Psychological Variables and Quality of Life in Women with Endometriosis

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1. Introductory Chapter

Chapter one is a systematic review that aimed to investigate predictors of quality in life (QoL) in women who experience chronic pelvic pain (CPP). Twelve papers were considered to be suitable for the review. The area of CPP was chosen for the review, as although QoL has been extensively studied in this patient population, no systematic reviews have been published that have looked at the predictors of QoL.

Chapter two is an empirical paper that examined the relationship between psychological variables and QoL in women with endometriosis using a regression analyses. Endometriosis is believed to be the most common cause of CPP in women (Mounsey, Wilgus & Slawason, 2006) and similarly to CPP has been found to have a detrimental impact upon women's QoL. A key difference between women with a diagnosis of CPP and those with a diagnosis of endometriosis is that pathology is not always present in women with CPP (Weijenborg, ter Kuile, Gopie & Spinhoven, 2008). Often the cause of CPP is not known and women are commonly re-referred between services and undergo numerous medical investigations. Like CPP, management of women with endometriosis frequently involves pain medication and surgery, however guidelines have suggested that women with ongoing pain should have access to specialist pain clinics, which provide an interdisciplinary model of care (Royal College of Obstetricians & Gynaecologists, 2012).

The aim of the empirical paper was to investigate whether four psychological variables were able to predict women's reported QoL, with potential clinical implications regarding the development and adaptation of interventions to include a psychological focus.

The empirical paper will be submitted to the British Journal of Health Psychology for publication. The author chose this journal, as the British Journal of Health Psychology is interested in publishing research that focuses upon the management of chronic conditions,

psychosocial factors of health-related behaviours and psychological interventions. The author felt that the study's aims and findings were appropriate in terms of fulfilling the journals scope and objectives.

2. Chapter One

What Predicts Quality of Life in Women with Chronic Pelvic Pain?

3. Abstract

Background and Objectives: Extensive research has shown that chronic pelvic pain (CPP) can have a detrimental impact on a woman's quality of life (QoL). QoL is a subjective, multidimensional concept that refers to an individuals' perception of their social, emotional, physical and psychological wellbeing. There is currently very little literature exploring the possible psychological predictors of QoL in this patient group. Therefore the purpose of this report was to provide a systematic review of the literature concerning predictors of QoL in women who experience CPP. **Design:** Systematic review. **Method***:* Relevant papers were obtained through scanning five electronic databases and searching references and bibliographic lists. Studies were selected if they included women who had a diagnosis of CPP, included a standardised QoL measurement tool and predictors (psychological, social or clinical features), used a quantitative design and were available in English. A total of 12 studies were eligible for the review. All 12 papers were assessed for their quality using the 16 item Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh, Lawton, Gardner & Armitage, 2011). **Results***:* Similarly to other studies investigating QoL, income, number of years of education, the effect of CPP on a woman's job and having a partner present were found to be statistically significantly associated with improved QoL. The frequency and intensity of pain, sexual dysfunction, comorbid physical health conditions, higher BMI, higher number of physician visits and surgical procedures were statistically related to a lower QoL. Dyspareunia and intermenstrual pelvic pain were both found to be statistically significantly related to a poorer QoL. Having a diagnoses of endometriosis or deep infiltrating endometriosis (DIE) or fibromyalgia were also found statistically to be significant predictors of a poorer QoL. Psychological factors found to be statistically associated with a poorer QoL included increased catastrophizing, depression, anxiety, perception of poorer pain control and a history of sexual and physical abuse and other

lifetime trauma. **Conclusions:** This review has demonstrated that there are a number of possible predictors of poorer QoL in women with CPP. Interventions to target these predictors, may be worthy of further investigation.

3.1. Key Words: Chronic pelvic pain (CPP), endometriosis, gynaecology, quality of life (QoL), systematic review.

4. What Predicts Quality of Life in Women with Chronic Pelvic Pain

Chronic pelvic pain (CPP) is a common condition that affects approximately one million women in the United Kingdom (Baranowski, Lee, Price & Hughes, 2014) and 40% of women experiencing infertility (Reiter, 1990). CPP is defined as pain in the lower abdomen that is constant or intermittent, with a minimum duration of six months (Collett, 2008). CPP is not directly linked to a woman's menstrual cycle or sexual activity (Moore & Kennedy, 2000). In the UK, CPP accounts for 40% of the referrals made to gynaecologists in secondary care (Zondervan et al., 1999) and is identified as a reason for having a hysterectomy in 12-15% of cases (Gelbaya & El-Halwagy, 2001; Howard & Sanchez, 1993; Zondervan et al. 2001).

Endometriosis is reported to be the most prevalent cause of CPP and accounts for approximately 30-45% of this population (Meuleman et al., 2009). Endometriosis is when endometrial-like tissue is present outside of the uterine cavity, which can lead to the development of cysts and anatomical pelvic changes (Kold, Hansen, Vedsted-Hansen & Forman, 2012).

Davies, Ganger, Drummond, Saunders and Beard (1992) reported that CPP costs the National Health Service (NHS) an estimated £158 million a year, with additional economic costs due to high absenteeism from work (Grace & Zondervan, 2006).CPP can have a significant effect on a woman's psychological wellbeing, impacting upon daily functioning,

occupational productivity and personal relationships (Barcelos, Conde, Deus & Martinez, 2010; Dalpiaz et al., 2008; Mathias, Kuppermann, Liberman, Lipschutz & Steege, 1996). CPP has also been shown to have a large impact on a woman's sexual functioning and intimate relationships, with approximately 50-75% reporting dyspareunia (Selfe, Matthews & Stones, 1998), 50% experiencing anorgasmia and postcoital discomfort (Collett, Cordle, Stewart & Jagger, 1998; Richter, Holley, Chandraiah & Varner, 1998). Unsurprisingly, women with CPP frequently report a higher level of psychological distress, sleep disturbance and fatigue compared to women without CPP (Grace & Zondervan, 2004; Kumar, Gupta & Maurya, 2010; Zondervan et al., 2001).

The aetiology of CPP is complex and poorly understood, and frequently no underlying medical condition can be identified (Weijenborg et al., 2008), with an estimated 35% to 40% of laparoscopies failing to detect pathology (Howard, 2000; Swank et al., 2003). Reaching a diagnosis and managing CPP is not a straightforward process, as the CPP can be a symptom of another condition, such as endometriosis, or may be a condition in its own right (Aslam, Harrison, Khan & Patwardhan, 2009; Daniels & Khan, 2010).

CPP has been recognised as one of the most challenging conditions to manage in gynaecology (Walker, 2001), with GPs commonly describing this group of women as "heartsink patients" (McGowan, Pitts & Clark-Carter, 1999). Furthermore, there is a dearth of effective treatments, which mainly consist of analgesics, psychotropic medications, ovarian cycle suppression, surgical intervention including hysterectomy, and cognitive behavioural therapy (Butt & Chesla, 2007). The literature suggests that the recurrence of CPP is high following both pharmacological and surgical treatment (American College of Obstetricians and Gynaecology, 2004; Yap, Furness & Farquhar, 2004). Subsequently, women are commonly not given a definitive diagnosis and are likely to experience cycles of being re-referred between different services, undergoing countless investigations and recurrent

hospital admissions (Savidge, Slade, Stewart & Li, 1998). This can lead to an increased sense of hopelessness and frustration for both the woman and the health professional and also raises questions concerning how the condition should be best managed (McGowan, Escott, Luker, Creed & Chew-Graham, 2010).

Literature investigating chronic pain has illustrated that the traditional biomedical model is no longer adequate when explaining the complex causes of chronic pain (Turk & Holzman, 1986), and that psychosocial factors play an important role in the understanding and management of complex chronic health conditions (Daniels & Khan, 2010). Guidelines produced by the European Association of Urology (Engeler et al., 2013) and Royal College of Obstetricians and Gynaecologists (2012), both recognise the detrimental biopsychosocial consequences of CPP and suggest that treatment should be delivered using a framework of interdisciplinary care. The need to work from a biopsychosocial approach is also stated in the British Pain Society's (Baranowski et al., 2014) care pathway for patients with CPP.

A larger number of studies have been conducted to investigate the impact of CPP on women's QoL. QoL is a subjective, multidimensional concept that refers to an individuals' perception of their social, emotional, physical and psychological wellbeing (Bender et al., 2015). The World Health Organisation (WHO; 1997) defines QoL as:

An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (WHO, 1997, pp.1).

Research has documented that women with CPP have a reduced QoL in comparison to women without CPP (Ferrell, 1995; Romao et al., 2009). Although QoL has previously been studied in this patient group, to date there has been no published systematic review

investigating the predictors of QoL in CPP. Identifying potential predictors of QoL would enable health professionals to gain an enhanced understanding of the biopsychosocial mechanisms that are associated with a poorer QoL in this patient group. Gaining a greater understanding into the possible biopsychosocial factors associated with a poorer QoL could lead to adaptations in the way pain management interventions are developed and implemented by targeting and modifying variables that are believed to have a negative influence on a woman's QoL.

The aim of this systematic review was therefore to determine the predictors of QoL in women with CPP.

5. Method

5.1. Study Identification

An extensive literature search was carried out that screened five electronic databases: CINAHL (2014-2015), MEDLINE (2014-2015), PsychARTICLES (2014-2015), PsychINFO (2014-2015) and the University of Liverpool's Catalogue (2014-2015). Additionally, reference lists and bibliographies of all relevant articles were hand-searched. The search was conducted using the following terms and abbreviations: "Quality of life or QoL or health-related quality of life or functional status AND chronic pelvic pain or CPP or pelvic pain or endometriosis or gynaecolog* or gynecolog* or female health or women's health or dyspareunia NOT pregnancy or males or men or boys".

5.2. Eligibility Criteria

The following inclusion criteria were used: (1) women reporting CPP (2) women with a diagnosis of CPP with or without identified pathology (3) CPP that is reported in papers that have a gynaecological focus rather than another potential cause of CPP, for instance

gastrointestinal, urological and musculoskeletal (4) the study used quantitative methodology (5) a standardised tool was used to measure QoL (6) women were able to offer their experience of CPP through self-report measures (7) the study was required to include predictors (psychological, social or clinical features) (8) the full text was available in English.

The following exclusion criteria were used: (1) women who had malignant conditions (2) studies that focused on infertility or sexually transmitted infections (3) qualitative methodology (4) pregnant women.

5.3. Assessment of Study Quality

Study quality was assessed using the 16 item Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh et al., 2011). Two of the items of the QATSDD were omitted as they applied to qualitative studies and all of the 12 studies in the review used quantitative methodology, so only 14 items were scored. Each item was scored between 0 and 3 and all of the papers were awarded an overall quality rating score that was presented as a percentage. Higher percentages were indicative of better quality research. The tool provided the author with some guidance on how to score each item, but an additional degree of personal judgement was required. The QATSDD has been found to have good validity and inter-rater reliability ($\kappa = 71.5\%$) when assessing studies with diverse designs (Sirriyeh et al., 2012). The quality assessment is illustrated in Table 2.

5.4. Data Abstraction and Synthesis

Similarly to other reviews of QoL, the findings were considered to be unsuitable for meta-analysis, due to the use of multiple measures, heterogeneity of samples and diverse methodological designs (Egger, Schneider & Smith, 1998; Juni, Altman & Egger, 2001).

6. Results

The electronic search of databases identified 7,635 citations and of these there were 52 articles that fulfilled criteria for consideration (Figure 1). The reference lists were then checked for relevant articles and a further 15 citations were checked for suitability. Twelve articles fulfilled criteria for review (De Graaff et al., 2013; Grandi et al., 2012; Johnson, 2011; Laursen, Bajaj, Olsen, Delmar & Arendt-Nielsen, 2005; Montanari et al., 2013; Nunes, Ferreira & Bahamondes, 2014; Petrelluzzi, Garcia, Petta, Grassi-Kassisse & Spadori-Bratfisch, 2008; Rannestad, Eikeland, Helland & Ovarnstrom, 2000; Romao et al., 2009; Sepulcri & Amaral, 2009; Souza et al., 2011; Weijenborg et al., 2008).

Figure 1. Article Selection Process

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        │ 15,270 studies retrieved from   │
        │ database search                 │
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                        │
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        ┌─────────────────────────────────┐
        │ 7,635 retrieved after duplicates│
        │ removed                         │
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┌──────────────────────────────┐         │
│ 7,583 studies excluded follow-│◄────────┤
│ ing screening of titles and   │         │
│ abstracts                      │         ▼
└──────────────────────────────┘  ┌─────────────────────────────────┐
                                   │ 52 full text articles assessed  │
                                   │ for review availability         │
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                        │ From the 52 articles, 15 further potential   │
                        │ studies were obtained from searching their   │
                        │ reference lists = 67 studies in total        │
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                        │ 55 publications excluded:                    │
                        │ 5 studies excluded due to intervention       │
                        │ design                                       │
                        │ 6 studies excluded due to malignant          │
                        │ condition                                    │
                        │ 2 studies excluded due to not being          │
                        │ available in English                         │
                        │ 5 studies excluded due to qualitative        │
                        │ methodology                                  │
                        │ 26 studies excluded due to not               │
                        │ measuring QoL or have used a                 │
                        │ standardised QoL measurement tool            │
                        │ 11 studies excluded due to not including     │
                        │ any predictors                               │
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                        │ 12 publications were assessed for            │
                        │ quality and included in the review           │
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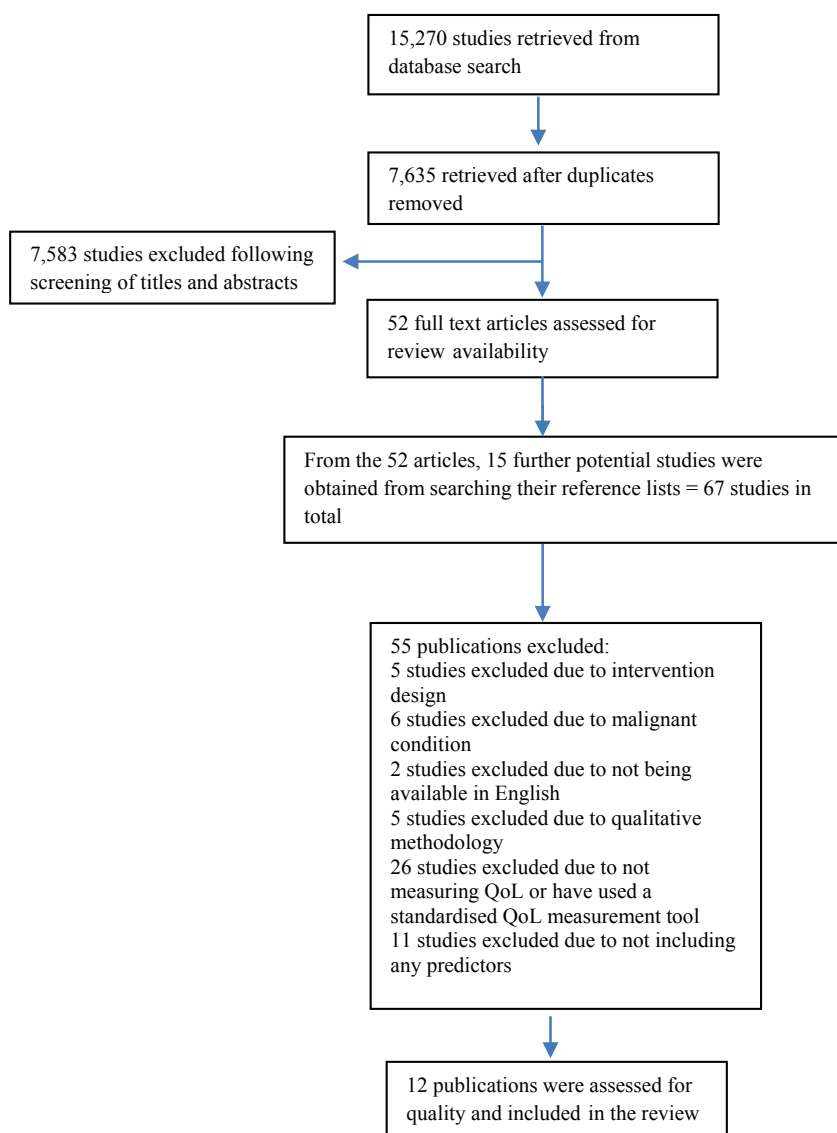
Table 1.

A Summary of the Design and Outcomes for each of the 12 Studies

First author, country, language, year of publication	Primary Focus of Article	Sample characteristics (N)	Control Group	Age	Design	Data collection methodology	Measurement tools	Reported outcomes	Quality Rating
Sepulcri, Brazil, 2009	Depression, Anxiety, Pain and QoL in Endometriosis	(104) women with surgically diagnosed and histopathologically confirmed endometriosis	N/A	19-48 (range), 34.6, (SD) 6.3	Cross-sectional	Questionnaires	Beck Depression Inventory (BDI), Hamilton Rating Scale for Depression (HAM-D), Spielberger State-Trait Anxiety Inventory (STAI), Hamilton Rating Scale for Anxiety (HAM-A), World Health Organization Quality of Life instrument (WHOQOL-BREF), Visual Analogue Scale (VAS)	Age and QoL non-significant *Weak (-) correlation between duration of treatment and QoL (physical domain)** Non-significant correlation between duration of treatment and QoL (other domains) *Weak (-) correlation between current intensity of pain and QoL (physical domain)** Non-significant correlation between current intensity of pain and QoL (other domains) Non-significant correlation between type of pain and QoL	48%
Petrelluzzi, Brazil, 2008	Pain, Stress and QoL in Endometriosis and CPP	(93) Women with surgically diagnosed endometriosis who had experienced pelvic pain for a minimum of seven years	(83) Healthy women who had no pain-related conditions	Endo group: 33.85, (SEM) 1.04 Controls: 30.9, (SEM) 0.92	Case-control Endometriosis group: Intensity of pain was measured daily for one week All participants collected three saliva samples daily for one week and completed the PSQ and SF-36 at one time point	Questionnaires and salivettes.	VAS, Perceived Stress Questionnaire (PSQ), Short Form Health Survey (SF-36)	Non-significant (-) correlation between QoL (mental health domain) and PSQ score Non-significant (-) correlation between pain intensity and QoL (physical domain) Non-significant (-) correlation between pain intensity and QoL Non-significant (-) correlation between pain intensity and general health	57%
Souza, Brazil, 2011	Depression, Anxiety, Pain and QoL in CPP	(57) Women with pelvic pain who were due to have a laparoscopy	N/A	25-48 (range), 35.8, (SD) 8.6	Cross-sectional	Questionnaires	VAS, WHOQOL-BREF, HAM-A, BDI	*Moderate (-) correlation between QoL (psychological domain) and pain intensity** Non-significant (-) correlation between QoL (other domains) and pain intensity	62%

Rannestad, Norway, 2000	Pain and QoL in Gynaecological Disorders	(111) Women with benign gynaecological disorders, due to have a hysterectomy.	(173) Non-hysterectmised women	Patient group: 45.2, (SD) 6.62 Control: Unknown	Case-control	Questionnaires	Quality of Life Index (QLI), McGill Pain Questionnaire (MPQ)	*Frequency of pain had a (-) effect on QoL **** *Interaction effect between pain, group and QoL (health/functioning domain)** No significant difference in QoL between participants with pelvic pain and the control group	57%
Grandi, Italy, 2012	Pain and QoL in CPP	(248) Women with CPP	N/A	31.9, (SD) 7.6	Cross-sectional	Questionnaires	VAS, SF-36, Zung Self-Rating Scale for Depression (SDS)	*QoL was lower in women with intermenstrual pelvic pain than in those with dysmenorrhea**** Non-significant correlation between age and QoL *Weak (-) correlations between QoL and the intensity of intermenstrual pelvic pain***, dysmenorrhea*and of dyspareunia*** *Weak (-) correlations between QoL (mental health domain) and the intensity of intermenstrual pelvic pain*** and dyspareunia*** *Moderate (-) correlation between QoL and intermenstrual pelvic pain**** Non-significant correlation between QoL and dysmenorrhea *Moderate (-) correlations between QoL (physical domain) and intermenstrual pelvic pain*** and dysmenorrhea** *Weak correlation between QoL (mental health domain) and intermenstrual pelvic pain**** *Strong (-) correlation between QoL and depression****	48%
Laursen, Denmark, 2005	Pain and QoL	(40) Women with chronic non-malignant pain triggered by either fibromyalgia or whiplash, low back pain, rheumatoid arthritis or endometriosis	(41) Women who do not have a chronic or recurrent pain syndrome and a VAS score of 0	Patient sample: 28-61 Control group: 42	Case-control	Questionnaires, the Pressure pain threshold (PPT)	SF-36, VAS	Non-significant correlation between the mean PPT and the mean of any SF-36 domains *Moderate (+) correlation between PPT measured from the sites with lowest PPT (non-pain areas) and physical and mental health domains of QoL in all four patient groups (physical*) (mental health*)* *Strong (-) correlations between pain intensity and QoL in all four patient groups (Fibromyalgia/whiplash group* Low back pain group* Endometriosis group** Rheumatoid arthritis group*)*	52%
De Graaff, Holland, 2013	Wellbeing and QoL in Endometriosis	(931) Women with a diagnosis of endometriosis	N/A	14-67 (range), 36.1, (SD) 6.8	Cross-sectional	Questionnaires	World Endometriosis Research Foundation Global Study of Women's Health (WERFGS), SF-36	QoL (physical domain) was positively associated to income and negatively associated to the number of comorbidities, presence of chronic pain, number of physicians consulted, presence of	52%

								dyspareunia, and number of laparotomies Adjusted R² = 0.334, F = 10.65, p < 0.001 QoL (mental health domain) was positively associated with having a partner present and negatively associated to BMI, presence of chronic pain, number of comorbidities and presence of dyspareunia Adjusted R² = 0.221, F = 7.56, p < 0.001	
Weijenborg, Holland, 2008	Pain, Coping Style and QoL in CPP	(84) Women with CPP	N/A	40.2, (SD) 11.3	Cohort Two time points: baseline and 3.2 year follow-up	Questionnaires	VAS, SF-36, Hospital Anxiety and Depression Scale (HADS), Pain Coping and Cognition List (PCCL)	Demographic variables at baseline were not significantly associated with changes in pain intensity and changes in adjustment to pain (physical domain of QoL) *Moderate (-) correlation between catastrophizing, pain intensity and QoL at baseline and follow-up*** *Moderate (+) correlation between perceived pain control, pain intensity and QoL at baseline and follow-up***	69%
Johnson, USA, 2011	Pain, QoL, Abuse, Trauma, and Coping in CPP	(688) Women with CPP (416) Cross-sectional phase (272) longitudinal phase	N/A	Cross-sectional phase: 35.68, (SD) 9.87 Longitudinal phase: 35.56, (SD) 10.51	Cohort Two time points: baseline and 12 month follow-up	Questionnaires	An adapted Sexual and Physical Abuse Questionnaire (SPAQ), an adapted Other Lifetime Trauma Instrument (OLTI), RAND 12-Item Health Survey (SF-12), an adapted Medical Symptom Checklist (MSC), Short-Form McGill Pain Questionnaire (SF-MPQ), Coping Strategies Questionnaire (CSQ), IBS Quality of Life Questionnaire (IBS-QoL)	*Strong (-) correlation between catastrophizing and QoL at time point one (T1)*** *Weak (-) correlation between QoL at T1 and the number of incidents of lifetime trauma*** *Weak (-) correlation between QoL and physical and sexual abuse at T1*** *Moderate (-) correlation between pain T1 and QoL T1*** *Moderate (-) correlation between pain T1 and QoL T2*** *Moderate (-) correlation between pain T2 and QoL T1*** *Strong (-) correlation between pain T2 and QoL T2*** *Moderate (+)correlations between QoL and mental health at T1 and T2*** *Weak (+) correlations between physical health and QoL at T1 and T2*** *Weak correlations between QoL and the number of years of education, number of doctor's visits, number of doctor's visits for pain in the past three months and pain related surgeries at T1 and T2*** *Weak correlations between QoL and history of psychiatric treatment, diagnosis of endometriosis and hysterectomy prior to the study** Catastrophizing contributed significant variance to T1 QoL above that contributed by lifetime abuse, lifetime trauma,*	86%

								health status (physical and mental) and medical symptoms*** Catastrophizing and the number of medical symptoms at T1 were both independent predictors of QoL at T2, with T1 catastrophizing being the strongest predictor; Catastrophizing R²= .17; Full model R²= .29***	
Romao, Brazil, 2009	Pain, QoL, Depression and Anxiety in CPP	(52)Women with CPP	(54) Women without CPP	CPP group: 31.70, (SD) 8.1 Control group: 30.28, (SD) 6.2	Case-control	Questionnaires	VAS, WHOQOL-BREF, HADS	*QoL was significantly higher in CPP participants who did not have anxiety; physical domain***psychological domain*** social relationships domain* environment domain* QoL was significantly higher in CPP participants who did not have depression, physical domain** psychological domain***social domain** environment domain***	43%
Montanari, Italy, 2013	Pain, QoL, and Sexual Functioning in Endometriosis	(182) Women who had preoperative clinical and ultrasound diagnoses of deep infiltrating endometriosis (DIE)	N/A	34.40, (SD) 5.42	Cross-sectional	Questionnaires and transvaginal sonography	Sexual Health Outcomes in Women Questionnaire (SHOW-Q), VAS, SF-36	*Moderate (+) correlation between sexual function (SHOW-Q) and QoL****	69%
Nunes, Brazil, 2014	QoL in Endometriosis and Fibromyalgia	(257) Women with a diagnosis of endometriosis.	(253) Women without any signs or symptoms of endometriosis	Endo group: 34.4, (SD) 5.7 Control group: 33.3, (SD) 6.2	Case-control	Questionnaires, physical examination	American College of Rheumatology (ACR) criteria for fibromyalgia, SF-36	*There was a significant difference between the endometriosis and control group in terms of QoL; physical functioning*** role-physical*** bodily pain*** general health*** vitality** social functioning*** role-emotional** and mental health*** There was no significant difference in QoL between the women with stage 1 and 2 endometriosis compared with those with stage 3 and 4 *In all groups, women who had no pain at any of the points evaluated (fibromyalgia classification) had better QOL compared to the women with pain at one or more points***	52%

Note. Weak correlation *r* = 0.1 - 0.3, Moderate correlation *r* = 0.3 - 0.5, Strong correlation *r* = ≥ 0.5; Significant results *Italicised*, * Significant < 0.05, ** Significant < 0.01, *** Significant ≤ 0.001, non-significant >0.05.
ACR; Wolfe et al., (2010); BDI; Beck, A.T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961); CSQ; Rosenstiel & Keefe (1983); HADS; Snaith & Zigmond (1983); HAM-A; Hamilton, (1959); HAM-D; Hamilton (1960); IBS-QOL; Patrick, Drossman, Frederick, DiCesare & Puder (1998); MPQ; Melzack (1975); MSC; Leserman et al., (1996); QLI; Ferrans & Powers (1993);; OLTI; Felitti et al., (1998); PCCL; Stomp-van der Berg et al., (2001); PSQ; Levenstein et al., (1993); SDS; Zung (1965); SF-12; Ware, Kosinski & Keller (1996); SF-36; Ware & Sherbourne (1992); SFMQ; Melzack (1987); SHOW-Q; Learman, Huang, Nakagawa, Gregorich & Kuppermann (2008); SPAQ; Drossman et al., (1990); STAI; Spielberger, Gorsuch, Lushene, Vagg & Jacobs (1983); VAS; Huskissan (1974); WERFGS; Nnoaham et al., (2011); WHOQOL-BREF; World Health Organisation Group (1998)

Table 2.
Quality Assessment Ratings for the chosen 12 Studies

Quality Criteria	Studies											
	Sepulcri 2009	Petrelluzzi 2008	Souza 2011	Rannestad 2000	Grandi 2012	Laursen 2005	De Graaff 2013	Weijenborg 2008	Johnson 2011	Romao 2009	Montanari 2013	Nunes 2014
Explicit theoretical framework	1	2	1	2	1	2	2	2	3	1	2	1
Statement of aims/objectives in main body of report	2	2	3	3	1	3	2	3	3	3	3	3
Clear description of research setting	3	3	2	3	2	3	2	3	3	3	3	3
Evidence of sample size	1	0	2	0	0	0	1	0	3	0	0	3
Representative sample of target group of reasonable size	1	1	1	1	2	1	2	2	2	2	1	1
Description of procedure for data collection	2	3	2	1	1	1	1	3	2	0	3	2
Rationale for choice of data collection tools	1	3	3	3	2	3	1	3	3	0	2	1
Detailed recruitment data	0	0	1	2	1	0	2	3	3	0	2	0
Statistical assessment of reliability and validity of measurement tools	1	1	1	2	1	1	0	1	3	0	3	1
Fit between stated research question and method of data collection	3	3	3	2	3	3	2	2	3	3	3	3
Fit between research question and method of analysis	3	3	3	3	3	3	3	3	3	3	3	3
Good justification for analytical method section	1	1	2	1	2	1	2	2	3	1	2	1
Evidence of user involvement	0	0	0	0	0	0	0	0	0	0	0	0
Strengths and limitations critically discussed	1	2	2	1	1	1	2	2	2	2	2	0
Total quality rating	48%	57%	62%	57%	48%	52%	52%	69%	86%	43%	69%	52%

Note. 0 = Not at all, 1 = Very slightly, 2 = Moderately, 3 = Completely; QATSDD; Sirriyeh et al., (2011)

Table 1 provides a summary of the characteristics of the 12 studies selected for review, including a description of the sample, methodological design and measurement tools, reported outcomes and the quality rating percentage for each paper. Table 2 provides the individual quality assessment ratings for each study.

Overall, the studies obtained relatively low quality percentages, with five scoring within a range of 50 to 60% (De Graaff et al., 2013; Laursen et al., 2005; Nunes et al., 2014; Petrelluzzi et al., 2008; Rannestad et al., 2000). Romao and colleagues (2009) scored the lowest quality assessment rating of 43% and Johnson (2011) scored the highest quality score of 86%. These quality assessment ratings will impact upon how reliable and valid the findings are for each study, and determine what conclusions can be drawn, based on the best available scientific evidence.

Five of the studies were carried out in Brazil, one in Norway, two in Italy, one in Denmark, two in Holland and one in the USA. None of the studies were conducted in the UK, which may have implications when trying to generalise the findings to British women with CPP. One potential difference between women in the UK and those in the review, is that the cost of healthcare differed between countries regarding women paying privately for their healthcare, which may have had an impact on a woman's decision to seek treatment and therefore possibly influenced which women were invited to participate in the studies.

Out of the 12 studies, 50% included a sample of women who had a gynaecological diagnosis of endometriosis. The six studies that did include women with endometriosis (De Graaff et al., 2013; Laursen et al., 2005; Montanari et al., 2013; Nunes et al., 2014; Petrelluzzi et al, 2008; Sepulcri & Amaral, 2009; Souza et al., 2011), all stated that the participants were only included in the study if they had histological and/or laparoscopic evidence of endometriosis. It is likely that the authors chose to use this inclusion criteria to

try and rule out potential confounding issues which may impact upon the findings, for instance including women who present with symptoms that overlap with endometriosis but have a different underlying cause, for example irritable bowel syndrome (IBS).

Five of the 12 studies used a cross-sectional design (De Graaff et al., 2013; Grandi et al., 2012; Montanari et al., 2013; Sepulcri & Amaral, 2009; Souza et al., 2011), four used case-control methodology (Laursen et al., 2005; Nunes et al., 2014; Petrelluzzi et al., 2008; Romao et al., 2009) and three used a cohort design (Johnson, 2011; Rannestad et al., 2000; Weijenborg et al., 2008). The Short Form 36 Health Survey (SF-36; Ware & Sherbourne, 1992) was the most commonly used measure of QoL and was implemented in seven of the studies. All of the studies measured participants' experience of pain, concerning severity and frequency. The Visual Analogue Scale (VAS; Huskissan, 1974) was the most popular measure of pain and was implemented in eight of the studies.

6.1. Demographic Variables

Age was not found to be a significant predictor of QoL (De Graff et al., 2013; Grandi et al., 2012; Johnson, 2011; Weijenborg et al., 2008; Sepulcri & Amaral, 2009). De Graaff et al. (2013) reported that a woman's income and having a partner present were both positively correlated with a higher QoL. Weijenborg et al. (2008) however reported that none of the demographic variables were significantly related to QoL, including living with a partner, being employed or receiving disability insurance. In Weijenborg et al.'s (2008) study, the sample size was relatively small, which means that there is a possibility that the study was under-powered and therefore the demographic data did not reach statistical significance. Alternatively, De Graaff and colleagues' (2013) study had a very large sample of 931. A weakness in this study is that the authors did not provide any statistical information about

their chosen measures, so it raises questions as to how valid the findings are and whether they reached clinical significance.

Johnson (2011) found that there was a positive statistical correlation between women's QoL and their level of education. Furthermore, De Graaff et al. (2013) found that income and the impact that CPP had on a woman's job, was statistically related to QoL.

6.2. Clinical Features and Help Seeking Behaviour

A higher comorbidity of physical health problems and a higher BMI were found to be statistically related to QoL in De Graaff et al.'s (2013) study. Both Johnson (2011) and De Graaff et al. (2013); reported a statistically significant correlation between QoL and the frequency of help-seeking behaviour, in terms of the number of physician visits and surgical procedures.

Surprisingly, two studies identified that there were no differences on outcome measures between women who reported infertility problems and those who did not (Petrelluzzi et al., 2008; Sepulcri & Amaral, 2009). Neither study provided information concerning how they measured infertility, so it is therefore difficult to try and ascertain how valid and reliable the findings are.

6.3. Pain Experiences and Sexual Functioning

Having a diagnosis of endometriosis, deep infiltrating endometriosis (DIE) or fibromyalgia was found to be statistically associated with a reduced QoL (De Graaff et al., 2013; Johnson, 2011; Montanari et al., 2013; Nunes et al., 2014). Participants who experienced dyspareunia and intermenstrual pelvic pain were also found to have a statistically significantly lower QoL (De Graaff et al., 2013; Grandi et al., 2012). The staging of a

woman's endometriosis was not found to be a statistically significant predictor of QoL (Nunes et al., 2014) or psychiatric symptoms (Sepulcri & Amaral, 2009).

Six studies reported that there was a statistically significant association between pain intensity and QoL (Grandi et al., 2012; Johnson, 2011; Laursen et al., 2005; Weijenborg et al., 2008; Souza et al., 2011; Sepulcri & Amaral, 2009). Sepulci and Amaral (2009) additionally found that there was a statistically significant positive relationship between pain intensity, physical limitations and reported anxiety. Petrelluzzi and colleagues (2008) also reported that pain intensity was inversely related to QoL, however the findings did not reach statistical significance. In relation to the impact of pain frequency on QoL, Rannestad et al. (2000) found that there was a statistically significant inverse relationship.

Reduced sexual functioning was found to be a statistically significant predictor of poorer QoL (Montanari et al., 2013). Montanari et al. (2013) reported that women who experience severe dyspareunia had statistically significantly impaired orgasm, satisfaction and desire in comparison to women with moderate dyspareunia. The sexual activity of women with deep infiltrating endometriosis (DIE) was also statistically significantly affected, particularly in regards to their reported sexual desire, satisfaction and pelvic problem interference.

6.4. Psychological Factors

Johnson (2011) and Weijenborg et al. (2008) both found that higher scores of catastrophizing were statistically significantly related to a reduced QoL. Additionally, Weijenborg et al. (2008) found that there was a moderate statistical correlation between perceived pain control and QoL. A reduction in catastrophizing and an increase in perceived pain control were statistically associated with a lowered pain intensity rating from baseline to follow-up and an increase in QoL (in particular in the physical health domain). Furthermore,

Johnson (2011) reported that baseline catastrophizing was statistically related to baseline and follow-up pain and QoL.

Reported symptoms of depression were found to be a statistically significant predictor of poorer QoL in both studies conducted by Grandi et al. (2012) and Romao et al. (2009). Additionally, Grandi et al. (2012) found that anxiety was a further significant predictor of QoL in women with CPP. Although there was consensus that depression was strongly related to QoL, both of the studies received low quality assessment scores (48% and 43%), so caution should be taken when trying to determine the findings' reliability and validity.

Petrelluzzi et al. (2008) found that women with endometriosis and CPP reported significantly higher levels of perceived stress than those without CPP. Petrelluzzi and colleagues (2008) did not find a significant association between perceived stress and QoL or between pain intensity and perceived stress (Petrelluzzi et al., 2008).

In Johnson's (2011) study, the number of lifetime traumas and experience of physical and sexual abuse were both weakly but statistically significantly correlated with QoL, when assessed at baseline.

7. Discussion

7.1. Sample Size and Procedure

The majority of the studies did not provide any information about the sample size, in terms of whether it had adequate power to detect statistical significance. Johnson (2011) and Nunes et al. (2014) did however report that they had considered what sample size was required and had achieved sufficient power. Seven out of 12 studies provided adequate detail when describing the procedure for data collection, with four studies only providing a very basic and brief outline (De Graaff et al., 2013; Grandi et al., 2012; Laursen et al., 2005; Rannestad et

al., 2000). Romao et al. (2009) did not provide any information about how the data was collected.

7.2. Participant Samples

Seven out of 12 studies only scored a one out of a maximum of three points concerning their sample being representative of the population and of an adequate size. All of the studies recruited participants through hospital settings, including specialist tertiary referral centres, gynaecological outpatient departments and a multidisciplinary pain clinic. A number of the authors acknowledged the potential sampling biases within the limitation section of the study, by recognising that the findings may not be generalised to all women with CPP. As a number of studies included patients who were receiving care at tertiary centres, it is likely that the samples were overrepresented by women with moderate to severe CPP, who were likely to have experienced pain for larger amounts of time and present as complex and challenging cases to the health professionals. This patient population is also more likely to have undergone a larger number of investigations and surgical procedures and consequently report a poorer QoL. This means that the findings of the review are potentially biased to women who experience moderate to severe symptoms and limits the generalisability of the findings to other women with less severe CPP.

In Petrelluzzi et al.'s (2008) study, the women were gynaecological patients who had previously not responded to pharmacological or surgical intervention. Subsequently, it is very probable that these women will have experienced enhanced psychological distress and poorer QoL in comparison to other women who experience CPP. Petrelluzzi et al. (2008) also acknowledged that their sample included a very high proportion of women who were experiencing dyspareunia (90%). Previous literature has reported the prevalence of dyspareunia in endometriosis patients to be lower, ranging from 49.5% (Matalliotakis et al.,

2008) to 60% of cases (Carlton, 1996). As a result of sampling bias, the findings need to be considered with caution when trying to generalise the findings to other women with CPP who do not experience dyspareunia.

De Graaff et al. (2013) recommended that studies exploring QoL in CPP should consider recruiting women from diverse medical settings, including general outpatient departments and GP surgeries, in an attempt to improve generalisability of the findings.

Another possible issue about investigating a patient population is that it only includes women who are presenting to services and who are receiving care. For instance, in De Graaff'et al.'s (2013) study, all of the participants had made at least one contact with the gynaecological service. Women who seek support and are under the care of services may be significantly different compared to those who do not seek support. For instance, women may opt to see a health professional when they have a flare up in their symptoms or when they are finding it hard to tolerate their pain, which is likely to coincide with heightened distress and reduced QoL, and therefore raises potential difficulties when trying to generalise the findings to women who are not presenting to services.

A potential difference between women who do seek support and those who do not, is the possible influence of cognitive biases on an individual's beliefs and behaviour. Cognitive behavioural theory when applied to chronic pain, postulates that the way an individual appraises and interprets their pain and situation will influence the way they feel and behave (Pincus & Morley, 2001). Cognitive behavioural theory suggests that psychological difficulties are the product of maladaptive and unhelpful cognitive processes, which can include negative intrusive thoughts and cognitive biases that can result in a person becoming hypervigilant to potential threat and pain-related information (Vlaeyen & Linton, 2000).

Research has also demonstrated that pain-related information is more emotionally laden in those who experience chronic pain and that emotionally loaded information is linked with disruption of cognitive functioning in particular memory (Cahill & MacGaugh, 1995). It is likely that a moderate proportion of the women included in the review potentially experienced a higher level of unhelpful cognitive processes, which were likely to have impacted upon the women's experiences that were shared through self-report questionnaires. For that reason, it is difficult to try and generalise the findings to other groups of women with CPP, as these cognitive processes may have influenced their reported subjective experience of pain and QoL.

When assessing each study in relation to whether the sample was representative of the target population, two of the studies did not provide any details about how they had recruited their control participants (Rannestad et al., 2000; Romao et al., 2009). This is problematic when trying to determine how representative the findings are to other women with CPP. The control groups in three of the studies (Laursen et al., 2005; Nunes et al., 2014; Petrelluzzi et al., 2008) included students, hospital employees and women who had requested contraceptives at a hospital clinic. It is impossible to determine whether these groups were a good representation of the target population and therefore may reduce the generalisability of the findings. Laursen et al. (2005) identified that the control group sample was not selected specifically regarding its socio-economic profile, however, the authors stated that the controls matched the participant group in previous analyses.

Out of the five studies that included a control group, four excluded women who either had a diagnosis or signs and symptoms of endometriosis or CPP. In Laursen et al.'s (2005) study, the authors incorporated the VAS (Huskissan, 1974) to exclude controls reporting any chronic pain. In Rannestad et al.'s (2000) study, no difference was reported in QoL between the control group and women with gynaecological disorders. In their discussion section,

Rannestad and colleagues (2000) state that there was no difference between the two groups regarding the frequency and amount of pain that they experienced, but that the control group differed from the participants in that they reported headaches and not pelvic pain. This may account for why there were no statistically significant differences between the two groups, as literature has shown that living with headaches also has a detrimental impact on a person's wellbeing and QoL (Langeveld, Koot & Passchier, 1997).

In terms of the critical appraisal tool, there was no item that determined whether a study had adequately selected their control group. The only reference made to the choice of sampling was whether it was deemed to be representative of the target group.

Out of 12 studies, only Souza et al.'s (2011) paper did not provide any demographic data. Generally across the studies, the ethnicity of participants and controls was rarely reported. In Montanari et al.'s (2013) study, the authors acknowledged that the lack of heterogeneity was a limitation, as their sample consisted of 100% white women. This limitation was not acknowledged by the other studies. In Souza et al.'s (2011) study, the age range was narrow and only included women between the ages of 25 and 48 years. This suggests that the findings are limited to women with CPP within that age range.

7.3. Choice of Measurement Tools

Six out of the 12 studies offered detailed explanations in terms of how they had chosen their measures, based upon specific research aims whilst additionally reporting that the selected tool had good validity and reliability. Romao et al. (2009) did not offer any justification for why they had chosen to use the VAS (Huskissan, 1974), WHOQOL-BREF (World Health Organisation, 1998) and Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Furthermore, the majority of the studies did not state that they had conducted tests of reliability and validity on their chosen measures. A full description was

however provided by Montanari et al. (2013) and Johnson (2011), who illustrated that they had carried out a statistical assessment of internal consistency. Additionally, most of the studies had chosen appropriate methodologies and statistical analyses to test their research aims.

All 12 of the studies required the participants to provide a self-report of their level of pain and symptoms. The self-report of pain can be challenging and can create problems of confounding factors, as participants may struggle to differentiate between different types of pain and report a global pain experience. They may also find it difficult to distinguish their perception of pain from other related emotions, including fatigue, low mood, stress and apprehension. In Laursen et al.'s (2005) study, it was acknowledged that potential confounding factors, such as cognitive biases, may arise when asking people to describe their symptoms and level of pain and that this needs to be considered when making sense of the findings. Laursen et al. (2005) also reported in their discussion, that there was a strong association between participants' scores on the VAS (Huskissan, 1974) and SF-36 (Ware & Sherbourne, 1992) and that correlations between the VAS (Huskissan, 1974) and the mental health domain of the SF-36 (Ware & Sherbourne, 1992) were as strongly correlated as the VAS (Huskissan, 1974) and physical health domains of the SF-36 (Ware & Sherbourne, 1992). This finding implies that the VAS (Huskissan, 1974) scores captured a multidimensional mix of pain experience and not just reported pain intensity.

7.4. Choice of Methodology and Recruitment Data

A large proportion of the studies used a cross-sectional design, which seemed appropriate for their research question and study aims. De Graaff et al. (2013) and Johnson (2011) both highlighted that the main limitation of using cross-sectional methodology was that the

findings were unable to establish a cause-effect relationship between CPP and QoL in a definitive manner.

Finally, five out of the 12 studies did not provide any information on the recruitment data in terms of how many women were approached, the number of participants recruited and the amount of attrition. Weijenborg et al. (2008) did make reference to their studies response rate of only 64% in the discussion section. However Rannestad and colleagues (2000) did not acknowledge that the study's poor response rates (50% and 54%) may have impacted upon the generalisability of the findings.

7.5. Summary of Quality Assessment

In terms of quality ratings, Johnson's (2011) study achieved the highest score with 86%. A strength of Johnson's (2011) study, was that sufficient detail was provided throughout in regard to explicitly stating the theoretical framework, the study's aims and objectives and providing a clear description of the research setting. Johnson (2011) demonstrated how they had considered an appropriate sample size, their rationale for the choice of measures used and chosen statistical analyses. Johnson (2011) also provided moderate detail when describing the procedure for data collection and demonstrated that they had carried out suitable and thorough statistical analyses to check the reliability of the measurement tools.

Regarding the sample being representative of the target population, Johnson (2011) scored a two out of a possible three points. Although Johnson (2011) did highlight some of the study's limitations, it was not mentioned that the attrition rate was 49% for the cross-sectional phase and 30% for the longitudinal phase. Weijenborg et al. (2008) and Montanari et al. (2013) both scored 69% in terms of quality appraisal. Both of these studies did not make reference to how they had calculated or considered what would be an appropriate

sample size. Montanari et al. (2013) also scored only a one out of a possible three in terms of how representative the sample was.

Out of the 12 studies, Romao et al.'s (2009) study received the lowest quality rating of 43%. Grandi et al. (2012) and Sepulcri and Amaral's (2009) study both scored 48%. For the majority of the 14 items, the three studies lacked detail when describing what they had done or omitted items completely, for instance not providing information on how they had calculated an adequate sample size, how they had collected their data, how many participants they had approached and how they had chosen their measures. Limited information was also given about whether they had carried out any statistical analyses to test the reliability and validity of their chosen measures and why they had opted to use those particular statistical analyses. Both Sepulcri and Amaral (2009) and Grandi et al. (2012), only scored a one for their discussion of the limitations and strengths of the study.

None of the 12 studies demonstrated any evidence of service user involvement in the design. Furthermore, none of the authors scored a maximum score of three when discussing the strengths and limitations of the study, as the limitation sections were generally very brief, not considering the potential weaknesses across all aspects of the study, including the design, measures, procedure, sample and analysis. Identified strengths were illustrated in six of the studies (De Graaff et al., 2013; Montanari et al., 2013; Nunes et al., 2014; Petrelluzzi et al., 2008; Romao et al., 2009; Souza et al., 2011; Weijenborg et al., 2008).

7.6. Quality Assessment Tool

The quality assessment tool used in this review (QATSDD; Sirriyeh et al. 2011) was selected based upon the methodological diversity between the different studies. A key strength of using the tool meant that all of the studies in this review were assessed using the one critical appraisal tool, rather than through a number of tools suitable for each

methodology, which would have been likely to create difficulties when attempting to evaluate and summarise the overall quality of the evidence. The tool also provided guidance notes for each item, which helped to inform the author's decision making, whilst also facilitating critical thinking and providing a space for personal judgement.

With the QATSDD, each item is totalled and the study is given an overall quality score, which is presented as a percentage of the maximum potential score. This enables the reader to gain a quick impression of the overall quality of the study, but does not provide adequate information in terms of the individual strengths and weaknesses (Egger, Smith & Altman, 2001). For instance, some of the items on the tool may be considered more important in terms of determining a study's quality, for example the choice of methodological design and analyses and internal and external validity (Wright, Brand & Dunn, 2007). It is therefore possible for studies to gain a relatively high quality assessment percentage, regardless of potential fundamental flaws. Another limitation of the QATSDD was that it did not address whether the authors had selected an adequate control group, in that it was able to provide a true comparison with the participant group and was not a biased sample in itself.

7.7. Summary of Findings

This review found that there were a number of predictive variables of QoL in women with CPP. The variables that were found to have strong evidence of being significantly positively associated with QoL, included level of education and sexual functioning. Additionally, there was strong evidence to suggest that the number of physician visits and surgical procedures, pain intensity, experiencing dyspareunia and having a diagnosis of endometriosis and DIE were statistically inversely correlated with QoL. There was also good evidence to suggest that there was a negative statistical relationship between QoL and the experience of lifetime trauma, physical and sexual abuse, catastrophizing and depression.

Consistent findings of statistically significant correlations were found between QoL and the number of physician visits and surgical procedures, having a diagnosis of endometriosis, pain intensity and catastrophizing. The correlation between QoL and level of education, sexual functioning, having a diagnosis of DIE and the experience of trauma and abuse were only reported in single studies, however these two studies (Johnson, 2011; Montanari et al., 2013) had been critiqued as having high quality ratings so the findings suggest that there is good evidence for these predictors.

Additionally, depression was consistently found to be a statistically significant predictor of QoL, however caution is required when interpreting the findings reliability and validity, as both of the studies who reported this association scored very low quality ratings (43% and 48%).

There was strong evidence that age was not a significant predictor of QoL. Two studies reported that the staging of endometriosis was not statistically correlated with QoL. Despite a consistency in the findings, the methodological quality of both of the studies was poor (48% and 52%), so there is insufficient evidence to determine that the staging of a woman's endometriosis is not a predictor of QoL.

Living with a partner, as a predictor of a woman's QoL, was an inconclusive finding, as De Graaff et al. (2013) reported that there was a statistically significant correlation with QoL, whereas Weijenborg et al. (2008) did not find a significant correlation between the two. As mentioned previously, it is possible that Weijenborg et al.'s study was under-powered due to a relatively small sample size, so the findings did not reach statistical significance.

7.8. Limitations and Strengths

A limitation of this review is that the quality assessment was only carried out by one reviewer, and therefore there is an increased chance of interpretation bias. It would have strengthened the review if it had been possible to have an independent reviewer score a proportion of the studies, in order to establish whether there was a shared agreement in the quality findings and therefore good inter-rater reliability. It has been recommended in the literature that two independent reviewers should assess the quality of each of the papers and any differences should be agreed by a third reviewer (Wright et al., 2007). Antman, Lau, Kupelnick, Mosteller and Chalmers (1992) suggested that reviewers should also be blinded to the journal name, study title, authors and respective institutions, to reduce the risk of bias further. However, the constraints inherent in conducting this review did not enable a second independent reviewer to be included.

A further limitation of the review is that the author experienced challenges when attempting to try and control for possible confounding variables that may have impacted upon the findings. For instance, one of the exclusion criteria was to eliminate studies that focused on infertility, as it was thought that samples of women who were experiencing infertility difficulties would be more likely to report a poorer QoL. This may then potentially impact the findings, as the reduced QoL may be a product of the infertility rather than the CPP itself. As studies have shown that infertility problems are reported in an estimated 30-50% of women with endometriosis (Missmer et al., 2004), it is therefore highly likely that many of the women included in this review will have previously or currently been experiencing infertility related issues. Two of the studies in this review (Petrelluzzi et al., 2008; Sepulcri & Amaral, 2009) however, found that there were no differences in a range of outcomes between those women with and without infertility.

There was variation in the age ranges of the sample, with one study including a participant who was 67 years of age (De Graaff et al., 2013). It is therefore likely that some of the

women will have been currently menopausal or post-menopausal. Including women who were experiencing the menopause may have again influenced the findings of the review, as these women may have been feeling lower in mood and reported a poorer QoL as a result of the menopause and not because of their CPP. This is also the case for including women who have had a hysterectomy, as they may be finding it difficult to adjust to hormonal changes and potentially the fact that they will no longer be able to have children.

A further limitation of this review, is that it was very difficult to try and include studies that excluded any other physical or mental health condition. Women with CPP commonly report increased psychological distress and comorbid physical health problems, which makes it very hard when trying to identify whether the reported poorer QoL is a result of the CPP per se or whether it is the consequence of multiple difficulties. This review focused on studies that had included women with CPP or endometriosis and who were under gynaecological services. It is impossible to rule out other possible causes of CPP, as the condition is widely understood to be complex and can include a number of physiological systems, including reproductive, gastrointestinal, genitourinary and musculoskeletal (Karnath & Breitkopf, 2007). Therefore although the review adopted a gynaecological focus, it is difficult to determine whether the sample's CPP was caused by gynaecological problems.

Although extensive research has been conducted to investigate the impact of CPP on QoL, this is the first systematic review that has aimed to identify potential predictors of QoL in this patient group. This review has demonstrated that CPP is likely to have a significant detrimental impact upon a woman's wellbeing and that more research is required in order to try and gain a better understanding of the psychological factors that contribute to a reduced QoL. Therefore a strength of this review is that it has acknowledged that QoL in women with CPP is influenced by a number of different factors and not based entirely upon a woman's physical symptoms. A further strength of the review, it that it only included studies in which

the authors had used standardised QoL measures. This meant that the measurement tools had good validity and reliability, which enables the reader to have more confidence in the findings of the review.

7.9. Conclusion

The findings illustrated that CPP can have a detrimental impact upon a woman's QoL. The review also found that there are only a small number of published studies that have investigated possible predictors of CPP, however a number of potential psychological predictors were identified. If further research was able to ascertain which psychological predictors are likely to have a detrimental impact upon a woman's QoL, this could then lead to changes in the way women with CPP are assessed and managed.

Current management guidelines suggest that women with CPP should be referred to a pain management team or a specialist pelvic pain clinic if they are continuing to experience pain despite medical intervention (Royal College of Obstetrics and Gynaecology, 2012). Depending on service provision, some women with CPP may be referred on to a pain management programme (PMP), which is a multidisciplinary intervention underpinned by cognitive behavioural theory (Zarnegar & Daniel, 2005). The aim of a PMP is to assist the individual to learn new more helpful ways to manage their pain, increasing their functioning and QoL and reducing disability and distress (Zarnegar & Daniel, 2005).

Cognitive behavioural therapy in the form of PMP's has been found to be an effective approach for when working with individuals with chronic pain (Desrochers, Bergeron, Khalife, Dupuis & Jodoin, 2009; Williams, Eccleston & Morley, 2012). Despite treatment guidelines and findings evidencing the effectiveness of CBT PMPs, there is still a gap in service provision that offers group intervention designed specifically to provide care for women with CPP (Twiddy et al., 2015).

A recent study however carried out by Twiddy et al. (2015), described the development and pilot of a cognitive behavioural PMP that had been developed for women with CPP. The programme was devised in accordance with the British Pain Society's (2013) guidelines and included additional topics that were specific to CPP, such as issues related to intimate relationships, pregnancy and parenting. Twiddy et al. (2015) reported that preliminary data and feedback from the group showed that there was a value in providing specialist interdisciplinary pain management programmes for women with CPP, particularly when working with individuals who have continued to experience pain despite receiving regular care. This pilot study identified that there was an apparent need for further development and research into the effectiveness of interdisciplinary and multi-speciality approaches in pain management in women with CPP.

In conclusion, if researchers are able to identify which psychological factors are likely to impact upon women's QoL, these could then be incorporated into existing pain management interventions and tested for effectiveness, with the hope of developing new ways of helping women to manage their CPP with the aim of improving their QoL.

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9. Chapter Two

Psychological Variables and Quality of Life in Women

with Endometriosis

10. Abstract

Objective: Endometriosis is a common gynaecological condition that has a detrimental impact upon women's QoL. There is little literature exploring the predictive value of psychological variables on QoL in this patient group. This study aimed to investigate the impact of pain self-efficacy, health locus of control (HLOC), coping style and illness uncertainty on QoL in women who have endometriosis. **Design:** The design was cross-sectional, using an online survey method. Standard multiple regressions were used to assess the relationship between the psychological predictors and four domains of QoL. **Main Outcome Measures:** Measures included the Pain Self-Efficacy Questionnaire (PSEQ), the Multidimensional Health Locus of Control Scale Form C (MHLC-C), the Vanderbilt Pain Management Inventory (VPMI), the Mishel Uncertainty in Illness Scale Form C (MUIS-C) and the World Health Organisation Quality of Life-BREF Assessment (WHOQOL-BREF). **Results:** The psychological predictors accounted for a statistically significant proportion of the variance in scores on QoL across the four domains ($p < .0005$). The model accounted for 55%, 26%, 10% and 32% of the scores in the physical, psychological, social and environmental QoL domains. Pain self-efficacy was shown to make the largest unique contribution, followed by illness uncertainty. **Conclusions:** The model consisting of pain self-efficacy, HLOC, coping style and illness uncertainty accounted for a statistically significant proportion of the variance in scores across all of the QoL domains. This suggests that interventions targeted in particular at improving pain self-efficacy and reducing illness uncertainty may impact upon women's reported QoL.

10.1. Key Words: Chronic pelvic pain (CPP), endometriosis, quality of life (QoL), psychological predictors

11. Psychological Variables and Quality of Life in Women with Endometriosis

Endometriosis is a progressive and chronic gynaecological condition found in approximately 10% of women of reproductive age (Kaatz, Solari-Twadell, Cameron & Schultz, 2010), and between 30 to 45% of women who experience CPP (Meuleman et al., 2009). Endometriosis occurs when endometrial tissue exists outside of the uterine cavity and each month responds to hormonal changes, by bleeding and causing an inflammatory response (Kold, Hansen, Vedsted-Hansen & Forman, 2012). This can cause pain and adhesions and anatomical pelvic changes (Mao & Anastasi, 2010).

CPP is the main symptom of endometriosis, which is defined as pain that has a duration of more than six months and is constant or intermittent and impacts upon a woman's daily functioning (McGowan, Luker, Creed & Chew-Graham, 2007). Women with endometriosis can experience an array of debilitating symptoms, including dysmenorrhoea, dyspareunia, dysuria, dyschezia, fatigue and subfertility (Jones, Jenkinson & Kennedy, 2004).

Endometriosis is often referred to as the missed disease (Mastro, 2000), as women's symptoms frequently are not recognised in primary care settings (Harvey & Warwick, 2010). Nnoaham et al. (2011) reported that women present to their GP up to seven times before being referred to a gynaecologist. Husby, Haugen and Moen (2003) found that it takes approximately 6.7 years in the UK and US for women to receive a diagnosis. A definitive diagnosis of endometriosis can only be reliably achieved via laparoscopy (Royal College of Obstetricians & Gynaecologists, 2000). Establishing a diagnosis therefore can be challenging for health professionals, but additionally can result in many women having their symptoms overlooked or misdiagnosed, which can be distressing and leave them feeling misunderstood and their experience of pain invalidated (Ballard, Lowton & Wright, 2006). A delay in

Dysmenorrhea: Pain in the pelvis occurring just before and during menstruation (Banikarim, Chacko & Kelder, 2000); Dyspareunia: Recurring genital pain associated with sexual activity (American Psychiatric Association, 2000); Dysuria: Pain or discomfort during urination (Bremnar & Sadovsky, 2002); Dyschezia: Pain with defecation (Seracchioli et al., 2008).

diagnosis and treatment further increases the risk of women developing central nervous system sensitisation, as a consequence of living with chronic pain (Evans, Moalem-Taylor & Tracey, 2007).

Treatment generally focuses on the removal of endometrial lesions, symptom management and preserving a woman's fertility, via surgery and the use of pain killers, oral contraceptives and other hormonal agents (Banerjee, Mallikarjunaiah & Murphy, 2010). Regardless of treatment, women regularly continue to experience pelvic pain (Sutton, 2011).

11.1. QoL and Endometriosis

Not surprisingly, women with endometriosis commonly experience psychological difficulties, with an estimated 60% reporting mood disturbances and anxiety (Sepulcri & Amaral, 2009). Many studies have demonstrated that women with endometriosis report a significantly reduced QoL (De Graaff et al., 2013; Nunes, Ferreira & Bahamondes, 2014). A study conducted by Surtees and colleagues in (2003) reported that scores of QoL in women with endometriosis were comparable to those reported in women with cancer. Despite a number of qualitative studies exploring the experiences of women with endometriosis, Harvey and Warwick (2010) reported that the impact of endometriosis on women's wellbeing remains under-researched, with few studies investigating the relationship between psychological variables and QoL. A proportion of the literature examining QoL in this patient group, have found that QoL is not statistically related to demographic variables or symptom duration (Grandi et al., 2012; Sepulcri & Amaral, 2009; Weijenborg et al., 2008).

11.2. Psychological Factors and QoL

In accordance with the biopsychosocial model of pain, research into chronic health conditions has illustrated that psychological factors can play a significant role in the

development and maintenance of chronic pain, subsequently impacting upon QoL (Cui, Matsushima, Aso, Masuda & Makita, 2009; Ramirez-Maestre, Esteve & Lopez, 2007).

Pain self-efficacy is defined as the belief in one's capability to accomplish a desired goal and succeed in particular situations, despite experiencing pain (Nicholas, 2007). Individuals' beliefs can differ between thinking in self-enhancing or self-debilitating ways, which can affect the way somebody is able to manage pain (Borsbo, Gerdle & Peolsson, 2010). Studies have shown that self-efficacy is frequently affected in individuals who experience chronic pain (Turk & Okifuji, 2002), and that low self-efficacy is related to increased pain intensity and poorer QoL in patients with musculoskeletal pain (Denison, Asenlof & Lindberg, 2004), headache (Nicholson, Houle, Rhudy & Norton, 2007) and other chronic pain conditions (Yazdi-Ravandi et al., 2013). Pain self-efficacy has also been found to be a predictor of treatment outcomes (Keefe et al., 2004).

HLOC refers to an individual's perceived degree of control that they have over their health condition (Laffrey & Isenberg, 2003). Internal HLOC is when an individual perceives that they are in control of their symptoms, whereas with an external HLOC, the individual believes that control lies somewhere else, for example with a physician (Goli, Scheidt, Gholamrezaei & Farzanegan, 2014). Studies have demonstrated that high internal HLOC is related to improved physical and psychological wellbeing and increased proactive health behaviours (Pucheu, Consoli, D'Auzac, Francais & Issad, 2004; Weis, Fitzpatrick & Bushfield, 2008). Additionally, HLOC has been found to impact upon reported pain severity and coping behaviour in patients experiencing chronic pain (Coughlin, Badura, Fleischer & Guck, 2000).

The way an individual copes with their pain has been found to impact upon QoL and adjustment in those with chronic pain conditions (Schulz, Hartung & Riva, 2013; Sullivan et al., 2001). Lazarus and Folkman (1984) theorised that individuals become increasingly

stressed when their threat perceptions exceed their perceived coping ability and that people carry out either emotion-focused or problem-focused coping strategies. Brown and Nicassio (1987) offered an alternative classification of coping, incorporating active versus passive coping styles. Active coping refers to strategies that patients use as an attempt to manage their symptoms, whereas passive coping includes strategies that relinquish control of the pain to others (Brown & Nicassio, 1987). Studies have shown that active coping is strongly associated with reduced pain and improved QoL, while passive coping is linked to increased depression and functional impairment (Jensen, Turner, Romano & Karoly, 1991) and poorer psychological adjustment (Roesch & Weiner, 2001).

Finally, illness uncertainty occurs when an individual perceives a loss of control and a perceptual state of doubt over the status of their health condition, which fluctuates over time (Penrod, 2001). It is believed that illness uncertainty develops when an individual is unable to gain a sense of control over their condition or adequately describe their illness, due to the unpredictability of symptoms and lack of information (Mishel, Padilla, Grant & Sorenson, 1991). Illness uncertainty is commonly reported in patients with chronic illnesses (Mishel, 1988) and has been found to be associated with reduced tolerance of pain and maladaptive coping styles (Wright, Afari & Zautra, 2009). LeFort (2000) found that high illness uncertainty was significantly related to a reduced self-efficacy and life satisfaction in patients with idiopathic pain, including abdominal and musculoskeletal conditions.

11.3. Psychological Factors and Endometriosis

Due to the unpredictable nature of endometriosis in terms of symptoms, prognosis and management, research has found that women commonly report a high level of illness uncertainty, which is related to increased psychological distress (Lemaire, 2004). Delays in diagnosis can also result in women feeling confused, frustrated and hopeless (Huntington & Gilmour, 2005). Jacox (1996) reported that a lack of knowledge and understanding about the

condition is associated with low pain self-efficacy and consequently poorer management of their pain. McGowan et al. (2007) reported that women with CPP were less likely to engage in active coping strategies, as a result of low self-esteem and feelings of hopelessness, as a consequence of perceiving that clinicians had not validated their experience of pain.

Furthermore, literature in endometriosis has shown that women regularly report they believe that luck has a role to play in how they feel and whether their condition will deteriorate, with little control over their symptoms (Jones et al., 2004). Similarly, Denny (2004) found that women with endometriosis appear to lack a sense of internal HLOC over their pain and will seek medical care in the form of medication and laparoscopy.

Overall research suggests that pain self-efficacy, coping style, illness uncertainty and HLOC may have an impact on QoL in women with endometriosis. More research is required to investigate these psychological variables further, in the hope of developing an interdisciplinary model of care that manages both the physical and psychological aspects of the condition (Mendes & Figueiredo, 2012).

11.4. Study Aim and Hypotheses

The present study aimed to investigate the role of pain self-efficacy, HLOC, coping style and illness uncertainty on women's reported QoL. Based upon CPP and endometriosis literature, the following hypotheses were proposed:

A low level of illness uncertainty, passive coping style and external HLOC will be statistically associated with a higher QoL. A high level of active coping, internal HLOC and pain self-efficacy will be statistically associated with a higher QoL. The four psychological variables will be able to predict a significant amount of the variance in QoL scores, over and above that accounted for by demographics, duration of symptoms and current health care input.

12. Method

12.1. Ethics

Ethical approval was obtained from the University of Liverpool's Research Ethics Committee. Women provided informed consent online prior to commencing the questionnaires.

12.2. Participants

Two hundred and thirty participants were recruited through Endometriosis UK, an organisation that provides support services and information to women affected by endometriosis. The recruitment process involved an advert placed on the news page of the charity's website and on their Facebook page. The study was additionally advertised on Health Unlocked and Twitter. Participants were recruited between November 2014 and April 2015.

Eligibility for the study required women to be between the ages of 18 and 50 and to have experienced CPP for the last six months. A diagnosis of endometriosis was essential, which had to have been confirmed by laparoscopy. The participants were required to have access to a computer to complete the questionnaires. Women were excluded if they experienced additional chronic health conditions or had significant mental health difficulties, which had required either psychological or psychiatric input prior to the onset of experiencing symptoms of endometriosis.

12.3. Procedure

All the participants accessed the online survey by clicking a link on the study's advert page. Before starting the questionnaires, participants were instructed to read the information sheet and complete the consent form. Participants were also asked to complete demographic

and clinical information items. Participants were then asked to complete five questionnaires, which took approximately 25 minutes to complete. At the end of the survey, national helpline contact numbers were provided with a statement of advice asking participants to seek medical help, should they be experiencing psychological difficulties. The researcher also provided her contact details to enable participants to contact the principal investigator, should they want further information about the study.

12.4. Measures

12.41. Measure of Illness Uncertainty

Illness uncertainty was measured using the Mishel Uncertainty in Illness Scale Form C (MUIS-C, Mishel, 1981). The 23 item MUIS-C was developed for non-hospitalised adults with a chronic health condition.

12.42. Measure of Coping Style

The Vanderbilt Pain Management Inventory (VPMI; Brown & Nicassio, 1987) is an 18-item measure, split into two subscales designed to assess how often chronic pain sufferers use active and passive strategies when their pain reaches moderate or high intensities.

12.43. Measure of HLOC

The Multidimensional Health Locus of Control Scale Form C (MHLC-C; Wallston, Stein & Smith, 1994) is an 18 item, condition-specific locus of control scale. The scale was developed to assess health-related control beliefs of individuals with an existing medical condition.

12.44. Measure of Pain Self-Efficacy

The 10 item Pain Self-Efficacy Questionnaire (PSEQ; Nicholas, 1989) measures the confidence that people have in carrying out activities while in pain, using a seven-point Likert scale from zero (not at all confident) to six (completely confident).

12.45. Measure of QoL

The World Health Organisation Quality of Life-BREF (WHOQOL-BREF; WHOQOL Group, 1998) is a 26-item version of the WHOQOL-100 assessment scale (WHOQOL Group, 1994). The WHOQOL-BREF measures subjective QOL covering four domains; physical health, psychological health, social relationships and the environment.

12.5. Statistical Analysis

The data was analysed using the Statistical Package for Social Science (SPSS) version 20. Normality checks were conducted for each measure, which involved examining the distribution of Q-Q Plots and histograms and computing the Komogorov-Smirnov normality statistic (Smirnov, 1948). All of the scales were found to be significant, which indicated violation of the assumption of normality. This finding was confirmed through interpretation of the Q-Q plots and histograms. A series of bivariate correlations were carried out between the independent and dependent variables to check the strength and statistical significance of the relationships. The author chose to use the non-parametric Spearman rank order correlation statistic, as the data was not normally distributed.

Originally, the author had planned to carry out a hierarchical multiple regression and hypothesised that the psychological variables would account for a statistically higher proportion of the variance of the dependent variable (QoL) than the demographic and clinical information. The demographic and clinical information were removed from the analyses, as they were not found to be statistically significantly correlated with any of the QoL domains.

Since the data was found not to be normally distributed, the author chose to carry out a series of multiple regressions using the bootstrapping method.

13. Results

Two hundred and thirty women participated in the study. Participants ranged from 18 to 50, with a mean age of 31years. The majority of the sample were white British women (94%), with 72% reporting that they were under the care of a gynaecologist. The mean symptom duration of CPP was 11.5 years, with a range of one to 39 years. Of the participants, 47.8% described themselves as being single or never married and 44.8% were married. More than half of the women had obtained a degree (54.8%).

Descriptive information of participants' scores on each of the measures is shown in Table 1 and Table 2.

Table 1.
Participants' Dependent Variable Scores

Transformed Scores of QoL	Mean	Median	Standard Deviation	Range	Range of possible scores
Physical Health	46.30	48.21	19.30	93.00	0-100
Psychological Health	48.00	50.00	15.10	71.00	0-100
Social Relationships	49.00	50.00	23.80	100	0-100
Environment	60.02	59.38	16.67	84.40	0-100

Table 2.
Participants' Independent Variable Scores

Total Scores Of measures	Mean	Median	Standard Deviation	Range	Range of possible scores
Pain Self-efficacy	28.42	29.00	12.83	60	0-60
Internal HLOC	13.67	13.00	5.40	23	6-36
Chance HLOC	18.50	19.00	6.41	28	6-36
Doctor HLOC	9.51	10.00	3.13	14	3-18

Other People HLOC	9.37	9.00	3.80	15	3-18
Passive Coping Style	26.80	27	5.65	26	10-40
Active Coping Style	18.10	18.00	3.60	21	8-32
Illness Uncertainty	73.00	74.50	12.10	68	23-115

13.1. Psychological Predictors of QoL

Standard multiple regression using bootstrapping was used to investigate how well scores of pain self-efficacy, HLOC, coping style and illness uncertainty predict scores of QoL in the physical health, psychological health, social relationships and environment domains.

13.2. Relationship between Psychological Predictors and Physical Health Domain (QoL)

Using the enter method, the prediction model was statistically significant, F 8, 221= 35.86, $p < .0005$, and accounted for 55% of the variance of QoL ($R^2 = .565$, Adjusted $R^2 = .549$).

A higher pain self-efficacy and a lower doctor HLOC and illness uncertainty were found to be statistically significant predictors of a higher QoL. Pain self-efficacy was found to account for the largest amount of variance of QoL, with a beta coefficient of 1.108, $p < .001$, followed by doctor HLOC (-.732, $p < .007$) and then illness uncertainty (-.211, $p < .019$). Internal, chance and other people HLOC and coping style were not found to be statistically significant predictors of QoL. Table 3 reports the individual beta coefficients and standard errors for each of the predictors.

Table 3.
Bootstrap Coefficients for the Predictor Variables and QoL (Physical Health Domain)

Predictors	B	Standard Error	Significance	95% Confidence Interval Lower	95% Confidence Interval Upper
Pain self-efficacy	1.108	.090	.001***	.943	1.292
Internal HLOC	-.006	.175	.963	-.348	.361
Chance HLOC	.117	.144	.416	-.174	.387
Doctor HLOC	-.732	.280	.007**	-.174	-.161
Other People HLOC	.054	.256	.832	-.426	.612
Passive Coping Style	.181	.230	.442	-.233	.659
Active Coping Style	-.387	.236	.100	-.858	.072
Illness Uncertainty	-.211	.085	.019*	-.375	-.034

Note. * p < .05, ** p < .01, *** p < .001

13.3. Relationship between Psychological Predictors and Psychological Health Domain (QoL)

Using the enter method, the prediction model was statistically significant, F 8, 221= 10.61, p < .0005, and accounted for 26% of the variance of QoL (R^2 = .277, Adjusted R^2 = .255).

A higher pain self-efficacy and lower internal HLOC and illness uncertainty were found to be statistically significant predictors of a higher QoL. Pain self-efficacy was found to account for the largest amount of variance of QoL, with a beta coefficient of .548, p < .001, followed by internal HLOC (-.363, p < .038) and then illness uncertainty (-.182, p < .035). Chance, doctor and other people HLOC and coping style were not found to be statistically significant predictors of QoL. Table 4 reports the individual beta coefficients and standard errors for each of the predictors.

Table 4.
Bootstrap Coefficients for the Predictor Variables and QoL (Psychological Health Domain)

Predictors	B	Standard Error	Significance	95% Confidence Interval Lower	95% Confidence Interval Upper
Pain self-efficacy	.548	.093	.001***	.362	.721
Internal HLOC	-.363	.177	.038*	-.719	-.029
Chance HLOC	-.077	.139	.576	-.377	.181
Doctor HLOC	.110	.312	.739	-.475	.754
Other People HLOC	-.385	.274	.171	-.946	.136
Passive Coping Style	.035	.213	.875	-.366	.461
Active Coping Style	.137	.292	.625	-.411	.701
Illness Uncertainty	-.182	.087	.035*	-.359	-.007

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

13.4. Relationship between Psychological Predictors and Social Relationships Domain (QoL)

Using the enter method, the prediction model was statistically significant, F 8, 221= 4.12, $p < .0005$, and accounted for 10% of the variance of QoL ($R^2 = .129$, Adjusted $R^2 = .101$).

The psychological predictors were found to account for 10% of the variance in QoL scores. A higher pain self-efficacy and lower illness uncertainty were found to be statistically significant predictors of a higher QoL. Pain self-efficacy again was found to account for the largest amount of variance of QoL, with a beta coefficient of .530, $p < .002$. None of the subscales of HLOC and coping style were found to be statistically significant predictors of QoL. Table 5 reports the individual beta coefficients and standard errors for each of the predictors.

Table 5.
Bootstrap Coefficients for the Predictor Variables and QoL (Social Relationships Domain)

Predictors	B	Standard Error	Significance	95% Confidence Interval Lower	95% Confidence Interval Upper
Pain self-efficacy	.530	.160	.002**	.190	.841
Internal HLOC	-.471	.320	.169	-1.045	.202
Chance HLOC	-.373	.236	.114	-.832	.063
Doctor HLOC	.288	.485	.560	-.641	1.276
Other People HLOC	.212	.453	.641	-.675	1.107
Passive Coping Style	.182	.386	.657	-.565	.921
Active Coping Style	.676	.487	.166	-.142	1.708
Illness Uncertainty	-.323	.148	.029*	-.617	-.034

Note. * p < .05, ** p < .01, *** p < .001

13.5. Relationship between Psychological Predictors and Environment Domain (QoL)

Using the enter method, the prediction model was statistically significant, F 8, 221= 14.41, p < .0005, and accounted for 32% of the variance of QoL (R^2 = .343, Adjusted R^2 = .318).

A higher pain self-efficacy and lower illness uncertainty were found to be statistically significant predictors of a higher QoL. Similarly to the other regression analyses, pain self-efficacy was found to account for the largest amount of variance of QoL, with a beta coefficient of .518, p < .005. None of the subscales of HLOC and coping style were found to be statistically significant predictors of QoL. Table 6 reports the individual beta coefficients and standard errors for each of the predictors.

Table 6.
Bootstrap Coefficients for the Predictor Variables and QoL (Environment Domain)

Predictors	B	Standard Error	Significance	95% Confidence Interval Lower	95% Confidence Interval Upper
Pain self-efficacy	.518	.100	.005**	.296	.728
Internal HLOC	-.218	.183	.235	-.579	.126
Chance HLOC	.070	.146	.632	-.225	.355
Doctor HLOC	.290	.321	.367	-.328	.917
Other People HLOC	-.195	.269	.469	-.734	.341
Passive Coping Style	.255	.231	.271	-.181	.697
Active Coping Style	.411	.258	.112	-.208	1.008
Illness Uncertainty	-.511	.083	.001**	-.702	-.331

Note. * p < .05, ** p < .01, *** p < .001

14. Discussion

This study investigated the impact of psychological factors on QoL in women with endometriosis. The findings supported the hypothesis, as the model of psychological predictors did account for a statistically significant proportion of the variance of QoL scores. There was not a statistically significant relationship between QoL and demographics, duration of CPP and whether the participant was receiving care from a specialist. The four psychological predictors as a model accounted for 55%, 26%, 10% and 32% of the variance across the four QoL domains, with a statistical significance of $p < .0005$. Pain self-efficacy and illness uncertainty were found to be significant predictors of QoL across the four domains, with a positive relationship between pain self-efficacy and QoL and a negative relationship between illness uncertainty and QoL. A low level of doctor HLOC was found to be a statistically significant predictor of higher QoL in the physical health domain. The findings did not support the hypothesis that a high internal HLOC would be positively related

to a high QoL. Alternatively, internal HLOC was statistically inversely related to QoL in the psychological health domain. Coping style, chance and other people HLOC were not found to individually account for a significant proportion of the variance in QoL in any of the four domains.

In comparison to other chronic pain studies, this sample of women appeared to have a lower internal and doctor's HLOC (Wallston et al., 1994), passive coping style (Brown & Nicassio, 1987) and QoL across the physical, psychological and social relationship domains (Souza et al., 2011). The women in this study had a lower QoL in comparison to participants with CPP and endometriosis in Souza and colleague's (2011) study. The QoL scores were similar to those reported by Romao et al. (2009), who examined the impact of anxiety and depression on QoL in women with CPP. This illustrates that the women in this study appeared to have high levels of distress and a poor QoL. An exception in the findings was that the women reported a higher environment QoL, which was higher than those reported by Romao et al. (2009) and similar to the QoL scores reported by Souza et al. (2011). Unlike Roth, Margaret and Bachman's (2001) study, the women in this sample were found to have a poorer QoL across the physical, psychological and social relationship domains despite having a higher level of education and adequate environmental QoL.

The participants also had a higher level of illness uncertainty when compared to findings obtained from Lemaire's (2004) study. In contrast to the findings reported by Menezes, Maher, McAuley, Hancock and Smeets (2011) and Vong, Cheing, Chan, Chan and Leung (2009), the women in this study reported a significantly lower pain self-efficacy. The current findings however were similar to a study conducted by Nicholas, Asghari and Blyth (2008), who investigated pain self-efficacy in a population of female chronic pain patients. Finally, this sample of women had a higher chance HLOC (Wallston et al., 1994) and were similar to

other chronic pain samples concerning other people HLOC (Wallston et al., 1994) and active coping style (Brown & Nicassio, 1987).

Pain self-efficacy was consistently found to account for the largest amount of the variance in QoL scores, which is consistent with findings from other studies reporting a significant association between low self-efficacy and increased disability (Ferreira-Valente, Pais-Ribeiro & Jensen, 2011). Similarly to this study, Yazdi-Ravandi et al. (2013) found that pain self-efficacy was statistically significantly related to QoL across all of the domains of the WHOQOL-BREF (World Health Group, 1998). The reported low pain self-efficacy in this study suggests that the participants perceived their condition and pain to be overwhelming and difficult to manage, possibly impacting upon their QoL. The sample additionally had a high level of illness uncertainty. The illness uncertainty items included beliefs including: that they lack information about their condition or the effectiveness of treatments; whether they were able to understand the information provided by the health professional, or that they had been given differing opinions; if they believed that their symptoms were unpredictable and unclear as to whether their condition was getting worse. This again supports the literature which has illustrated how greater uncertainty is related to poorer functioning and QoL (Carroll, Hamilton & McGovern, 1999). It is not surprising that women in this study had raised levels of illness uncertainty, considering that high illness uncertainty is commonly reported in women with this condition (Lemaire, 2004).

14.1 Clinical Implications

The findings of this study suggest that psychological variables including pain self-efficacy and illness uncertainty may influence QoL in women with endometriosis. These findings suggest that it is important that interventions acknowledge and manage psychological factors as part of a woman's treatment.

The current treatment guidelines for CPP recommend that women should be referred to a pain management team or a specialist pelvic pain clinic if they continue to experience symptoms despite standard intervention (Royal College of Obstetrics and Gynaecology, 2012). Depending on service provision, some women may be referred on to a pain management programme (PMP), which is an interdisciplinary intervention underpinned by cognitive behavioural theory (Zarnegar & Daniel, 2005). The aims of PMPs are to help patients with chronic pain achieve as normal life as possible, by decreasing their psychological distress and functional impairment and to raise their ability to manage their own pain (British Pain Society, 2013). A reduction in pain is not a principal aim (Hoffman, Papas, Chatkoff & Kerns, 2007), however a large amount of research has demonstrated that PMPs compared to standard treatment is more effective in lowering individuals' pain and mood and raising activity levels (Koes, van Tulder & Thomas, 2006; Williams, Eccleston & Morley 2012).

Psychological components of PMPs include cognitive restructuring of unhelpful or restricting beliefs, graded activation and exposure to lower fear and avoidance and teaching principles of acceptance and mindfulness (Bailey, Carleton, Vlaeyen & Asmundson, 2010; Hayes, Strosahl & Wilson, 2012).

The European Association of Urology guidelines (Engeler et al., 2013), and the British Pain Society pathway for CPP (Baranowski, Lee, Price & Hughes, 2014) emphasise the biopsychosocial consequences of CPP and state the need for interdisciplinary care. Despite these recommendations, there is still a gap in service provision, with few PMPs tailored specifically to manage women with CPP (Twiddy et al., 2015).

As the findings in this study show that pain self-efficacy and illness uncertainty are likely to influence a woman's QoL, these could be included into the current PMP interventions. For instance, interventions could be adapted to include targeting and modifying a woman's

appraisal of pain, including increasing pain self-efficacy and reducing beliefs of illness uncertainty, whilst addressing any self-perpetuating unhelpful coping behaviours.

Additionally, to help lower illness uncertainty, health professionals need to provide women with clear and accessible information, to enable patients to make sense of their condition and learn to adapt to the psychological and physical changes they are faced with. It is advisable for clinicians to signpost women to local and national organisations that can provide further information about endometriosis, and encourage the individual to learn more about self-management of their condition. Health professionals should be encouraged to acknowledge that all women are different in relation to where they are in the process of accepting their condition. Information provided should be individually tailored to the needs of the patient in terms of the choice of language and depth of information, but also timing.

14.2. Strengths and Limitations

A potential limitation of using an online, anonymised design was that the author did not have access to participants' medical records and so was unable to verify if women had a diagnosis of endometriosis which had been confirmed by a laparoscopy. Research into the use of online studies has highlighted that a sampling bias is a further possible limitation, with online samples commonly consisting of young, white, educated, middle-class and technologically proficient individuals (Hewson, 2014). This was the case in this study, as the majority of women were white British (94%) and educated at first degree level or higher (54.8%). This sampling bias should be considered when attempting to generalise the findings to other groups of women with CPP, as there may be differences in the way these women perceive and manage their pain.

Using an online survey method meant that the author was not able to gather information concerning the study's attrition rate, regarding how many people had looked at the advert but had chosen not to participate. Additionally, the online design also meant that the author was

unable to obtain information to compare the characteristics of the women who had participated with those who did not. This potentially raises difficulties when attempting to generalise the findings to other women with endometriosis.

A limitation of using self-report, is that people sometimes struggle to differentiate between different types of pain and report an overall pain experience. They may find it difficult separating their perception of pain from other feelings, including fatigue, low mood, stress and anxiety.

As women with endometriosis often experience comorbidity of physical health problems, including conditions such as migraine (Nyholt et al., 2009) and fibromyalgia (Pasoto et al., 2005), it is difficult to determine whether the QoL score is impacted by other causes of pain alongside endometriosis.

A final limitation is that the study used a cross-sectional design, which enabled the author to identify statistically significant correlations between the predictor variables and QoL but did not permit causal inference to be determined.

One of the strengths of using an online survey method was that the author had access to a large, potentially diverse population of potential participants. Validation studies examining the use of online methodology have found that data were comparable in quality to those gathered offline and are able to capture a varied sample of the target population (Arnett, 2008). Hewson and Charlton (2005) found that there was no difference between the use of an online questionnaire and face to face questionnaire in terms of reliability and validity when using the Multidimensional Health Locus of Control Scale (MHLC; Wallston & Wallston, 1981). A further strength of recruiting through Endometriosis UK was that a high proportion of the studies investigating QoL in women with CPP and endometriosis have recruited patients under the care of a gynaecologist who were attending pelvic pain clinics. This

recruitment strategy is likely to include women with more severe disease, who are struggling

to manage their symptoms and are likely to experience a higher level of psychological

distress and poorer QoL. Alternatively, this study attempted to reach women with

endometriosis who have not necessarily presented to services or who may not be under the

care of a gynaecologist.

The study also appeared to have good face validity, as 30 of the participants (17%)

emailed the researcher to thank her for choosing a health condition that is commonly not

studied, but also additionally shared their personal story about how endometriosis had

impacted upon their lives.

Despite increasing amounts of research illustrating the detrimental impact that

endometriosis can have on an individual's wellbeing, no study has been published that has

investigated the influence of psychological variables on QoL in women with endometriosis.

This study therefore is the first to demonstrate the statistically significant associations

between pain self-efficacy and illness uncertainty with QoL for women experiencing

endometriosis.

14.3. Future Research

Further research is needed to investigate the effectiveness of a psychological intervention

that aims to raise women's QoL by modifying beliefs of pain self-efficacy and illness

uncertainty. To inform the intervention, women's opinions on how to lower illness

uncertainty could be obtained through a focus group. Focus group feedback could be used to

guide and test the psychological intervention and inform health practitioners' communication

style during consultations. The study design should be case control and include pre and post

measures of QoL, using standardised measurement tools. Women should be asked to rate

their level and frequency of pain using the Visual Analogue Scale (VAS; Huskissan, 1974).

Using an experimental design would enable causal inferences to be made and could possibly lead to the development of a psychological model of wellbeing in women with endometriosis. A further qualitative study could involve interviewing women with endometriosis who are living well with the condition, which would enable researchers to explore what psychological factors appear to exist in women with a better QoL.

14.4. Conclusion

In conclusion, this study has shown that endometriosis is associated with lower levels of QoL. In accordance with other chronic pain studies, this research found there is a statistically significant relationship between psychological variables and QoL, and that there is a clear need for further research into the effectiveness of psychological approaches when attempting to improve a woman's wellbeing.

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