruited from private setting 	<ul style="list-style-type: none"> *To determine the relationship between women's symptoms of endometriosis and self-esteem. 	<ul style="list-style-type: none"> *Quantitative *Cross sectional *Descriptive <p>Outcome measures used:</p> <ul style="list-style-type: none"> *Rosenberg Self esteem scale *Questions of demographic characteristic, health history, menstrual history and symptoms of endometriosis 	<ul style="list-style-type: none"> *Self-esteem scores predominantly high, mean=32.17, range = 23-37. *main symptoms: pelvic pain, dysmenorrhea & dyspareunia) *No sig. correlation between self-esteem and the number, frequency and severity of endometriosis symptoms. *High levels of reported life interference *Infertility did not appear to affect self-esteem. 	<ul style="list-style-type: none"> *NO self esteem difficulties *NO relationship to endometriosis symptoms (pain, dysmenorrhea & dyspareunia) *NO relationship to infertility 	<ul style="list-style-type: none"> *May not representative sample as recruited from private setting, therefore have had mainly included women from higher socio-economic groups *Limited diversity within sample *Self esteem affected or protected by other variables *Small convenience sample size *No control group
4	Cox et al.,	*N=1031	*To obtain	*Quantitative & qualitative	*5 main themes emerged,	*Lack of	*Does not provide much

	(2003a) Australia	*Response rate 65% * Recruited from EA membership & Endometriosis centre database	information from women who have experienced endometriosis & laparoscopy in order to a) identify and meet the information needs of women experiencing endometriosis. b)develop strategies to raise awareness of endometriosis	methodology *Questionnaire with open & closed questions. Had 5 sections: i)diagnosis ii) endometriosis iii) laparoscopy iv) managing at home v) general comments *Data analysed in terms of frequency of response & themes that arose	one of which was emotional turmoil *Lack of understanding of endometriosis & laparoscopy on behalf of the patients & practitioner led to communication of misinformation extended physical pain & emotional distress *Shock & disbelief when unexpectedly diagnosed with endometriosis. *Depression a possible after effect o laparoscopy *Emotional suffering was commonly reported due to symptoms, negative experiences of services, lack of information, feeling alone & infertility worries.	information or misinformation *Negative experiences of services *Being discredited/di smissed *Symptoms *Laparoscopy *Fertility issues.	verbatim evidence to back up themes *Paucity in explanation regarding how analysed, does not specific indicate method of analysis
5	Cox et al., (2003b) Australia	*N=1031 *Response rate 65% *From this, sample used for focus groups (n=61) – split into 5 groups *Recruited from EA membership &	*To identify the information needs of women facing a laparoscopy for endometriosis. *To provide a forum for communicating	*Qualitative methodology *Focus groups conducted – given areas to discuss & facilitated by main author. *Thematic analysis used to analyse data. *Participant validation checks used.	*3 master themes emerged. *Depression was a sub-theme, under the master theme of living with endometriosis. *Sub-theme of depression reported that women	*Response of others *Fertility issues *Life interference *Negative experiences	*Not representative sample e.g. EA members *Possible influence on focus groups by the presence of the researcher. *Few verbatim extracts to validate themes.

		Endometriosis centre database	their experiences of endometriosis & laparoscopy.		described the development of depression & even suicidal ideation. *Mood difficulties related to response of others to symptoms e.g. workplace discrimination, being judged a hypochondriac. *Other difficulties associated with mood:- marriage breakdown, loss of partner or friends, feeling alone, & negative experiences of services. *Also reported impact on self esteem and feeling worthless & useless and *Fertility issues *Incidents of trauma, distress & anger of not being taken seriously	of services.	
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6	Denny & Mann (2007) UK	<ul style="list-style-type: none"> *N=30 *Sample derived from reaching saturation *Recruited from specialist endometriosis outpatients clinic *Purposive sample *Diagnosed via laparoscopy 	<ul style="list-style-type: none"> *To assess how much of an impact the experience of deep dyspareunia has on QOL in women with endometriosis. *To gather quantitative data to gauge the extent of the problem. 	<ul style="list-style-type: none"> *Qualitative & quantitative methodology used. *Semi structured interviews *Data analysed using narrative analysis *Participants validation checks used *Inter-rater reliability checks conducted. 	<ul style="list-style-type: none"> *Dyspareunia experienced by 86% *Experience of dyspareunia extremely distressing *All women who reported it stated that it had a negative effect on self esteem e.g. not feeling feminine/attractive, felt guilty or inadequate regarding avoidance of sex *Reported tension/arguments caused by lack of sexual relations. Partners felt rejected, jeopardised or broke up relationships. *Overall, impact on self esteem & relationships 	<ul style="list-style-type: none"> *Dyspareunia *Life interference 	<ul style="list-style-type: none"> *Differences in intensity of dyspareunia not explored *Does not control for other variables *A large quantitative study could be used to explore the relationship between depression and experience of dyspareunia, controlling for other variables such as chronic pelvic pain.
7	Eriksen et al., (2007) Denmark	<ul style="list-style-type: none"> *N=63 *Sample split into 2 groups: <ul style="list-style-type: none"> i) women with endometriosis & pain (n=43) ii) women with endometriosis & pain free (n=20) 	<ul style="list-style-type: none"> *To compare patients with and without pain symptoms to see whether they differed on psychological parameters. 	<ul style="list-style-type: none"> *Quantitative *Cross sectional Outcome measures used: <ul style="list-style-type: none"> * Visual Analogue scale (VAS; pain intensity) *BDI *STAI *Courthald Emotional 	<ul style="list-style-type: none"> *Strong negative correlation between rational & detached coping & anxiety & depression. *Sig. positive correlation between emotional & avoidant coping & depression & anxiety. 	<ul style="list-style-type: none"> *Coping style *NOT pain severity 	<ul style="list-style-type: none"> *Does not give the correlational data for the pain free group to validate findings.

		<ul style="list-style-type: none"> *women laparoscopically diagnosed endometriosis *Recruited from hospital O&G outpatient population *67% response rate 		Control Scale (CECS) *Coping style Questionnaire (CSQ) *Project developed questionnaire for demographic information.	<ul style="list-style-type: none"> *No difference in depression between groups. *BDI scores not clinically sig. (below cut off) *Sig. correlation between pain severity & psychosocial impairment *No correlation between pain severity & depression/anxiety 		
8	Hassa et al., (2004) Turkey	<ul style="list-style-type: none"> *N= 60 *Surgically diagnosed endometriosis *G1= fertile with endometriosis (n=33) *G2= infertile with endometriosis (n=27) *Additionally categorised in basis of ASRM classification: early (46) & late (22) and location of endometriosis i)peritoneal ii)ovarian iii)Both *Recruited from O&G dept. 	<ul style="list-style-type: none"> *To evaluate endometriosis patients symptoms and relate them to different stages and locations of endometriosis and also to fertility/infertility of patients. 	<ul style="list-style-type: none"> * Quantitative *Cross sectional observational study *Outcome measures not reported. 	<ul style="list-style-type: none"> *Prevalence of depressed mood = 21% *Depressive state did not differ with stages of endometriosis *Depressive state did not differ with fertility status. *Depressive state did not differ with location of endometriosis 	<ul style="list-style-type: none"> *NOT fertility status *NOT stage on endometriosis *NOT location of endometriosis *Quality of life *Life interference 	<ul style="list-style-type: none"> *Does not define 'depressed mood' *Outcome measures not reported.
9	Hirsh et al., (2001)	<ul style="list-style-type: none"> *N=32 *Sample consisted of 	<ul style="list-style-type: none"> *To determine the aspirations of 	<ul style="list-style-type: none"> *Cross sectional *Interviews 	<ul style="list-style-type: none"> *Depression relatively common. 28% reported 	Didn't specify.	<ul style="list-style-type: none"> *Symptom data collected through verbal interview

	UK	<p>20 outpatients & 12 inpatients.</p> <p>*Recruited consecutively from outpatients gynaecological clinic or consecutive surgical admissions</p> <p>*All had been diagnosed via a laparoscopy and had a history of pelvic pain of at least 3 months.</p> <p>*Age range = 20-49yrs</p>	women with endometriosis in terms of the management of their disease.	*Semi structured interviews incorporating demographics, symptoms and impact of symptoms of QOL & services	depression as a symptom of endometriosis.		rather than structured measures. Therefore, depressive symptoms were self reported rather than measured using standardised tools.
10	<p>Jones et al., (2004)</p> <p>UK</p>	<p>*N=24</p> <p>*Sample size based on saturation point</p> <p>*Recruited from gynaecological outpatients clinic</p> <p>*Diagnosed via laparoscopy</p>	*To identify & understand from the patients perspective the areas of HRQOL that are affected by endometriosis & explore the effects of the disease on QOL.	<p>*Qualitative</p> <p>*Semi-structured interviews</p> <p>*Analysis using grounded theory.</p> <p>-constant comparative method used</p> <p>-theoretical sampling</p> <p>-inter-rater reliability checks</p>	<p>*86 concepts identified forming 15 descriptive categories</p> <p>*One of which was emotional wellbeing:</p> <p>-women described not being able to cope with pain, made them feel 'miserable' and 'depressed'.</p> <p>*Reported feeling weepy & tearful.</p> <p>*Reported being moody & short tempered.</p> <p>*Reported feelings of frustration, worry,</p>	<p>*Pain</p> <p>*Life interference</p> <p>*infertility</p>	*Researcher bias possible in interviews and analysis

					powerlessness, lack of confidence & sexual dysfunction.		
11	Laurson et al., (2005) Denmark	*4 groups of females with chronic non malignant pain syndromes; -fibromyalgia (n=10) -endometriosis (n=10) -low back pain (n=10) -arthritis (n=10) *Control group -pain free women (n=41) *Recruited from pain clinic and hospitals. Control groups were medical staff. *Endometriosis diagnosed in accordance to Danish National Board of Health Diagnosis classification system.	*To assess, compare and correlate pain response to an experimental pain stimulus, pain intensity of the habitual pain & QOL parameters in groups of females with chronic non malignant pain syndromes.	*Quantitative *Cross sectional Outcome measured used: *SF-36 health survey * VAS (pain intensity) *Pressure pain threshold using an algometer.	*For endometriosis group = strong negative correlation between pain VAS and role limitations (emotional) *Scores for endometriosis group on SF-36 suggested endometriosis not as debilitating and disabling as some of the other conditions examined. *Endometriosis group median score on mental health subscale = 70/100, ranging from 44-88.	N/A	*Does not used ASRM classification system. *Recruited from tertiary services, therefore may mainly include the more severe cases of endometriosis – may not be a representation sample *Small sample sizes in each group *SF-36 is a generic questionnaire and may lack sensitivity
12	Lemaire (2004) USA	*N=298 *Response rate = 61% *Recruited from a conference by EA. *Convenience sample *Sample = women	*To explore the frequency, severity, interference with daily life & symptoms distress	*Quantitative *Descriptive cross sectional *Correlational & factor analysis	*Symptom distress positively correlated with uncertainty *Uncertainty positively correlated with psychological distress	*Uncertainty *Perceived knowledge	*May not a representative sample due to recruitment procedure. *Sample biased towards women from higher socio-economic groups

		with endometriosis surgically diagnosed.	associated with endometriosis *To explore the relationship between among symptom, emotional distress, uncertainty & preference for & adequacy of information.	Outcomes measures used: *Symptoms checklist designed by author. *Mishel Uncertainty Illness scale – community form *Revised Krantz Heath Opinion Survey- Information subscale *Perceived knowledge Questionnaire *Feelings and reaction scale (FAR)	*Negative correlation between uncertainty & emotional distress *Depressed feelings (75.4%) and anxious feelings (64.4%) reported some or most of the time *Mean score for emotional distress = 49.51 on the FAR scale (out of 120), range = 10-120.		*FAR scale designed by the author, not standardised.
13	Lewis et al., (1987) USA	*N=16 *Laparoscopy diagnosed endometriosis *Age range: 20-37 yrs *Consecutively selected from women's clinic at a university hospital	*To study systemically the possible relationship between endometriosis & mood disorder.	*Quantitative *Cross sectional *DSM-III criteria *Interview schedule drawing upon other psychometric tools covering depressive symptoms, manic symptoms & family history	*12 women met criteria for mood disorder:- 7 bipolar (mixed) 3 Bipolar (manic) 2 Major depression 2 equivocal *Mood disorder prevalent in 1 st & 2 nd relatives *Patients with well documented bipolar or major depression gave history of having initial episode before diagnosis of endometriosis	*Hormonal factors *Genetic patterns- history of psychiatric problems within the family	*Very small sample size *No control group *Diagnosis based on psychiatric interview rather than psychometric tools

14	Lorencatto et al., (2006) Brazil	<ul style="list-style-type: none"> * N= 100 *2 groups i) Women with CPP (n=50) ii) Women without CPP (n=50) *Endometriosis formally diagnosed *Recruited from outpatients clinic *Inclusion criteria = to have experienced CPP for at least 6mths 	<ul style="list-style-type: none"> *To compare the prevalence of depression in women surgically diagnosed with endometriosis according to the presence or absence of pelvic pain. *To look at prevalence of depression in relation to CPP, age, marital status, No. of children & use of medication 	<ul style="list-style-type: none"> *Quantitative *Cross sectional *prospective study <p>Outcome measures used:</p> <ul style="list-style-type: none"> *BDI 	<ul style="list-style-type: none"> *High prevalence of depression in pain group. *86% in CPP group 38% pain free group *Only CPP sig. associated with depression *Use of hormonal or non-hormonal medication was unrelated to prevalence of depression in either group. 	<ul style="list-style-type: none"> *CPP *NOT medication *NOT demographics 	<ul style="list-style-type: none"> *Degree of pain and depression not investigated *Set in a developing country may influence levels of depression.
15	Low et al., (1992) UK	<ul style="list-style-type: none"> *N=40 *Women diagnosed with endometriosis with CPP *Recruited from gynaecological clinic *Severity of endometriosis classified according to AFS classification 	<ul style="list-style-type: none"> *To examine the nature of self-reported pain of endometriosis patients in relation to severity of endometriosis and other psychological variables. 	<ul style="list-style-type: none"> *Quantitative *Cross sectional *Assessed blind to diagnosis. *Multiple regression used to analyse data <p>Outcome measures used:</p> <ul style="list-style-type: none"> *BDI *Golombok Rust Inventory 	<ul style="list-style-type: none"> *Extraversion & psychiatric morbidity most predictive of present pain intensity & total pain score for endometriosis patients. *Severity of endometriosis not related to pain ratings or other psychological variables 	<ul style="list-style-type: none"> *NOT severity of endometriosis *pain 	<ul style="list-style-type: none"> *Small sample size *Does not indicate how many participants in each group when divided in severity classifications.

				Marital State *Eysenck Personality Questionnaire (EPQ) *State Trait Anxiety Inventory (STAI) *GHQ *SF McGill Pain Questionnaire.	*BDI scores: -minimal endometriosis (16.4) -mild endometriosis (11.7) -mod/severe (17.3) Relatively high BDI scores *In comparison to normative data, psychiatric morbidity more prevalent.		
16	Low et al., (1993) UK	*N=81 *sample split into 2 groups: i)women diagnosed with endometriosis with CPP (n=40) ii)women with other gynaecological problems with CPP (n=41) *Consecutive referrals to gynaecological clinic *14 women excluded because they did not have pelvic pain.	*To evaluate the psychological profile of pelvic pain pats with endometriosis compared to pelvic pain patients with other gynaecological disorders.	*Quantitative *Cross sectional *Assessed blind to diagnosis. *Analysis of covariance Outcome measures used: *BDI *Golombok Rust Inventory Marital State *Eysenck Personality Questionnaire *State Trait Anxiety Inventory *GHQ *SF McGill Pain Questionnaire.	*No sig. relationship found between duration of pain & the various psychometrics *No sig. between endometriosis patients with differing severity of physical pathology on pain or psychological state *No group differences on BDI, both groups falling within mild –minimal range. *Both groups had neuroticism & psychiatric morbidity scores higher comparison to normative data.	*Pain *NOT duration of pain	*No pain free control group.

					*Both groups satisfactory marital status		
17	Marques et al., (2004) Brazil	*N=60 *Surgically diagnosed endometriosis *consecutive sampling of women attending outpatients endometriosis clinic *Grouped according to stage of disease.	*To assess QOL in women with pelvic pain associated with endometriosis and to compare the different stages of endometriosis.	* Quantitative *Cross sectional *Descriptive study Outcome measure used: *SF-36 Health survey (validated for Brazilian Portuguese language)	*Overall, poor quality of life. * No correlates found between life parameters and level of pain. *Women with moderate or severe endometriosis scored better for emotional aspects and mental health. *Role limitations (physical and emotional) most affected. *Emotional aspects and mental health variables showed low scores overall. *Exercise related to good mental health	*Stage of disease *Exercise *NOT level of pain	*Does not state how classified severity of disease. *Does not give correlational data. *Does not state how measured level of pain *Recruited from specialist clinic, therefore may incorporate the more severe cases of endometriosis and hence not be representative. *Set in a developing country may influence levels of depression. *SF-36 Is a generic questionnaire and may lack sensitivity
18	Mathias et al., (1996) USA	*17, 927 households contacted. *88.8% agreed to take part *CPP group (n= 773) made up of: i)diagnosed with endometriosis (n=74) ii)gynaecologic diagnosis (n=149)	*To determine the prevalence of CPP in US women and examine its association with HRQOL, work productivity and health care utilisation.	*Quantitative *Large-scale population based study. *Telephone administered questionnaire *Questionnaire QOL based upon Medical Outcomes Survey long form	*Respondents with CPP reported sig. lower scores for general health than those not in pain. *Women who had been in pain for the past month (n=557) showed that: - 56% report that CPP interfered with mood moderately, quite a bit or	*Pain *Life interference	*Reported diagnosis, diagnosis could not be clinically confirmed *Sampling restrictive by only including women who have a phone and were English speaking. *Pain free control group – pain free women did not complete QOL, work

		iii)non-gynaecologic diagnosis (n=31) iv)no diagnosis (n=472) *Recruited via random telephone digit dialling of US households *Recruitment based upon pelvic pain within past 3 mths that persevered for 6 mths. *Control group – pain free women, however they did not complete QOL, work productivity and health care utilisation measures.			extremely. -47% reported feeling ‘down-hearted and blue’ most, some or all the time. -88% experienced dyspareunia. *Women diagnosed with endometriosis reported greatest health distress, higher scores for dyspareunia and greatest interference with activities because of pain. *QOL affected most in endometriosis group *No sig. differences in mental health scores between groups. *Mental health score for endometriosis = 63/100, suggesting reasonable mental health.		productivity and health care utilisation measures and therefore could not conduct comparison.
19	Peveler et al., (1995) UK	*N=91 *Sample spilt into 2 groups: i)women with medically unexplained pain (n = 51) ii)women with	*To compare groups of laparoscopy negative pelvic pain patients & patients with laparoscopically	*Quantitative *Cross sectional *AFS score obtained Outcome measures used: *BSI *EPQ	*No sig. difference in mood or personality characteristics between groups. *About 35% of both groups had global severity indices suggestive of	*NOT disease severity *Pain	*Lack of pain free control group *Interviews conducted on the same day as laparoscopic surgery could be skewed due to emotional effects of

		<p>endometriosis (n= 40)</p> <p>*Recruited from identified pre-laparoscopy via theatre lists and patient notes on the inpatient ward and day unit.</p>	<p>confirmed endometriosis.</p>	<p>*Social adjustment scale</p> <p>*VAS</p> <p>*Interviewer rated pain index</p>	<p>probable mood disorder.</p> <p>*41% of Group I) and 70% of Group ii) reported suffering from 'nerve trouble', stress or feeling depressed.</p> <p>*Endometriosis group had greater social dysfunction</p> <p>*Greater disease severity was not associated with more severe mood symptoms</p>		<p>surgery and impact of diagnosis. Also may not have be given enough time to give informed consent.</p> <p>*Other interviews were conducted at participants home – variation in setting may also influence findings.</p>
20	<p>Walker et al., (1989)</p> <p>USA</p>	<p>* N=69</p> <p>*Sample split into 2 groups:</p> <p>i)women with endometriosis (n= 14)</p> <p>ii)women without endometriosis, including chronic pelvic pain patients and pain free controls (n=55)</p> <p>*Endometriosis diagnosed with a laparoscopy</p> <p>*Recruited from hospital, O&G dept & private practice</p> <p>*sequentially selected</p>	<p>*To determine the relationship between endometriosis & affective disorder.</p>	<p>*Quantitative</p> <p>*Cross sectional</p> <p>*Psychiatric evaluation using NIMH Diagnostic interview schedule (administered blind to laparoscopy results)</p> <p>*Family history research diagnosis criteria (inter-rater reliability checks)</p>	<p>*No sig. differences in prevalence of affective disorder (bipolar illness, major depression, alcohol abuse, CPP, 1st degree relatives with affective disorder diagnoses & histories of sexual abuse)</p>	N/A	<p>*Low sample number in endometriosis group.</p> <p>*Diagnosis based on psychiatric interview rather than psychometric tools</p> <p>*Comparison group is a mixture of pain and pain free participants, would have been useful to separate these variables out.</p>

21	Waller & Shaw (1995) UK	<p>*N= 117</p> <p>*Split into 4 groups:</p> <p>i)Control group-sterilisation/ no pathology (n=38)</p> <p>ii) patients with infertility & mild endometriosis (n=31)</p> <p>iii) patients with mild symptoms with at least 1 classic symptom (n=18)</p> <p>iv) patients with pelvic pain symptoms but no pathology (n=30)</p> <p>*Recruited tertiary referral centres for endometriosis.</p>	<p>*To investigate whether there are psychological differences between women with symptomatic as opposed to asymptomatic mild endometriosis.</p>	<p>*Quantitative</p> <p>*Cross sectional</p> <p>*Questionnaires administered blind to laparoscopy results</p> <p>Outcome measures used:</p> <p>*BDI</p> <p>*STAI</p> <p>*Golombok Rust Inventory Marital State</p> <p>*Endometriosis symptom questionnaire</p>	<p>*None of the groups total BDI scores met clinical significance (>13).</p> <p>*Group iii) & iv) had sig. higher mean BDI scores than Group i) & ii)</p> <p>*Proportion of BDI scores for each group that meet clinical cut off (>13):</p> <p>i)7.9% ii)13% iii)23.5% iv) 30%</p> <p>*There was no sig. difference on BDI between pelvic pain (iv) & endometriosis groups (iv). Both above cut off.</p> <p>*Groups iii) & iv) had higher scores for infrequent sexual intercourse than Groups i) & ii).</p> <p>*Women with endometriosis exhibited mild disorders of sexual dysfunction.</p> <p>*Women with symptomatic endometriosis had higher scores for dyspareunia &</p>	<p>*Pain</p> <p>*NOT infertility</p>	<p>*Does not state sampling strategy</p> <p>*Recruited from specialist clinic, therefore may incorporate the more severe cases of endometriosis and hence not be representation sample</p> <p>*Does not indicate whether infertility controlled for within the symptomatic groups.</p>
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					pelvic pain		
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Appendix C

Principal Investigator's story of endometriosis

Endometriosis came into my life about 5 years ago when my sister was diagnosed after having a laparoscopy and laser treatment. This was the first I knew that she had been having any problems, although now I know that she had been suffering in silence since she was a teenager with chronic pelvic pain, heavy bleeding and nausea. No one in the family knew. At this time, I had no idea what endometriosis was, I had never heard of it before and I knew nothing about its effects. I was worried about my sister and I guess I was also worried that I could develop it or that I may have fertility problems of some sort of another too. Things at my age that you don't really think about until something like this comes up.

It was surprising that once she was diagnosed, how many other people we knew disclosed that they had endometriosis or knew someone with it, emphasising its general concealment within society.

My sister told me stories about the endometriosis, for example, how it had caused excruciating pain leading to hospital admissions. Hearing about her being in that much pain upset me and left me feeling quite powerless and guilty. Hearing about her negative experiences with services, such as not being listened to or believed, the repeated visits to the GP and the consequent delay in diagnosis made me feel really angry.

Looking back, I think at one stage endometriosis did impact on my sister's womanhood in terms of how she felt about herself as a woman due to uncertainties surrounding fertility and feeling unfeminine. However, these worries seem to have faded now.

As time as gone on, my sister has been through subsequent operations due to the reoccurrence of endometriosis. Her journey has been a long one and probably not yet finished, however along the way she has coped, adapted, become resilient and empowered. She has built up many strategies to manage the endometriosis and its effects and as she would say 'you've gotta deal with it'.

Therefore, I know of some of the difficulties that endometriosis can bring to a women's life from a personal perspective including the impact on self, challenges and barriers into services, the benefits of treatment and how it can be successfully lived with.

I think my sister's experiences were similar to that of the participants I interviewed. Many of the themes found in the analysis resonated with my sister's experiences, such as difficulties with services, the concealment of endometriosis from others and it being a secret condition, not often publicly talked about.

Appendix D

Participant Information Pack

Covering letter from Consultant Gynaecologist

[Date]

[Potential participants address]

Dear *[name]*

I am writing to inform you of a research project that is taking place within our department. This project is being conducted by Fay Osborne from the University of Leicester and it is exploring the effects of endometriosis on womanhood. I wondered whether you would be interested in participating in this project and sharing your experiences. I have enclosed further information describing the purpose of the research and what would be involved if you decided to take part. If you would like to be involved in the project, please contact Fay Osborne as indicated in the Participant Information Sheet.

Yours Sincerely

[name]

Consultant Obstetrician & Gynaecologist

LETTER OF INVITATION

Dear

My name is Fay Osborne and I am a Trainee Clinical Psychologist from the University of Leicester. I am writing to invite you to take part in a research study investigating the effects of endometriosis on womanhood.

I have enclosed an information sheet, which explains everything you need to know about the research study and instructions of what to do next if you are interested in taking part.

Thank you for taking the time to read this letter.

I look forward to hearing from you!

Yours Sincerely

Fay Osborne

PARTICIPANT INFORMATION SHEET

Endometriosis and womanhood

A study to explore how endometriosis affects you as a woman...

What's the purpose of the study?

Endometriosis is a relatively common condition, yet few people have heard of it or have an understanding of the impact that it can have on a woman's life. This study aims to explore your experiences of endometriosis to gain an insight into how the condition affects your sense of womanhood i.e. your identity as a woman. Topics such as the impact on femininity, self-identity, sexuality, relationships and motherhood will be explored. Furthermore, this study will consider how gaining an understanding of the effects of endometriosis on womanhood may be significant for health care services, possibly having implications on management of care, the doctor – patient relationship and health professionals' recognition and understanding of the impact of endometriosis on a woman's life. Overall, the study aims to promote awareness in society and health care services about endometriosis; its impact on womanhood and the associated consequences.

Who is doing the research?

Principal Investigator: Fay Osborne

I am from the University of Leicester and am carrying out this research as part of an educational qualification. If you decide to take part, I will be the person who interviews you. If you would like to take part I can come and see you, so that you can ask any questions or discuss any concerns you might have about taking part. Alternately, we could discuss the study further on the telephone. My contact details are given at the end of this leaflet. Additionally, please feel free to discuss this study with other people to help you decide whether to take part such as your family, hospital consultant, a member of Patient Advice and Liaison Service (PALS; 0116 256 3100) or a member of the Research and Development Office.

Can anyone take part?

To take part in this study, it is important that:

- You are 16 years or over,
- Have received a diagnosis of endometriosis based on laparoscopic surgery.
- Have experienced some symptoms associated with endometriosis.

What will I have to do if I agree to take part?

If you agree to take part, I will ask you to fill out two brief forms to collect some information about you and your endometriosis and then I will invite you to attend an interview.

Forms:

- 1) A personal details form to gain some basic demographic information.
- 2) A history of endometriosis form to gain some information concerning your endometriosis and associated symptoms.

These forms can be sent out to you in advance of the interview so that you can fill them out and bring the completed forms with you to the interview or extra time can be allocated so that you can fill out the forms either before or after the interview.

All your personal information will be kept confidential and will be anonymised.

Interview:

I would like you to take part in an interview with me. The interview should last between 60 - 90 minutes and it will be recorded. You can choose where you would like the interview to be held e.g. your home, on one of the hospitals sites, or at the University of Leicester. Any travel expenses will be reimbursed.

Consent

‘Consent’ means agreeing to take part in this research study after you have been given all the necessary information, given time to consider the information and have discussed the study thoroughly with myself. If you decide to take part you will be given this information sheet to keep and will be asked to sign a consent form before the interview commences. You can change your mind at any stage and can leave the study at any time

without giving a reason. Any information collected at that point would be removed from the study.

Whether you decide to take part in the study or not, your current medical care will not be affected.

Confidentiality

‘Confidentiality’ means that all information collected during the course of the research study will be kept private. The only time that confidentiality would be broken would be if I was worried that you or someone else was in danger, or at risk of being hurt. All information collected and final reports will be anonymised, therefore all personal details will be removed so that you cannot be recognised. Direct quotations will be used in final reports, however pseudonyms will be used so that your identity is protected. All information collected will be kept safely secured and data will be destroyed after five years of the study being completed. As part of good practice, it would be necessary for me to notify your hospital consultant that you are taking part in this study.

What happens if I become upset?

Due to the effects of endometriosis and its impact, it is possible that talking about your experiences may be upsetting. If you become upset during the interview, we can take a break or stop the interview completely. You have the right to withdraw from the study at any time. After the interview, I will review the interview with you and check how you are feeling. If necessary, I may suggest that you contact your GP or hospital consultant for further support, questions/concerns or information. You will also be given the contact details of support agencies and other relevant organisations for further support and information should you need it.

What if something goes wrong?

Medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

After the research has finished...

It is anticipated that the study will be completed by June 2008. After the study has finished, you can decide if you want me to inform you of the study findings. This will involve sending you a written summary, outlining what I have found. The findings will also be shared with all the health professionals involved with the study. I would also like

to send the results of this study to the National Endometriosis Society and other endometriosis related organisations, so that the findings can be shared with other women with endometriosis. Additionally, any other opportunities to present the study findings to other health professionals or the general public will be used to increase awareness of endometriosis and its impact on a woman such as at conferences or by writing a journal article.

If you are interested in taking part...

Please fill in the reply sheet on the next page and send it back me in the envelope provided and I will contact you to arrange a meeting to discuss the research further and answer any questions you may have.

Contact for further information

If you would like more information or would like to discuss this study further, please contact me,

Thank you very much for reading this leaflet.

I hope to hear from you soon!

Fay Osborne

Appendix E

PERSONAL DETAILS

Date: / /

PLEASE WRITE IN BLOCK CAPITALS

SECTION 1: PERSONAL DETAILS	
1.1. Surname / Family name:	
1.2. Other names:	
1.3. Mrs / Ms / Miss / Other:	
1.4. Date of birth:	
1.5. Age:	
1.6. Ethnicity:	
1.7. Religion and spirituality	
1.8. Address:	
1.9. Postcode	
1.10. Telephone Number (Home):	

1.11. Telephone number (Mobile):	
It may be necessary to contact you regarding the study, please indicate what would be the most convenient time to telephone:	
SECTION 2 : RELATIONSHIP STATUS	
2.1. What is your relationship status?	Please tick ✓
Married:	
Living with partner:	
Boyfriend/ girlfriend:	
Single:	
Other:	
If you are in a relationship, how long have you been together?	

SECTION 3: CHILD STATUS	
(Please circle answer)	
3.1. Do you have any children?	<div>YES</div> <div>NO</div>

Section 4: Education & Employment	
4.1. What level of educational qualification did you reach?	Please tick ✓
No qualifications:	
GCSE or equivalent:	
A' Levels or equivalent:	

University degree	
Postgraduate qualification:	
Other (please state):	
4.2. Do you have a job? (Please circle answer)	YES NO
4.3. If Yes, what is your job?	
4.4. Is it full time or part time? (Please circle answer)	F/T P/T
4.5. How many hours do you normally work each week?	

SECTION 5: SUPPORT	(Please circle answer)
5.1. Are you a member of the Endometriosis UK? (formerly known as the National Endometriosis Society) (Please circle answer)	YES NO
5.2. Do you go on endometriosis message boards or chat forums on the internet? (Please circle answer)	YES NO
5.3. Are you a member of an endometriosis support group? (Please circle answer)	YES NO

THIS INFORMATION WILL BE KEPT CONFIDENTIAL AND WILL BE
SECURELY STORED.

THANK YOU FOR COMPLETING THIS FORM

Appendix F

HISTORY OF ENDOMETRIOSIS FORM

Name:.....

Date: / /

SECTION 1: DIAGNOSIS

1.1. How old were you when you first noticed your symptoms?

1.2. How old were you when you were diagnosed with endometriosis?

Section 2: symptoms

2.1. What are your main symptoms that you believe are connected to endometriosis?

Please tick ✓
(further comments are welcome)

Pelvic pain:

Back pain:

Pain elsewhere in the body:

Pain during sexual intercourse:

Headaches

Fatigue:

Abdominal bloating:

Diarrhoea:

Constipation:

Painful urination:

Nausea:

Vomiting:

Mood swings:	
Heavy bleeding:	
Irregular periods:	
Others (please state):	
2.2. Out of the symptoms that you have ticked, which do you find the most distressing? (state more than one symptom if applicable)	
Section 3: Fertility	
Please circle answer	
3.1. Do you have any fertility difficulties?	<div>YES</div> <div>NO</div> <div>Don't know</div>
3.2. Are you currently trying to have a family?	<div>YES</div> <div>NO</div>
3.3. Are you receiving fertility treatment?	<div>YES</div> <div>NO</div>
section 4: treatment	
4.1. What, if any, medical treatment for endometriosis have you received?	Please tick ✓
No treatment:	
Surgery:	
Medication:	
Other (please state):	

4.2. Please give a brief summary of the medical treatment that you have received in the space below.
(Please continue on page 4 if you need more space to respond)

4.3. How satisfied were you with your medical treatment? (Please rate on the scale below)

(Please continue on page 4 if you need more space to respond)

Dissatisfied

Quite Satisfied

Satisfied

Very Satisfied

1

2

3

4

Please comment:

section 5: additional management strategies

5.1. What, if any, other methods or strategies do you use to manage your symptoms?

Please tick ✓

No additional management strategies used:

Over the counter painkillers:

Dietary amendments:

Complimentary therapies:
e.g. reflexology, herbal medicine, massage,
aromatherapy, homeopathy, acupuncture, reiki,

Relaxation / Meditation:

Hot baths:

TENS machine

Exercise:

Others (please expand)

THIS INFORMATION WILL BE KEPT CONFIDENTIAL AND WILL BE
SECURELY STORED.

THANK YOU FOR COMPLETING THIS FORM

continuation sheet

Please continue on this page if you need more space to respond to questions.

Appendix G

Provisional interview schedule

1. Background

- a) Can you give me a brief overview of your experiences of having endometriosis.**
- b) What does having endometriosis mean to you?**
- c) What does the term ‘womanhood’ mean to you?**

2. Effects of endometriosis (including treatment) on womanhood

- a) How does endometriosis affect you as a woman?**

Prompts: gender related roles, female roles in society, physical differences (e.g. menstruation, fertility, feelings towards the body), femininity, identity as a woman.

- b) Does endometriosis affect your sexual relationships or sexuality?**

Prompts: sex drive, enjoyment and satisfaction, physical difficulties, physical attractiveness, identity as a woman, relationship with partner (if in a relationship).

- c) Can you tell me how endometriosis affects your sense of motherhood?**

Prompts: female roles in society, fertility, interaction between motherhood and womanhood, identity as a woman.

d) Overall, do you think that endometriosis has changed how you feel about yourself?

➤ If so please give a description.

Prompts: self-esteem, confidence, identity, changes over time

e) Do you think that having endometriosis has changed the way other people perceive or feel about you as a woman?

Prompts: partner, family, friends, work colleagues, health professionals, society.

Prompts: support, attitudes, expectations, social norms

3. Impact on life

a) How have the effects of endometriosis impacted on your life?

Prompts: home, work, social, relationships, roles, psychological difficulties.

b) To what extent do these effects on your life impact on your sense of womanhood?

4. Implications for services

a) Do you think that the issues raised related to the effects of endometriosis on womanhood are important?

Prompts: self-esteem, psychological difficulties, sexual difficulties, relationship Difficulties

b) Have these issues been discussed with your doctor/specialist?

If Yes:

- Was this discussion helpful? How was it helpful?
- What differences (if any) did it make to you or your care that these issues had been acknowledged and understood by your doctor/specialist?

Prompts: management of care, doctor-patient relationship, feelings towards self

- Was it difficult to discuss these issues with your doctor/specialist? What would have made the discussion easier/harder?

Prompts: gender of the doctor/specialist, time, understanding of endometriosis and its impact.

If not:

c) Would you have liked to have had the opportunity to have discussed these issues?

- If not, why not?
- What differences would have been made to your care if these issues had been acknowledged and understood by your doctor/specialist?

Prompts: management of care, doctor-patient relationship, feelings about self

d) Do you have any suggestions of how services could be improved to take into consideration these issues?

Prompts: time, listened to, referral to counsellor/psychologist, holistic person centred assessment, awareness of gender stereotypes/societal influences

- e) **What do you think doctors/specialists should be aware of or acknowledge when meeting with women with endometriosis?**

5. Additional

Is there anything else you would like to discuss that we haven't covered?

Appendix H

Research Approval

(letter from University Hospital of Leicester R&D office granting approval)

Appendix I

Ethics Approval

(Letter from National Research Ethics Service granting approval)

Endometriosis and womanhood

Participant Consent Form

Principal Investigator: Fay Osborne

This form should be read in conjunction with the Participant Information Sheet, Version 1, dated 12th August 2007.

I have read the Participant Information sheet.

☐

I have had the opportunity to discuss the details of the study with Fay Osborne and ask any questions. I understand what will be required if I take part in the study.

☐

I understand that the interview will be recorded. I understand that all information collected for this study will be kept in a safe and secure place and that the information I give will be used for this study only.

☐

I understand that the information I give will be confidential, unless there are concerns regarding risk.

☐

I understand that I can change my mind and withdraw from the study at any time without justifying my decision.

☐

I understand that taking part in this study will not affect my medical care.

☐

I AGREE TO TAKE PART IN THIS PROJECT

☐

Name of participant

Date

Signature

I confirm I have explained the nature of this study, as detailed in the Participant Information Sheet, in terms, which in my judgement are suited to the understanding of the patient.

☐

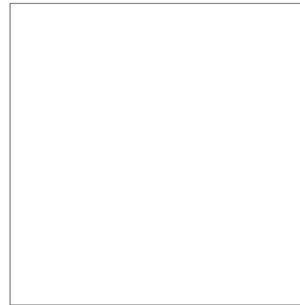
Name of Principal Investigator
Signature

Date

When completed, one copy for participant, one copy for the site file and one copy for medical notes.

Appendix K

Contact details for support and information agencies



ENDOMETRIOSIS SUPPORT

*Endometriosis UK (National
Endometriosis Society)*
www.endo.org.uk

*Endometriosis UK is the leading UK charity that supports
women living with endometriosis. It provides services that
enable those with endometriosis to understand their disease*

Helpline: 0808 808 2227

	and to take control of their condition. These services include Local Groups and a free UK Helpline, both of which are staffed by trained volunteers.	
Endometriosis.Org www.endometriosis.org	Endometriosis.org is the global platform for news and information in endometriosis. It facilitates collaboration and information sharing between women with endometriosis, physicians, and scientists. It delivers the most factual, up to date, evidence based information about endometriosis.	
Endometriosis SHE TRUST (UK) www.shetrust.org.uk	Endometriosis SHE TRUST offers help, information and support to women with endometriosis and interested others	t 08707 743665 Email: shetrust@shetrust.org.uk
Endometriosis in the UK – you're not alone www.endometriosis.org.uk	This site is a message forum, which brings together women with endometriosis, to offer support to each other and their partners. On this site there are various stories from women with endometriosis and general information about the condition and useful links to other sites.	
HEALTH AND FERTILITY SUPPORT		
NHSDirect www.nhsdirect.nhs.uk	NHS Direct provides 24-hour health care advice - delivering telephone and e-health information services day and night direct to the public.	t 0845 4647
Hysterectomy Association	The Hysterectomy Association provides support and	Email: info@hysterectomy-

www.hysterectomy-association.org.uk	information to women across the world. This site provides information about having a hysterectomy, gives perspectives from other women that have already had a hysterectomy and offers practical hints and tips about the operation and for recovery.	association.org.uk
Infertility Network UK www.infertilityNetworkUK.com	INUK is committed to providing a comprehensive support network to its members and to all those affected by infertility by actively promoting INUK services. This site provides authoritative information, and practical and emotional support.	s 08701 188088
UK fertility + parenting forum www.fertilityzone.co.uk	Message forum regarding fertility and parenting	M08701 188088
PAIN SUPPORT		
The British Pain Society www.britishpainsociety.org	Go into 'For patients' section for information that may be of use to people suffering with pain, including a list of UK-based patient organisations, a frequently asked questions section and a suggested reading section.	
Chronic pain management www.painmanagement.org.uk	For information on generic chronic pain management.	
EMOTIONAL AND MENTAL HEALTH SUPPORT		
Depression alliance	Depression alliance works to relieve and to prevent	Depression Alliance does not

www.depressionalliance.org	depression by providing information and support services to those who are affected by it via our publications , supporter services and network of self-help groups for people affected by depression.	currently run a helpline but you can call the information pack request line on: 0845 123 23 20 to request an information pack.
Samaritans www.samaritans.org	<i>The Samaritans is available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress or despair, including those which may lead to suicide.</i>	08457 90 90 90 Usual hours open to receive callers: 8.30am - 9.30pm Email: jo@samaritans.org local branch: 1a Elmfield Avenue Leicester, LE2 1RB
SANE www.sane.org.uk	SANE is one of the UK's leading charities concerned with improving the lives of everyone affected by mental illness. SANEline is SANE's national telephone helpline offering support and information to callers throughout the UK.	SANEline: S 0845 767 8000
M.I.N.D. www.mind.org.uk	MIND is a mental health information service, offering information, support and understanding on mental health issues.	MindinfoLine Open Monday to Friday 9.15am to 5.15pm t 0845 766 0163 Email: info@mind.org.uk

RELATIONSHIP SUPPORT		
Relate www.relate.org.uk	<i>Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through it's website.</i>	Leicester Branch: 83 Aylestone Road, Leicester, LE2 7LL 7 0116 254 3011 Email: info@relateleics.org
Marriage care www.marriagecare.org.uk	<i>Marriage care aims to help people prepare for, achieve and sustain successful marriages and to support them should their marriages break down.</i>	t 0800 389 3801

Additionally, you can also contact your GP or hospital consultant for further support and information.

Appendix L

Steps on how to conduct IPA (adapted from Smith, Jarman & Osborn, 1999)

Step	
1	Preparation of transcript Once the interview has been transcribed, the transcript needs to be page numbered and line numbered. Wide margins need to be set on either side of the text for annotation. Double spacing is beneficial.
2	Initial notes Read through transcript and annotate anything of interest or significance in the left hand margin. E.g. summarising, paraphrasing, connections that come to mind, preliminary interpretations, sense of the person coming across.
3	Development of emerging theme titles Re-read through the transcript and transform initial notes into concise phrases in the right hand margin. These phrases should articulate something about the identified concept.
4	Clustering and connection of emergent themes (subthemes) List emerging theme titles into chronological order and look for connections. Place emergent themes into analytical order by clustering together related emerging themes. Constant checking of themes with the data is essential.
5	Development of master (superordinate) themes Label each cluster of related emerging themes with an overarching master theme that conveys their connection. Produce master list of themes with the associated subthemes.
6	Table of master themes Construct a table outlining the master themes, their associated subthemes and an identifier for each theme, which indicates where in the transcript instances of the theme can be found. An identifier includes an extract from the transcript with the associated page and line number.
7	Continuing the analysis with the following interviews Analysis of subsequent interviews is done using the same steps outlined. The master theme list from the first interview can be used to analyse subsequent interviews, looking for more instances of the themes already identified and as well as new ones arising. If new themes emerge in subsequent interview, they should be tested against earlier transcripts.
8	Master table of themes Once all the transcripts have been analysed, the main master themes can be presented in a table. Data should be prioritised, choice of master themes does not need to be based on prevalence but rather richness and significance. Again themes should be illustrated with extracts from the data and identifier (which interview, page number and line number).

Appendix K

Development of themes

(raw data from transcripts, clustering of themes and preliminary analysis)

Appendix N

Additional verbatim extracts

The fluctuating and unpredictable experiences of endometriosis	
Identifier (Participant: page: line)	Extract
Rebecca: 1: 22-30	“I was about... 19... 20 I had my first laparoscopy and erm they diagnosed it then erm they zapped it away erm and I was already for a bit and then I started having problems again and I had another procedure, had another laparoscopy a couple of years later and they didn’t find any endometriosis at that stage and sort of adhesions and things and they sorted all that out ... and then the problems still continued so I had a third laparoscopy in October last year and erm they found quite a lot of endometriosis, it had come back”
Olivia: 28: 693-695	“At one point I said to the doctor I just don’t know where I’m going at the minute with this, I said I’m just going backwards and forwards and round and round”
Olivia: 11: 269-273	“I think it’s always at the back of my mind, can this come back and then having had the treatment twice now”
Danielle: 12: 277-278	“I say not knowing what what the future holds is the most frustrating... thing... but I’m still here”
Rebecca: 3: 70-86	“What if it spreads obviously because it’s not something that is necessarily curable erm and am I going to have to keep going through this process every couple of years, going into hospital, having procedures because obviously the more times you have a procedure, the more risky it gets and you know, they’re going through scar tissue and then you end up with adhesions and they’re then trying to sort that out and it seems to be a sort of circle going on and on erm so I do worry about will it affect fertility, will I have to keep going through surgery, you know, will I still get this pain all the time and have time off work and things erm but unfortunately there’s no way of, they can reassure you against that because it’s still fairly unknown, as to, there’s not that much in respect of treatment that they can offer you so it’s you know, it’s not something that I constantly worry about, think about everyday but when you get the pain your thinking, you know, it’s at the back of your mind”
Olivia: 1: 13-17	“It is a lot more manageable than it ever was. I, you know, I don’t think it’s gone completely, and I still have days where I don’t feel 100% but I I live with it now erm and on that basis I suppose that you know it’s just like anything it’s like having arthritis isn’t it or something you just... you adapt”

Olivia: 14: 340-345	“I’ve got endometriosis but it’s no big deal... I’ve just learnt to live with it I think. It’s because I don’t get all the pain. If you took me off the pill again and you spoke to me when I wasn’t on the pill I I would be very very down uhm you know and I I know I would erm weepy and such like but yes because I’ve got it under control you see the more sort of positive side of things I think.”
The journey to motherhood	
Identifier (Participant: page: line)	Extract
Danielle: 3: 61 – 70	“I suppose that means to me, ehm, whether I can have children or not, and that’s something I don’t know, ehm, I know it’s still possible but until you try , but obviously my circumstances now, I’m not with anybody I’m single, ehm... I don’t now but just or I’m always told that the older I get, the harder, it, you know, the possibility could be, uhm, but obviously I’m not about to go and have a child just for the sake of it (<i>laughs</i>) you know, being too old but that has always, that’s always an issue that does worry me, and being 32 , but ehm, I don’t want to leave it too long cos I do want a family but... I think with everything that I went through it’s it’s got to be the right time ... so... Just one of those things that I suppose I’ll find out (<i>laughs</i>) when I do want a baby.”
Lisa: 7: 154-158	“I’ve got to decide in the next year but there’s so many things going on in my life generally that then I’ve got that to think about at the same time and i sort of think... what if this relationship doesn’t work and I end up being pregnant for the sake of being pregnant, that isn’t fair on the baby so”

Olivia: 16: 383-392	“I feel fairly good about myself.... But I’ve not set out to achieve what a lot of woman would, which is to have children. If endometriosis... stopped me from having children when I wanted to have children, I think I could feel very very negative about about myself because I don’t personally care whether I have children, I mean don’t get me wrong I I thought I would have children in my life. I always believed I was going to be a mother and I always thought I’d have, you know, my 2 little children that I’d take to school in the morning and you know, do the coffee morning business and everything. It hasn’t happened that way for me but if endometriosis had stopped that and I’d wanted that, that would have been absolutely devastating”
Ana: 6: 140-144	“I see people out there and I think, you don’t give a shit about your child and yet if that was mine, you know, I would give anything in my power to you know, look after it, get it to excel in life in what whatever way that it needed to sort of thing and I just think life is so shit sometimes, it’s just not fair, it really isn’t fair”
Impact of womanhood	
Identifier (Participant: page: line)	Extract
Danielle: 11: 267-269	“I suppose its hard because when your... that age your only just really becoming a woman so you don’t know, you don’t know yourself really what’s what’s going on and how your suppose to feel”
Ana: 13: 322-328	“I’d say you know I felt really unwell is it possible to go home because I feel so bad and she’d she’d look at me with absolute disgust but then when I found out what I had and then realised I wasn’t being a wimp. She was sort of sympathetic, more so than she had been so it made me feel really uncomfortable the fact that she thought.... That I was being a wimp about having bad period pains and the fact that she frowned...”
Olivia: 34: 830-833	“I am me and I’ve always been me and even at my down time, I’m more affected by my weight than I am by my endometriosis, you know, that, I can’t be seen as far as I’m concerned, nobody can see that I’ve got it” (

Ana: 17: 413-415	"I don't think knowing the endometriosis, knowing that I've got endometriosis made me feel any different esteem wise or anything. I still like the same person"
Ana: 5: 108-109	"the fact that I can't really have children unless I have IVF erm it that makes me feel less of a woman, definitely."
Amy: 17: 414-419	"You just don't feel very feminine, I suppose... It's a very peculiar thing to explain because I mean women's sexual organs aren't on display like men's are but you still feel, well as a woman I'm not quite the way I should be and... Yeah, I suppose in that sense you feel... less of a woman I suppose, which is silly because I'm not."
Helen: 6: 138-139	"I suppose it has there cos it makes me feel like bad about myself that I've got something wrong with me"
Amy: 3: 67-69	"I think I just feel abnormal, different to other women because all of my friends have children, all my relations have children; I am the only one now that doesn't."
Amy: 20: 499- 504	"Its, the medical profession are just more interested in physical symptoms, no, nobody asked me ever... how I felt in myself... at all. It was all very, well we're going to do this and we're going to do that and you fill out your sheet of all your medical history... and its just assumed that you'll just do what they say you should do... and that's it... You know, it's it's their profession, to them it is like that. It is sort of, you're a case"
Amy: 8: 178-182	"I'm still not the same person... at all and our relationship is different; we're not as close as we were which I put to the back of my mind.... Because we had that year where we weren't how we used to be with each other... and its taking, its coming back, its all coming back into place but its, its slow."
Rebecca: 9: 201-24	"you know waking up in the middle of the night absolutely doubled over in agony erm and him not really being able to do anything about it, I think that that's always difficult when your in a relationship and the other person's suffering and you can't help"
Olivia: 24: 575-577	"it upset him as well, I know it did, because he didn't used to like me either being uncomfortable, hurting erm, you know, or upset"
Danielle: 4: 84-88	"the ehm tablets that I went on put me through the menopause so your having hot and cold sweats, ehm, I had, I put on a lot of weight... ehm really bad skin, made you feel really... horrible about yourself to be honest with you, and at sort of 20-21 you not, you know (<i>laughs</i>) it's not good is it?"
Daniella: 7: 161-163	"wasn't interested at all...you didn't, you just, if you feel, if you don't feel good about yourself, how can you see anybody else would be interested, wasn't interested in sex at all."

Helen: 4: 82-91	“there’s been times when we’ve probably nearly split up because obviously sex is quite a big part of a relationship. I mean, obviously there’s other areas as well but that’s where you become very intimate with each other so... it has the main part of endometriosis for me has been the sexual side and that’s it’s been quite a lot of friction between us at times if you like because it’s it’s not that it’s difficult to talk about because [J] is very understanding but I think there’s been times when I’ve like no stop and like pushed him off and then he’s like all grumpy so obviously you can imagine what it must be like.”
Rebecca: 5: 113-115	“you just feel, not inadequate, but it it does get to you a bit that that you know it puts you off wanting to be intimate because there’s the pain and that side of it so it it does have an impact”
Helen: 7: 175-177	“I’m thankful I haven’t got it any worse to be honest, knowing other people that suffer so yeah, I’m thankful in that respect”
Amy: 16: 396-398	“I’m actually calmer and... happier than before. This is crazy now I think about it. It, because it’s changed me and some of the changes are for the better”
Amy: 5: 105-106	“it’s taken me a long time to get back to who I used to be”
Emotional impact of endometriosis	
Identifier (Participant: page: line)	Extract
Ana: 16: 392-400	“People say I’ve changed over the last year, over the last 6 months sort of year, I’m not as bubbly and as out going as I used to be erm I tend to think about things a lot more than I ever did, you know, before it was like water off a duck’s back sort of things, but now things sort of play on my mind a lot more than they used to. I don’t know whether it’s to do with the endometriosis or what. I think I just feel negative erm towards a lot of things but I never used to be like that. I wasn’t like that at all, so I don’t know I don’t like to think that I’ve become a negative person because I’m not really... I’m not an optimist but I’m not a pessimist either”
Ana: 18: 426-431	“there are times when I feel really pants and I just thought erm I think... it’s it’s it’s everything erm when everything, you’ve had bad days at work, I’m having a bad period erm you know, it, you know, and I’ve got money issues or you know everything just comes at once and I sort of think oh I just feel I wanna hide and go to sleep and not, I have, sometimes, I think I just want to go to sleep and never wake up again”

Olivia: 23: 562-564	“yeah that that really upset me because to begin with your told you’ve got something, it’s like I’d never had anything wrong with me before”
Danielle: 5: 110-115	“I think it just because it’s not just, it’s not just sort of a physical thing, it is such an emotional thing and it is so stressful and to try and explain to somebody that has never had it and has never gone through it ehm people just think you have bad periods, that when you have sort of ... 2-3 weeks out of the month when you... feel so... rotten, you know, it’s it’s it is hard to describe but yeah, very low self esteem.”
Danielle: 12: 276-277	“it’s the long term effects that... how it leaves you, you know mentally scarred I suppose really”
Ana: 2: 39-40	“I just felt so low and I thought I’ve had enough. I’m 35 years old, I cry like a baby half the time when it comes to period pains.”
Lisa: 16: 391-393	“sometimes you can feel very low, very tearful, erm it does get you down sometimes. But... you don’t know whether you are putting it down to endometriosis or is it just your hormones”
Amy: 22: 529-532	“When I particularly when I first came home and I came out of hospital, I really could have done with somebody to talk to... because it took a while for everything to sort of sink in; the implications of everything... that he’d told me.... But I’ve coped. I’m alright”

Appendix O

Extract from reflective diary

Reflections post interview with Ana

“Originally, took a while to arrange interview. Worried about interview? Just busy? Unsure about whether to do it? Comes from an ethnic minority – cultural issues did not seem to come up during the interview. Recently diagnosed (in last couple of years) and not started treatment yet.

During interview felt quite sad when she was talking about fertility difficulties – possible countertransference. Shocked by how little information she had been given and lack of knowledge about endometriosis. Emotive interview – feelings of anger and frustration came across to me. Seemed like she was going through different stages e.g. shock and relief after diagnosis, then angry at services once she had come terms with diagnosis. Really angry at services. Had bad experience at GP level, huge delay in diagnosis, issues around being dismissed and trivialised. Very talkative, had a lot to say – does this reflect the anger directed at services? Main impact seemed relate to fertility and how that makes her feel as a woman. Some aspects of denial regarding fertility observed. Does denial reflect the reason why limited information seeking. Good sense of humour – lots of laughing throughout interview. Trying to lighten the tone? Coping mechanism?

Works within healthcare – does this have an impact on story e.g. cynical regarding financial constraints of NHS.”

Appendix P

Suggested journal for submission

(Journal of Health Psychology suggested)