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# The social and psychological impact of endometriosis on women's lives: a critical narrative review

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**BACKGROUND:** Endometriosis is a chronic condition affecting between 2 and 17% of women of reproductive age. Common symptoms are chronic pelvic pain, fatigue, congestive dysmenorrhoea, heavy menstrual bleeding and deep dyspareunia. Studies have demonstrated the considerable negative impact of this condition on women's quality of life (QoL), especially in the domains of pain and psychosocial functioning. The impact of endometriosis is likely to be exacerbated by the absence of an obvious cause and the likelihood of chronic, recurring symptoms. The aims of this paper are to review the current body of knowledge on the social and psychological impact of endometriosis on women's lives; to provide insights into women's experience of endometriosis; to provide a critical commentary on the current state of knowledge and to make recommendations for future psycho-social research.

**METHODS:** The review draws on a method of critical narrative synthesis to discuss a heterogeneous range of both quantitative and qualitative studies from several disciplines. This included a systematic search, a structured process for selecting and collecting data and a systematic thematic analysis of results.

**RESULTS:** A total of 42 papers were included in the review; 23 used quantitative methods, 16 used qualitative methods and 3 were mixed methods studies. The majority of papers came from just four countries: UK (10), Australia (8), Brazil (6) and the USA (5). Key categories of impact identified in the thematic analysis were diagnostic delay and uncertainty; 'QoL' and everyday activities; intimate relationships; planning for and having children; education and work; mental health and emotional wellbeing and medical management and self-management.

**CONCLUSIONS:** Endometriosis has a significant social and psychological impact on the lives of women across several domains. Many studies have methodological limitations and there are significant gaps in the literature especially in relation to a consideration of the

impact on partners and children. We recommend additional prospective and longitudinal research utilizing mixed methods approaches and endometriosis-specific instruments to explore the impact of endometriosis in more diverse populations and settings. Furthermore, there is an urgent need to develop and evaluate interventions for supporting women and partners living with this chronic and often debilitating condition.

**Key words:** endometriosis / social / psychological / quality of life / chronic illness

## Introduction

Endometriosis is a chronic condition affecting women of reproductive age. It is characterized by the presence of endometrial-like tissue outside the uterus which induces a local inflammatory response (Kennedy *et al.*, 2005; de Nardi and Ferrero, 2011). It is an enigmatic condition; the aetiology is uncertain and contested (Damewood *et al.*, 1997; World Endometriosis Society and the World Endometriosis Research Foundation, 2012). Common symptoms are chronic pelvic pain, fatigue, congestive dysmenorrhoea, heavy menstrual bleeding and deep dyspareunia (Lemaire, 2004; de Nardi and Ferrero, 2011), and it is suggested that 47% of infertile women have endometriosis (Meuleman *et al.*, 2009). The prevalence of endometriosis is difficult to assess but has been estimated at between 2 and 17% of the female population (Damewood *et al.*, 1997; Eskenazi and Warner, 1997; Bernuit *et al.*, 2011). There is no cure for endometriosis and so management focuses on symptom relief. This can involve a range of interventions including analgesics, hormonal therapy, both minimally invasive and radical surgery, and, where relevant, fertility treatment, with varying rates of success (European Society of Human Reproduction and Embryology, 2013).

Given the chronic nature of endometriosis, the potential impact on fertility and intimate relationships, the delays in diagnosis and the problematic experiences of care (Dancet *et al.*, 2012), the social psychological impact of endometriosis on women is worthy of attention. Furthermore, there are very significant costs associated with endometriosis. A recent large-scale multicentre study of the economic costs of endometriosis revealed substantial direct and indirect costs, with annual healthcare expenditure comparable with that of other major chronic conditions such as diabetes (Simoens *et al.*, 2012). Endometriosis is therefore of considerable importance both directly in terms of its potentially negative impact on the large number of women affected by the condition and indirectly on healthcare systems and society.

The aims of this paper are to review the current body of knowledge on the social and psychological impact of endometriosis on women's lives; to provide insights into women's experience of endometriosis; to provide a critical commentary on the current state of knowledge and to make recommendations for future psycho-social research. The research question is: 'What is the impact of endometriosis on women's lives and how has this been studied?'

## Methods

To meet these objectives we adopted a method of review which involves an interpretive process and which allows the inclusion of a diversity of questions and studies, both quantitative and qualitative, from a range of disciplines. The review therefore draws on a method of critical narrative synthesis (Dixon-Woods *et al.*, 2006; Popay *et al.*, 2006) rather than a classic systematic review methodology. We have, however, adhered to the PRISMA principles as far as applicable for this type of review (Moher *et al.*, 2009) and our reporting broadly follows this approach.

## Information sources and search strategy

In February 2012, a systematic search of 13 health, medical, multidisciplinary, social science and psychology-specific databases was conducted. Appropriate search terms were constructed by reviewing abstracts, titles and keywords from a sample of papers relating to the socio-psychological impact of endometriosis known to the authors. As there appeared to be little homogeneity in the terminology used a decision was made to use 'endometriosis' as the sole search term for the social science and psychology-specific databases to ensure an inclusive approach. Sixteen further search terms were subsequently combined with 'endometriosis' when searching health, medical and multidisciplinary databases in order to limit the results to papers relevant to the review. Table 1 shows the databases searched and the search terms used.

## Process for selecting papers

### Eligibility criteria

The review was designed to take a broad overview of the topic, going beyond conventional 'quality-of-life' studies, to include the contribution of work from several disciplines including sociology, psychology and anthropology and both qualitative and quantitative approaches, to provide a more comprehensive and holistic picture of the impact of endometriosis on the lives of women.

### Inclusion criteria

Peer-reviewed, English-language journal articles that examined the social and psychological impact of endometriosis, its treatment and management were

**Table 1 Literature review databases and search terms.**

Disciplines	Databases accessed	Search terms used
Social science and psychology specific	Social Science Citation Index Applied Social Sciences Index and Abstracts International Bibliography of Social Sciences PsycINFO PsycARTICLES	Endometriosis
Health, medical and multi-disciplinary	Pubmed Academic Search Premier CINAHL Plus British Nursing Index Scopus Cochrane Library Ingenta Connect CSA Illumina	Endometriosis AND (feel OR cope OR stress OR emotion* OR distress OR quality OR experien* OR impact OR psycho* OR qualitative OR depression OR anxiety OR affect OR coping OR social OR socio*)

included in the review. No age limits on participants or date restrictions were imposed.

#### Exclusion criteria

Papers solely investigating the prevalence, medical or clinical features of endometriosis or reporting clinical effectiveness of treatments were excluded. Reviews, opinion pieces, commentaries and clinical cases studies which did not include new data were also excluded.

#### Screening

Documents identified through database searching were screened and assessed for eligibility. First, duplicates and ineligible publication types were removed. Following this, titles and, if needed, abstracts and full texts were screened by two authors independently (H.M. and C.L.) based on clearly defined inclusion and exclusion criteria and those deemed ineligible were removed.

#### Quality assessment

A quality assurance tool appropriate for both quantitative and qualitative studies was applied to full text papers (Shepherd *et al.*, 2006). This included seven criteria and, consistent with its prior use, papers were required to achieve a score of at least four out of seven to be included (Dancet *et al.*, 2010). Three authors quality assured the papers (by L.C., E.D. and C.L.); papers identified for potential exclusion were then reviewed by a fourth author (N.H.) and a decision was made.

#### Data collection process

A data extraction sheet was developed and applied to each paper to independently extract data (by all authors). Papers which met the inclusion criteria and quality assessment criteria were examined comprehensively and information from each paper was collated in an Excel spreadsheet recording: authors; publication date; research setting; research aims; research design; participants; sample size; recruitment method; data analysis methods; key findings; key themes and methodological limitations including risk of bias. For each paper, one author acted as the primary reviewer and a second author verified the data extraction. Any discrepancies were discussed between reviewers and consensus was achieved.

#### Analysis

To report on paper findings, analysis and organization of the extracted data were conducted according to principles of systematic thematic analysis (Dixon-Woods *et al.*, 2005; Braun and Clarke, 2006; Ward *et al.*, 2009). Stage one included a process of 'open coding' which was used by all seven authors to organize data from each paper during data extraction. Open coding refers to a process of selecting and naming significant issues which arise from a body of data. This process was carried out for all 42 papers. Open codes were then collated by one author (C.L.) and organized under higher order categories, or substantial themes, according to standard principles of thematic analysis (Braun and Clarke, 2006). For example, the codes 'stress', 'self-esteem', 'depression', 'anxiety' and 'isolation' were grouped under the substantial theme 'mental health and emotional wellbeing'. The resultant framework of substantial themes was discussed and refined by three authors (L.C., C.L. and N.H.) and the final seven substantial themes were agreed. The extracted data were then reorganized according to these substantial themes, and they were employed as the structuring framework for the narrative summary.

To report on paper characteristics, quantitative data on the characteristics of papers were collated and counted. These are reported in the section 'Characteristics of papers'.

## Results: search, screening and selection

The database searches resulted in a total of 1963 papers and 2 further papers were identified via contacts while duplicates and ineligible document types were excluded. After screening the titles, 1760 papers were excluded, and after screening the abstracts, 129 papers were excluded. Following this full text papers were sought. One paper (Kumar *et al.*, 2010) was not included as it could not be located: an inter-library loan request was unsuccessful as a supplier could not be located, and the author did not respond to email requests. After screening full texts, 31 papers were excluded, and after quality assuring full texts, 2 papers were excluded, resulting in 42 papers for inclusion. An overview of the search results and screening criteria is summarized in Fig. 1.

## Characteristics of papers

Given the wide-ranging nature of this review, considerable variation was found in research aims and questions, methodology, sample size and outcome measures. Table II provides an overview of the heterogeneity of the data using the variables: author/date/country; study aim/research question; research design and method and sample. In some instances data from one study were reported on in two or more papers, and therefore the 42 papers do not represent 42 separate studies or samples.

### Settings

Over half of the papers were published between 2005 and 2010, indicating a recent increase in research on the social and psychological impact of endometriosis. The majority of papers came from just 4 countries: UK (10), Australia (8), Brazil (6) and the USA (5). Of the remaining papers, six were from Western Europe, two from New Zealand, two from Puerto Rico and one from Canada and two papers reported on cross-country studies (Argentina, Belgium, Brazil, China, Ireland, Italy, Nigeria, Spain, UK and USA, Nnoaham *et al.*, 2011; Belgium, Denmark, France, Germany, Hungary, Italy, the Netherlands, Switzerland, UK and USA, Simoens *et al.*, 2012). The majority of papers were therefore from high-income countries with developed healthcare systems. Participants were recruited from single hospitals/clinics (17), multiple hospitals/clinics (6), support groups (3) or from multiple (10) or other (4) settings, or the setting was not stated (2).

### Design

Papers reported on quantitative (23), qualitative (16) and mixed methods (3) studies. The majority of papers from the UK and Australia (12 of 18) reported on qualitative studies, whereas the majority of papers from Brazil and the USA (9 of 11) reported on quantitative studies. The quantitative studies used a range of quality of life (QoL) instruments and assessments/inventories of aspects such as symptoms (including pain), wellbeing, mental health, personality, impact on work, etc. Qualitative studies predominantly used interview data collection methods, although a small number collected data via focus groups, questionnaires and diaries. Cross-sectional studies accounted for 40 papers while 2 papers reported longitudinal studies.

**Table II Paper characteristics.**

Authors, year of publication, country of analysis and participants (if different)	Study aim/research question	Research design and methods	Sample
Ballard <i>et al.</i> (2006), UK	To investigate the possible reasons for a delayed diagnosis of endometriosis and the impact of delay on women's experiences of endometriosis	Qualitative Interviews	28 women with suspected or confirmed endometriosis. Recruited via hospital/clinic
Bernuit <i>et al.</i> (2011), Germany (analysis), cross country (participants)	To elucidate the differences in diagnoses and treatment experiences of women and to assess the impact of endometriosis on their QoL	Quantitative Author devised online survey	21 749 women of which 5.1% had surgically or non-surgically diagnosed endometriosis. Recruited via online market research company
Butt and Chesla (2007), USA	To investigate the responses in couples' relationships to living with chronic pelvic pain from endometriosis	Qualitative Interviews	13 women with endometriosis and 13 male partners of women with endometriosis. Recruited via hospital/clinic and support group
Chene <i>et al.</i> (2012), France	To compare pain symptoms and the QoL between epiphenomenon and endometriosis disease	Quantitative Author devised questionnaire; SF-36; simplified sexual satisfaction Subscale of the DSFI; pain VAS	437 women with endometriosis. Recruited via hospital/clinic
Christian (1993), USA	To determine the relationship between women's symptoms of endometriosis and self-esteem	Quantitative Author devised questionnaire; RSES	23 women with endometriosis. Recruited via hospital/clinic
Cox <i>et al.</i> (2003a), Australia	To identify the information and support needs of women with endometriosis	Mixed Author devised questionnaire	465 women with endometriosis. Recruited via hospital/clinic and support group
Cox <i>et al.</i> (2003b), Australia	To identify information needs of women facing laparoscopy for endometriosis	Qualitative Focus groups	61 women with endometriosis. Recruited via hospital/clinic and support group
Cox <i>et al.</i> (2003c), Australia	To determine women's needs for information related to laparoscopy for endometriosis	Mixed Author devised questionnaire and focus groups	61 women with endometriosis. Recruitment route not stated
Denny (2004a), UK	To explore women's experiences of living with endometriosis	Qualitative Interviews	15 women with endometriosis. Recruited via hospital/clinic, support group and snowballing
Denny (2004b), UK	To explore women's experiences of living with the pain of endometriosis and examine delay in the diagnosis of the disease	Qualitative Interviews	20 women with endometriosis. Recruited via hospital/clinic, support group and snowballing
Denny (2009), UK	To explore women's experiences of living with endometriosis in a prospective study over a 1-year period	Qualitative Interviews and diaries	30 women with endometriosis. Recruited via hospital/clinic
Denny and Mann (2007), UK	To determine how much of an impact endometriosis-associated dyspareunia has on the lives and relationships of women	Mixed Interviews	30 women with endometriosis. Recruited via hospital/clinic
Denny and Mann (2008), UK	To elicit the experience of endometriosis and the impact on women's lives; to explore the experience of women with endometriosis in the primary care setting	Qualitative Interviews	30 women with endometriosis. Recruited via hospital/clinic
Eriksen <i>et al.</i> (2008), Denmark	To compare patients with endometriosis with and without pain symptoms to see if they differed on four psychological parameters (coping, emotional inhibition, depression and anxiety); to examine the effects of pain caused by endometriosis on psychosocial functioning	Quantitative Author devised questionnaire; CSQ; CECS; BDI; State Anxiety Scale of the STAI	63 women with endometriosis. Recruited via hospital/clinic.
Fagervold <i>et al.</i> (2009), Norway	To investigate longitudinally the consequences of endometriosis in women diagnosed with the disease 15 years ago.	Quantitative Author devised questionnaire	78 women with endometriosis. Recruited via hospital/clinic
Ferrero <i>et al.</i> (2005), Italy	To characterize the sexual function in women with endometriosis and deep dyspareunia	Quantitative Adapted sexual satisfaction Subscale of the DSFI; GSSI; VAS	136 women of which 96 had endometriosis. Recruited via hospital/clinic

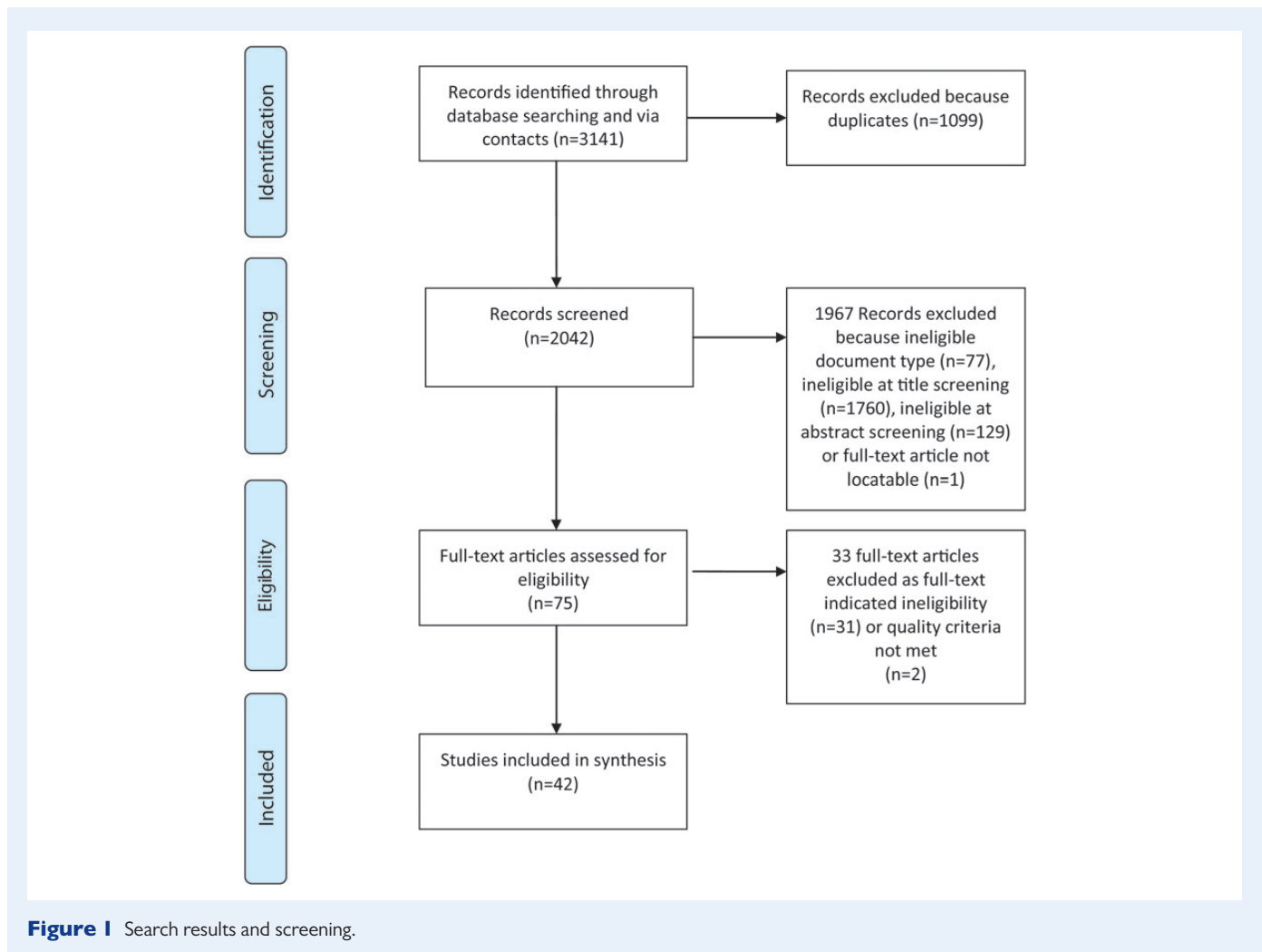
Fourquet <i>et al.</i> (2011), Puerto Rico	To quantify the impact of endometriosis-related symptoms on physical and mental health status, health-related QoL and work-related aspects	Quantitative SF-12; EHP-5; WPAI	193 women with endometriosis. Recruited via Endometriosis Research Programme
Fourquet <i>et al.</i> (2010), Puerto Rico	To assess the burden of endometriosis by obtaining patient-reported outcome data describing the experience of living with endometriosis	Quantitative Author devised questionnaire	107 women with endometriosis. Recruited via Endometriosis Research Programme
Gilmour <i>et al.</i> (2008), New Zealand	To explore the impact of symptomatic endometriosis on women's social and working lives	Qualitative Interviews	18 women with endometriosis. Recruited via support group
Huntington and Gilmour (2005), New Zealand	To explore women's perceptions of living with endometriosis, its effects on their lives and the strategies used to manage their disease	Qualitative Interviews	18 women with endometriosis. Recruited via support group
Jones <i>et al.</i> (2004), UK	To explore and describe the impact of endometriosis upon QoL; to identify and understand, from the patient's perspective, the areas of health-related QoL that are affected by endometriosis and to address the benefits of using a qualitative methodology for item generation in the development of disease-specific health status questionnaires	Qualitative Interviews	24 women with endometriosis. Recruited via hospital/clinic
Lemaire (2004), USA	To examine the frequency, severity, interference with daily life and symptom distress associated with endometriosis and to explore the relationships among symptoms, emotional distress, uncertainty and a preference for and adequacy of information	Quantitative Author devised questionnaire; MUIS-C; adapted HOSI	298 women with endometriosis. Recruited via support group
Lorençatto <i>et al.</i> (2006), Brazil	To compare the prevalence of depression in women with endometriosis according to the presence or absence of pelvic pain	Quantitative BDI	100 women with endometriosis. Recruited via hospital/clinic
Low <i>et al.</i> (1993), UK	To investigate the possibility of a specific psychological profile associated with endometriosis	Quantitative Author devised questionnaire; EPQ; BDI; GHQ 30; STAI; GRIMS; SF-MPQ	81 women of which 40 had endometriosis. Recruited via hospital/clinic
Manderson <i>et al.</i> (2008), Australia	To explore whether and how women's experience of gynaecological or reproductive health problems or conditions impacted their gendered, social and personal identities	Qualitative Interviews	40 women of which 25 had endometriosis. Recruited via community newsletter and snowballing
Markovic <i>et al.</i> (2008), Australia	To explore the influence of socio-demographic background and social and family norms on the illness narratives of endurance and contest among women with endometriosis	Qualitative Interviews	30 women with endometriosis. Recruited via community newsletter and snowballing
Marques <i>et al.</i> (2004), Brazil	To assess the QoL in women with chronic pelvic pain associated with endometriosis and to correlate QoL with personal characteristics	Quantitative Author devised questionnaire; medical records; SF-36	57 women with endometriosis. Recruited via hospital/clinic
Mathias <i>et al.</i> (1996), USA	To determine the prevalence of chronic pelvic pain in US women aged 18–50 and to examine its association with health-related QoL, work productivity and healthcare utilization	Quantitative Author devised telephone administered questionnaire, including section based on MOS	773 women with pelvic pain of which 74 had endometriosis. Recruited via research company
Noaham <i>et al.</i> (2011), cross country	To assess the impact of endometriosis on health-related QoL and work productivity	Quantitative Author devised questionnaire; SF-36; WPAI	1418 women of which 745 had endometriosis. Recruited via hospital/clinic
Petrelluzzi <i>et al.</i> (2008), Brazil	To evaluate the perceived stress index, QoL and hypothalamus–pituitary–adrenal axis activity in women with endometriosis and chronic pelvic pain	Quantitative Pain VAS; SF-36; PSQ; salivary cortisol concentrations	175 women of which 93 had endometriosis. Recruited via hospital/clinic
Peveler <i>et al.</i> (1996), UK	To compare the groups of laparoscopy-negative pelvic pain patients and patients with laparoscopically confirmed endometriosis, using measures of mood, personality and social adjustment; to investigate further the relative importance of psychological and social factors in such patients	Quantitative Pain index measure; pain VAS; BSI; EPQ; SAS	91 women of which 40 had endometriosis. Recruited via hospital/clinic

Continued

**Table II** *Continued*

Authors, year of publication, country of analysis and participants (if different)	Study aim/research question	Research design and methods	Sample
Roth <i>et al.</i> (2011), USA	To compare women with chronic pelvic pain from endometriosis with those with chronic pelvic pain from other reasons to determine if there are any psychological variables uniquely associated with endometriosis	Quantitative Clinic devised questionnaire; BDI; BSI; MPQ; PDI	138 women of which 30 had endometriosis. Recruited via hospital/clinic
Seear (2009a), Australia	No explicit study aim or research question, but focuses on factors associated with delayed diagnosis of endometriosis	Qualitative Interviews	20 women with endometriosis. Recruited via support group and snowballing
Seear (2009b), Australia	To explore the experiences of women living with endometriosis; to examine how women become experts in their own care and the ramifications of these processes for women	Qualitative Interviews	20 women with endometriosis. Recruited via support group and snowballing
Seear (2009c), Australia	To examine the phenomenon of non-compliance with health advice among women diagnosed with endometriosis	Qualitative Interviews	20 women with endometriosis. Recruitment route not stated
Sepulcri and do Amaral, (2009), Brazil	To assess depressive symptoms, anxiety and QoL in women with pelvic endometriosis	Quantitative Author devised questionnaire; pain VAS; BDI; HAM-D; STAI; HAM-A; WHOQOL-BREF	104 women with endometriosis. Recruited via hospital/clinic
Siedentopf <i>et al.</i> (2008), Germany	To identify if (i) psychosocial factors differ in endometriosis; (ii) related psychosocial aspects alter immune markers of depression/sickness behaviour and (iii) serum immune marker may be indicative for endometriosis (last two aims not included in review)	Quantitative Blood tests; ADS; SF-36; adapted PSQ; F-SoZU	69 women of which 38 had endometriosis. Recruited via hospital/clinic
Simoens <i>et al.</i> (2012), cross country	To calculate the costs and health-related QoL of women with endometriosis-associated symptoms	Quantitative Author devised questionnaire; WPAI; EuroQoL-5D	909 women with endometriosis. Recruited via hospital/clinic
Souza <i>et al.</i> (2011), Brazil	To compare the QoL in patients with chronic pelvic pain due to endometriosis or other reasons	Quantitative WHOQOL-BREF; Pain VAS; HARS; BDI	57 women with pelvic pain of which 32 had endometriosis. Recruited via hospital/clinic
Tripoli <i>et al.</i> (2011), Brazil	To evaluate the QoL of women with chronic pelvic pain with and without endometriosis	Quantitative WHOQOL-BREF; GRISS	134 women of which 49 had endometriosis. Recruited via hospital/clinic
Waller and Shaw (1995), UK	To investigate whether there are psychological differences between women with symptomatic as opposed to asymptomatic mild endometriosis	Quantitative Author devised questionnaire; BDI; STAI; GRISS	117 women of which 49 had endometriosis. Recruited via hospital/clinic
Whelan (2007), Canada (analysis), cross country (participants)	To analyse the epistemological strategies and standards used by members of an endometriosis patient community	Qualitative Focus groups and survey	24 women with endometriosis. Recruited via support group and online community

ADS, Allgemeine Depressionsskala, general depression scale; BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; CSQ, Coping Styles Questionnaire; CECS, Courthald Emotional Control Scale; DFSI, Derogatis Sexual Functioning Inventory; EHP, Endometriosis Health Profile; EPQ, Eysenck Personality Questionnaire; EuroQoL-5D, Health-related quality of life measure; F-SoZU, Fragebogen zur sozialen Unterstützung (measuring social support); GHQ, General Health Questionnaire; GRIMS, Golombok Rust Inventory of Marital State; GRISS, Golombok Rust Inventory of Sexual Satisfaction; GSSI, Global Sexual Satisfaction Inventory; HAM-A, Hamilton Rating Scale for Anxiety; HAM-D, Hamilton Rating Scale for Depression; HARS, Hamilton Anxiety Rating Scale; HOSI, Krantz Health Opinion Survey, Information Subscale; MOS, Medical Outcomes Study; MPQ, McGill Pain Questionnaire; MUIS-C, Mischel Uncertainty in Illness Scale-Community Form; PDI, Pain Disability Index; PSQ, Perceived Stress Questionnaire; RSES, Rosenberg Self-Esteem Scale; SAS, Social Adjustment Scale; SF, Short Form Health Survey; SF-MPQ, Short Form McGill Pain; STAI, State-Trait Anxiety Inventory; VAS, visual analogue scale; WHOQOL-BREF, World Health Organization Quality of Life instrument short version; WPAI, Work Productivity and Activity Impairment Survey.



## Participants

Sample sizes varied considerably: from 23 to ~1110 women with endometriosis with a mean of 207 in quantitative papers; from 13 to 61 women with endometriosis with a mean of 25 in qualitative papers and from 30 to 465 women with endometriosis with a mean of 185 in mixed methods studies. Most papers reported on studies of women with confirmed (i.e. surgically diagnosed) endometriosis, although in papers where women were recruited via routes other than hospitals and clinics, diagnosis was based on self-report and not clinically verified. Thirteen papers reported on studies with broader samples where women with endometriosis were included as a subset, and where data about women without endometriosis were used for comparison. Only one study included male partners alongside women with endometriosis.

## Findings on the social and psychological impact of endometriosis

Key categories identified in the thematic analysis were: diagnostic delay and uncertainty; 'QoL' and everyday activities; intimate relationships; planning for and having children; education and work; mental health

and wellbeing and medical and self-management. Pain is a significant symptom that arises in all of these categories, and as such the impact of pain is considered throughout the findings.

### Diagnostic delay and uncertainty

There were 21 papers (50%; 14 qualitative, 5 quantitative and 2 mixed methods) which reported findings relating to the impact of endometriosis in terms of diagnostic delay or uncertainty. Women with endometriosis frequently experience significant delays from symptom onset to diagnosis (Cox *et al.*, 2003a; Denny, 2004a, b; Denny and Mann, 2008; Sepulcri and do Amaral, 2009; Fourquet *et al.*, 2010; Bernuit *et al.*, 2011; Nnoaham *et al.*, 2011), ranging from 5 (Sepulcri and do Amaral, 2009) to 8.9 years (Fourquet *et al.*, 2010). Diagnostic delays have been shown to be associated with reduced health-related QoL (Nnoaham *et al.*, 2011). It is useful, therefore, to outline the findings regarding delayed diagnosis. The authors have distinguished between delays at the patient level and delays at the medical level (Ballard *et al.*, 2006).

#### *Diagnostic delay: factors at the patient level*

The delay at the patient level refers to the time between symptom onset and seeking medical help. Cox *et al.* (2003a, b) identified an average delay of 3.8 years between symptom onset and help-seeking behaviour. It is



suggested that women fail to seek medical help due to difficulty in distinguishing between normal and pathological symptoms; because they consider themselves 'unlucky' as opposed to 'unwell' and because they fear that disclosure would result in embarrassment and in them being perceived as weak (Cox et al., 2003b; Ballard et al., 2006).

Women themselves and those around them (family and friends) are frequently unaware of endometriosis as a condition (Denny, 2009; Fourquet et al., 2010). The perception of menstrual irregularities as 'normal' and the perception of menstrual pain as something to be endured also contribute to delay in seeking help (Cox et al., 2003b; Denny, 2004b; Ballard et al., 2006), particularly for adolescents (Manderson et al., 2008; Markovic et al., 2008). Denny (2004b) and Seear (2009a) refer to an 'etiquette of menstruation' (Laws, 1990) whereby in many societies, menstruation itself is perceived as something private and something to be hidden. Women may thus actively conceal their menstrual irregularities, especially from men. Others, such as mothers and friends, facilitate and encourage this concealment (Seear, 2009a). However, the influence of family and friends who are able to identify pain experiences as abnormal and encourage help seeking, as well as disrupted social roles such as in performing education or work tasks, may also serve as catalysts that shift a woman's understanding of her symptoms from being normal to pathological (Manderson et al., 2008).

#### *Diagnostic delay: factors relating to the medical profession*

Delays to diagnosis have also been identified once women have sought medical help for their symptoms and misdiagnosis is common (Denny, 2004b; Jones et al., 2004; Huntington and Gilmour, 2005; Denny and Mann, 2008). Studies demonstrate medical level delays, between help-seeking and diagnosis, of between 3.7 (Cox et al., 2003a) and 5.7 years (Denny and Mann, 2008). Delays were found to be common at the primary care level and reflect resistance to referral (Denny and Mann, 2008; Nnoaham et al., 2011). Several papers suggest that prior to diagnosis, women commonly experience repeated visits to doctors where symptoms are normalized, dismissed and/or trivialized, resulting in women feeling ignored and disbelieved (Cox et al., 2003a, b; Denny, 2004a, b, 2009; Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008; Manderson et al., 2008; Markovic et al., 2008). Women were often initially referred to inappropriate secondary care, or were misdiagnosed, most commonly with irritable bowel syndrome or pelvic inflammatory disease (Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008). General practitioners were reported as lacking knowledge, awareness and sympathy and displaying attitudes that perpetuate myths about endometriosis (Cox et al., 2003b; Denny, 2004b; Jones et al., 2004; Denny and Mann, 2008).

On receiving a diagnosis, symptomatic women frequently reported that they felt a sense of relief, legitimization (i.e. confirmation that their symptoms were genuine), liberation and empowerment, replacing feelings of fear and self-doubt (Cox et al., 2003a; Denny, 2004b; Huntington and Gilmour, 2005; Ballard et al., 2006; Manderson et al., 2008; Seear, 2009b). Others reported feelings of anger at the delay to diagnosis and feeling vindicated that their persistence was valid (Denny, 2004b; Denny and Mann, 2008). Diagnosis provides women with a language with which to explain their experiences and sanctions access to support services (Ballard et al., 2006). Conversely, asymptomatic women who were diagnosed opportunistically experienced a different response, often characterized by shock and disbelief (Cox et al., 2003a).

Uncertainty, which is a factor in delayed diagnosis especially at the patient level (see above), continues post-diagnosis; endometriosis is a disease characterized by uncertainty at several levels (Lemaire, 2004; Butt and Chesla, 2007; Whelan, 2007; Denny, 2009). Along with 'diagnostic uncertainty', women experience 'symptomatic uncertainty' (relating to the variability of symptoms and the trial and error approach to treatment) and 'trajectory uncertainty' (relating to uncertainty about their future) (Denny, 2009).

#### **'QoL' and everyday activities**

There were 17 papers (40%; 14 quantitative and 3 qualitative) which reported findings relating to the impact of endometriosis on QoL and everyday activities. QoL measures have been widely used in studies of endometriosis, and are discussed in several review papers (Gao et al., 2006; Jia et al., 2012). Most utilize general QoL measures [e.g. Short Form Health Survey-36 and -12 (SF-36 and SF-12)] rather than those specific to endometriosis [Endometriosis Health Profile-30 and -5 (EHP-30 and EHP-5)]. A number of studies demonstrate reduced QoL among women with endometriosis (Marques et al., 2004; Petrelluzzi et al., 2008; Siedentopf et al., 2008; Bernuit et al., 2011; Tripoli et al., 2011; Chene et al., 2012), and one study demonstrated that a minority of women consider themselves to have a current state of health 'worse than death' (Simoens et al., 2012).

Pain is consistently reported as a central and destructive feature of life with endometriosis and several studies report a negative correlation between pain and QoL (Sepulcri and do Amaral, 2009; Nnoaham et al., 2011; Souza et al., 2011; Tripoli et al., 2011). Endometriosis symptoms, and specifically pain, have a detrimental impact on daily life and physical functioning (e.g. sleeping, eating, moving) (Jones et al., 2004; Petrelluzzi et al., 2008). Between 16% (Simoens et al., 2012) and 61% (Fourquet et al., 2011) of women experience difficulties with mobility, daily activities and/or self-care. Fourquet et al. (2011) also found that women had SF-12 scores denoting statistically significant disability in physical and mental health components, indicating that the women in this study experienced substantial disability and Nnoaham et al. (2011) found that women with endometriosis had reduced physical health compared with the normative population. Sleeping has also been found to be negatively affected by endometriosis (Fourquet et al., 2010).

Household and housekeeping activities (e.g. cooking, shopping, cleaning, gardening and childcare) are also affected (Jones et al., 2004) for between 23% (Bernuit et al., 2011) and 71% (Fourquet et al., 2010) of women with endometriosis. Bernuit et al. (2011) found that of all the women who reported that endometriosis had a negative impact on their QoL (67% of the total sample), a third (36%) said it affected their relationships with family, whereas in a smaller scale study, Fourquet et al. (2010) found that 45% of women reported a negative impact on childcare.

Energy and vitality were also reported to be negatively impacted by endometriosis (Jones et al., 2004). For example, Fourquet et al. (2011) found that 27% of women with endometriosis reported low energy levels, while Petrelluzzi et al. (2008) reported that women had poor QoL (SF-36) scores for vitality. A negative impact of pain on sport and exercise has also been demonstrated (Fourquet et al., 2010; Bernuit et al., 2011).

Several authors have documented the impact of endometriosis on women's social lives. Studies report that between 19 and 48% of

women experience an impact on their social lives (Fagervold *et al.*, 2009; Fourquet *et al.*, 2010, 2011; Bernuit *et al.*, 2011). Petrelluzzi *et al.* (2008) found that women with endometriosis and chronic pelvic pain of moderate intensity showed a poorer QoL in the social functioning dimension than a control group. Gilmour *et al.* (2008) and Jones *et al.* (2004) reported that women experienced a reduction in social activities due to pain, fatigue and the need for toilet access, or worry about the onset of pain while they were out, leaving them feeling depressed, moody and angry. Women also described feeling less able to socialize when they are out (due to being preoccupied with worry about their condition), resulting in reduced confidence (Jones *et al.*, 2004).

However, the impact of endometriosis symptoms, especially pain, is dynamic: it changes over time and across life stages. A retrospective study of women diagnosed 15 years previously highlighted the way that pain changes over the life course: the majority of women who had been pain free at diagnosis reported experiencing pain post-diagnosis; but pain experiences changed again at menopause, as 96.9% of post-menopausal women reported being pain free, compared with 19.6% of premenopausal women (although other symptoms such as flatulence and urinary symptoms were common among post-menopausal women) (Fagervold *et al.*, 2009).

### Intimate relationships

There were 12 papers (29%; 6 qualitative, 5 quantitative and 1 mixed methods) which offered findings relating to the impact of endometriosis on intimate relationships, including, but not limited to, findings about the incidence and impact of dyspareunia (painful sexual intercourse).

Papers suggest a substantial impact of endometriosis on the quality of sex life: between 33.5% (Bernuit *et al.*, 2011) and 71% (Fourquet *et al.*, 2011) of women reported that endometriosis negatively affected their sex lives. Chene *et al.* (2012) reported that the quality of sex life was affected in both women with minimal and with severe endometriosis.

Specifically, incapacitating pain and dyspareunia were found to have an impact on sex life (Fourquet *et al.*, 2010). One large, cross-country study suggested that 24–25% of women with diagnosed endometriosis experienced dyspareunia (Bernuit *et al.*, 2011). Other, smaller scale studies have reported higher rates at between almost 50 and 100% (of sexually active participants) (Christian, 1993; Denny, 2004a, b; Jones *et al.*, 2004; Denny and Mann, 2007; Chene *et al.*, 2012). Denny and Mann (2007) found that for 69% of women, dyspareunia included pain in the hours and days after sex and Ferrero *et al.* (2005) suggested that women with endometriosis had frequently suffered dyspareunia during their entire sex lives. Responses to dyspareunia include starting but then stopping intercourse; changing positions; enduring intercourse because of a desire for pregnancy and enduring intercourse because of a reluctance to allow endometriosis to affect yet another aspect of life or because of a desire for closeness with a partner (Denny and Mann, 2007). Both Denny and Mann (2007) and Jones *et al.* (2004) report that the majority of women who experience dyspareunia subsequently avoid or limit sexual intercourse. This results in feelings of inadequacy and guilt (Jones *et al.*, 2004). A number of studies report that women with endometriosis and pain symptoms report less frequent sex than those with asymptomatic endometriosis and controls (Waller and Shaw, 1995; Tripoli *et al.*, 2011). Fagervold *et al.* (2009) found a correlation between dyspareunia (which 1/3 reported) and negative impacts on relationships. Qualitative research found that women were reluctant

to discuss dyspareunia with healthcare professionals and that women reported that healthcare professionals did not ask about this (Denny, 2004a, b). However, Bernuit *et al.* (2011) found that nearly half (47%) of women with diagnosed endometriosis who reported that pain affected their QoL had visited their doctor due to dyspareunia. Interventions to enable couples to address the impact of endometriosis on sexual relations are limited and those that are available are reported by couples to be unhelpful (Butt and Chesla, 2007).

Several studies have found that women feel that the symptoms and experience of endometriosis more generally (including but not limited to dyspareunia) have had a negative impact on their relationships and have in some cases contributed to relationship breakdown (Cox *et al.*, 2003c; Denny, 2004a, b; Jones *et al.*, 2004; Huntington and Gilmour, 2005; Fagervold *et al.*, 2009). Fagervold *et al.* (2009) reported that 40 out of 78 (51%) women felt that endometriosis had a negative effect on their relationship (but for most only at certain points in the cycle), that 12 reported serious problems with relationships and that 6 had experienced relationship breakdown as a result. However, in some cases partners were also identified as an important source of support (Denny, 2004a). In a rare though small-scale study of women and their male partners, Butt and Chesla (2007) found that the experience of living with endometriosis disrupted day-to-day life and intimate relatedness for couples. They identified five relationship 'coping' patterns: 'together but alone'; 'battling together'; 'conjoined through disability'; 'totalized by caregiving' and 'engaged in mutual care' (Butt and Chesla, 2007).

### Planning for and having children

There were 10 papers (24%; 5 quantitative, 4 qualitative and 1 mixed methods) which offered findings relating to the impact of endometriosis on planning for and having children. Sepulcri and do Amaral (2009) and Christian (1993) reported that ~50% of couples had experienced problems conceiving. Infertility may be more common however as Fourquet *et al.* (2010) found that 71% of women had attempted to conceive and 90% of these had experienced difficulties.

However, Fourquet *et al.* (2010) also found that only 47% of women who had difficulties conceiving sought infertility treatment and Mathias *et al.* (1996) found that only 4% of women were undergoing infertility treatment. Fagervold *et al.* (2009) reported that of 45 women with infertility, 76% went on to deliver a biological child and 44% of these were conceived via IVF.

Infertility, or concerns about possible infertility, is reported to result in worry, depression and feelings of inadequacy among women, and to contribute to relationship breakdown (Jones *et al.*, 2004). However, other studies found no correlation between infertility and negative effects on relationships (Fagervold *et al.*, 2009). Women felt that GPs' attitudes and knowledge, and their experiences of delayed diagnosis, subsequently influenced their experiences of in/fertility (Denny and Mann, 2008). Women experience uncertainty regarding fertility in the future (Denny, 2009) and report wanting more information about potential infertility (Cox *et al.*, 2003a).

### Education and work

There were 12 papers (29%; 7 quantitative, 4 qualitative and 1 mixed methods) which offered findings relating to the impact of endometriosis on education and work.

A focus on the impact of endometriosis on education has been included in a small number of papers with inconclusive findings. Whilst some studies reported that endometriosis had affected women's study activity and grades, and had caused some to leave education before completion (Huntington and Gilmour, 2005; Gilmour et al., 2008), others reported that only a minority of women had experienced negative consequences on their education (Fagervold et al., 2009).

More commonly, researchers have explored how endometriosis has impacted on women's working lives. The authors have suggested that women miss an average of 7.41 h of work per week when symptoms are at their worse (Fourquet et al., 2011), and that more generally they have an average of 13% loss of work time (Fourquet et al., 2011) or miss 19.3 days of work per year (Fourquet et al., 2010). Similarly, Nnoaham et al. (2011) found that women with endometriosis lost an average of 10.8 h weekly, but this was mainly due to reduced effectiveness at work, as opposed to absenteeism. Several papers suggest that women's endometriosis symptoms, particularly pain symptoms, impact on productivity at work with between 23 and 66% reporting limitations in their ability to perform work-related activities (Fourquet et al., 2010, 2011; Bernuit et al., 2011). Fourquet et al. (2010) also reported that 84–85% of women described a decrease in their quality of work, and elsewhere these authors report an average rate of work impairment and reduced effectiveness of 65% (presenteeism) and an average loss of efficiency levels of 64% (work productivity loss) (Fourquet et al., 2011). These findings have been echoed by other authors (Mathias et al., 1996; Cox et al., 2003c; Denny, 2004a; Huntington and Gilmour, 2005; Gilmour et al., 2008; Fagervold et al., 2009). According to Simoens et al. (2012), the average cost of productivity loss per woman with endometriosis is estimated to be €6298, double the average direct healthcare cost. Menstrual pain, incapacitating pain, abdominal pain and depression predict poor performance at work (Fourquet et al., 2010).

Informing employers of their diagnosis of endometriosis and of its symptoms causes tensions for women, as while it is felt to be a private condition, women also need support in employment (Gilmour et al., 2008). Women do not always inform employers of their diagnosis or symptoms for a range of reasons including the potential implications of this and because they find it difficult to discuss a gender-specific condition with male employers (Gilmour et al., 2008). Gilmour et al. (2008) suggest that the decision to disclose may be affected by women's past experiences of being disbelieved. Gilmour et al. (2008) and Denny (2004a) both found that women reported variability in employers' responses: for example, some were supportive, sympathetic and willing to make adjustments to working practices, whereas others lacked sympathy and understanding and trivialized or disbelieved symptoms.

## Mental health and emotional wellbeing

There were 21 papers (50%; 15 quantitative, 4 qualitative and 2 mixed methods) which offered findings relating to the impact of endometriosis on mental health and emotional wellbeing. The heterogeneity of papers in this theme precludes an overall thematic synthesis, and the results are presented first for quantitative studies and then the contributions of qualitative work are discussed.

### Quantitative studies: depression, anxiety and emotional distress

Papers reporting on quantitative studies into the links between endometriosis and mental health and emotional wellbeing have varying results,

both within and across papers. For example, Siedentopf et al. (2008) found that women with endometriosis reported higher levels of perceived stress compared with controls and Petrelluzzi et al. (2008) found that women with endometriosis and chronic pelvic pain of moderate intensity show higher perceived levels of stress than those of the standard population, and have low QoL scores relating to mental health. Conversely, Low et al. (1993) found the rates of psychoticism among women with endometriosis to be within normal range, and that women with endometriosis were at the boundary of mild depression and the normal range. Waller and Shaw (1995) found that women with endometriosis had similar anxiety levels compared with control groups. Overall, the weight of the evidence points to higher rates of depression, anxiety and emotional distress than control groups and the general population (Low et al., 1993; Peveler et al., 1996; Lemaire, 2004; Lorençatto et al., 2006; Petrelluzzi et al., 2008; Siedentopf et al., 2008; Sepulcri and do Amaral, 2009; Fourquet et al., 2011; Simoens et al., 2012).

No firm conclusions can be drawn about the role of pain when comparing women with endometriosis-related pain and those with endometriosis who do not have pain (Waller and Shaw, 1995; Marques et al., 2004; Lorençatto et al., 2006; Eriksen et al., 2008; Sepulcri and do Amaral, 2009), but overall findings comparing women with chronic pelvic pain associated with endometriosis to women with chronic pelvic pain from other or unknown causes suggest that it is the experience of pain, as opposed to endometriosis itself, that is associated with mental health difficulties and emotional distress (Low et al., 1993; Waller and Shaw, 1995; Peveler et al., 1996; Roth et al., 2011; Souza et al., 2011). However, some authors have pointed out that even when rates of depression, anxiety and emotional distress appeared to be higher for women with endometriosis-related pain, the causal direction could not be identified (Lorençatto et al., 2006; Sepulcri and do Amaral, 2009). Data regarding correlations between endometriosis stage and mental health and emotional wellbeing also appear inconclusive (Marques et al., 2004; Siedentopf et al., 2008; Sepulcri and do Amaral, 2009).

### Qualitative studies: the experience of emotional distress

Emotional distress is a pervasive theme throughout the range of papers reporting on qualitative studies and suggest that emotional distress is a key feature of living with endometriosis for many women and also for their partners. Endometriosis is reported to result in feelings of emotional distress, hopelessness, isolation, worthlessness and depression and feeling suicidal (Cox et al., 2003a, b; Whelan, 2007). Women feel they cannot cope with the pain, leaving them miserable, depressed, moody and short tempered. They experience loneliness as a result of social isolation and are reluctant to discuss their experiences with others as they feel their accounts are not always believed. Physical appearance and self-image may be affected by a range of factors including treatments that cause feelings of bloatedness, having greasy or spotty skin and weight gain (Jones et al., 2004). The impact of endometriosis on mental health and emotional wellbeing may extend to partners: Butt and Chesla (2007) described the emotional pain and multiple griefs and losses experienced by both women and their male partners.

## Medical management and self-management

There were 11 papers (26%; 10 qualitative and 1 mixed methods) which offered findings relating to the impact of endometriosis in relation to medical and self-management.

### Medical management

Treatments intended to reduce symptoms often carry side effects that impact on QoL (Denny, 2004a; Jones *et al.*, 2004) and offer only short-term relief (Denny, 2009). Denny (2004a) found that women felt more positive about surgical treatment than drug treatment. However, women worry about various aspects of treatment including side effects and hospital stays, and report frustration at having to rely on medical treatment, and anger at the lack of effective treatments (Jones *et al.*, 2004). Markovic *et al.* (2008) describe how the narratives of endurance that characterize women's experiences pre-diagnosis (e.g. endurance of pain) continue post-diagnosis as they endure treatments which may compromise overall health and wellbeing, and this was particularly true for adolescents who were more accepting of the dominant biomedical model. The long-term effects of medical treatment also concern many women (Denny, 2004a, b).

Women with endometriosis have experienced significant variability in healthcare professionals' attitudes and behaviours which are frequently described as problematic (see the section 'diagnostic delay and uncertainty'). For example, women report feeling that the quality, intensity, duration and impact of pain are central to their experiences. However, while healthcare professionals express interest in the level and location of the pain, they do not ask in depth questions about the nature of the pain (i.e. its quality, effect and duration) (Denny, 2004a, b, 2009).

### Self-management

In response to the limitations of medical treatment, some women also attempt to manage their endometriosis and alleviate symptoms through lifestyle changes (e.g. changes to diet and exercise) and through complementary and/or alternative therapies (Cox *et al.*, 2003c; Huntington and Gilmour, 2005; Gilmour *et al.*, 2008; Markovic *et al.*, 2008). However, healthcare practitioners' information and advice-giving regarding non-medical and self-management strategies has been described as lacking (Huntington and Gilmour, 2005; Gilmour *et al.*, 2008). For some women, non-medical management strategies were used alongside medical treatment (Cox *et al.*, 2003c), whilst others turned to this approach due to disenchantment with medical treatment and a rejection of the biomedical approach (Cox *et al.*, 2003c; Markovic *et al.*, 2008). This use of alternatives to biomedicine is largely described as an 'empowering' experience that has allowed women to 'take control' of their management (Cox *et al.*, 2003c; Huntington and Gilmour, 2005; Gilmour *et al.*, 2008; Seear, 2009b) and can promote healthier living more generally (Gilmour *et al.*, 2008). However, authors have also reported on the problematic aspects of non-medical- and self-management, including the financial constraints in access to some treatments (Cox *et al.*, 2003c; Seear, 2009c) and the extent to which such management methods can disrupt life (Huntington and Gilmour, 2005). Becoming an 'expert patient' by developing knowledge and engaging in self-management is demanding and has been found to both reduce and compound the stress of living with endometriosis (Seear, 2009b).

## Discussion

This is the first comprehensive review of the socio-psychological impact of endometriosis incorporating both qualitative and quantitative studies from a range of disciplines. We have used a thematic approach to

consolidate this body of knowledge and to provide insights into women's experience of endometriosis.

That women experience considerable delays between symptom onset and diagnosis has been well evidenced (e.g. Arruda *et al.*, 2003) and papers included in this review confirm this. These delays occur at both the patient level and the medical level. Receiving a diagnosis often results in feelings of relief and vindication. It is concerning that findings regarding the delay to diagnosis, and the features that contribute to this, have been well documented for several years, and yet these delays continue to be significant features of the experience of endometriosis for many women. Endometriosis is characterized by uncertainty and this uncertainty is not only a key feature of the diagnostic delay, but also of living with and making sense of endometriosis post-diagnosis. The uncertainty surrounding diagnosis, treatment and prognosis needs to be acknowledged and discussed with women in the clinical encounter.

Quantitative studies have concluded that endometriosis symptoms can negatively and substantially impact QoL and daily activities such as household tasks, energy and vitality and socializing as well as physical functioning. Qualitative studies suggest that the negative impact of endometriosis on daily life and on women's lives is complex, multidimensional and pervasive. Many women feel that endometriosis controls and restricts their lives, leaving them powerless. Again, these findings have persisted over time, and the paucity of effective and long-term treatments and the absence of a cure are likely to be key contributing factors. Findings regarding the incidence of dyspareunia vary, but suggest that it has a significant social and psychological impact.

However, research into the impact on QoL and everyday activities focuses almost entirely on women. While studies suggest that intimate relationships are affected by pain, dyspareunia and infertility, little is known about how endometriosis impacts on women's partners and children or how wider family members are affected by and respond to women with endometriosis. The very limited research with male partners suggests that relationships can be negatively impacted (Fernandez *et al.*, 2006), although elsewhere partners are also identified as important sources of support (Denny, 2004a). Given the pervasive impact of endometriosis across many social domains, the lack of research on partners and couples' relationships is particularly stark. This is all the more problematic, since there is evidence from other conditions that male partners are impacted by living with and caring for a partner with a chronic condition (Scott *et al.*, 2004).

Limited research suggests that the impact, or potential impact, of endometriosis on fertility causes worry, depression and feelings of inadequacy. Considering that almost half of infertile women have endometriosis, it is perhaps surprising that there has been little research into the social and psychological experience of infertility, or of anticipated infertility, among women with endometriosis.

There is consistent evidence of a negative impact of endometriosis on women's working lives and the difficulties they experience in disclosing information to employers. However, the links between research evidence and policy and law relating to disability and employment are rarely made. For example, there appears to have been little exploration of how equality legislation might apply to some women with endometriosis and women's experiences of reasonable adjustments.

The weight of evidence from quantitative studies suggests that rates of depression, anxiety and emotional distress are higher for women with endometriosis than control groups or the general population. While no firm conclusions can be drawn about the role of pain when comparing

women with endometriosis pain and women with pain-free endometriosis, the overall findings comparing women with chronic pelvic pain-related to endometriosis and women with chronic pelvic pain from other or unknown causes suggest that it is the experience of pain, as opposed to endometriosis itself, that is associated with mental health difficulties and emotional distress. Qualitative studies highlight the emotional distress that characterizes many women's lives, including feelings of isolation, guilt, worry, worthlessness and hopelessness, and feeling unable to cope. The mechanisms by which this occurs are unclear however, as pain, emotional distress, fatigue and dissatisfaction with health care and available treatments are all interwoven within the complex experience of endometriosis. Despite calls for care and support to better focus on psychological and emotional experiences and impact, depression, anxiety and emotional distress appear to prevail and there are few reports of systematic interventions to address these issues.

While this review does not consider treatment outcomes and efficacy, the reviewed papers suggest that the experience of medical treatment is often problematic for many women. In response to this, some women have attempted to self-manage their endometriosis through lifestyle changes and/or complementary and alternative therapies. However, these strategies can also be problematic since they may involve financial and practical difficulties and may themselves pose risks to wellbeing.

It is possible to suggest a number of strategies to reduce the negative social and psychological impact of endometriosis. Better awareness of the varied clinical features and manifestations of endometriosis and selection of the most appropriate investigations by healthcare practitioners may reduce delays to diagnosis at the medical level (Huntington and Gilmour, 2005; Ballard et al., 2006; Denny and Mann, 2008). This can only be achieved by improved education of all healthcare professionals who may come into contact with women with endometriosis. Increasing women's awareness of physiology and of endometriosis through education in schools and via support groups may help women to distinguish between menstrual pain and endometriosis and reduce patient delays in seeking help (Cox et al., 2003b; Lemaire, 2004). Seear (2009a), however, warns that strategies to increase awareness of endometriosis and to help women distinguish between normal and abnormal pain need to be grounded in an understanding of why pain is normalized, and of the stigma associated with menstrual irregularities.

Health care management post-diagnosis needs to be more holistic. It should be informed by an understanding of the multidimensional impact of endometriosis and underpinned by a biopsychosocial approach that includes emotional support, stress reduction, social support, adaptive coping strategies, psychosexual treatment and a focus on QoL issues, sex and relationships, pain management and career counselling (Peveler et al., 1996; Huntington and Gilmour, 2005; Lorençatto et al., 2006; Butt and Chesla, 2007; Denny and Mann, 2007; Siedentopf et al., 2008; Seear, 2009b; Roth et al., 2011). Recent research has identified problematic care experiences in endometriosis centres and identified the need for a more patient-centred approach to care (Dancet et al., 2012).

Women report receiving insufficient information at diagnosis, and express a desire for more information about surgery (e.g. anaesthetic procedures, the location and size of incisions, possible complications and recovery time and pain) (Cox et al., 2003a) and general information about living with and managing endometriosis (Huntington and Gilmour, 2005).

More information (both verbal and written) about the management, including non-medical- and self-management, of endometriosis should therefore be made available to women. This must be delivered in a helpful format and provided in a timely manner. However, in doing this we need to take account of the contested and problematic nature of endometriosis and of the 'knowledge' surrounding it (Seear, 2009b, c).

Support/information groups are of value and help women to interpret their experiences, feelings and emotions. Information and confidence gained from such groups allows women to evaluate medical information and negotiate with healthcare practitioners, insurers and employers (Whelan, 2007). Such groups also offer a route into wider patient communities, which are an important source of support. Indeed, women have deemed other women with endometriosis to be the most useful and valued source of information (Whitney, 1998). The rise in online communication has also provided women with new and different ways to share information and provide and receive support (Emad, 2006; Neal and McKenzie, 2011). Support groups also provide researchers with links to patients for research studies and are an invaluable mechanism to achieve patient and public engagement in research and service improvement activities.

## Methodological issues

Overall the quality of the papers was good, with just two excluded in the quality assessment phase. However, some limitations and weaknesses can be identified.

Quantitative studies of the impact of endometriosis are primarily concerned with establishing correlations between the characteristics of women with endometriosis and their symptoms and QoL. Many researchers rely on *a priori* categories pertaining to the impacts and implications of endometriosis, which may not be derived from qualitative, inductive research into how women experience the condition (see Jones et al., 2004 and Dancet et al., 2011 for exceptions to this). Most studies are cross-sectional and use general QoL instruments whose psychometric properties and internal consistency are not well established in endometriosis (Jia et al., 2012). Such instruments often exclude important issues such as infertility, which may be of considerable significance to a more holistic understanding of the endometriosis experience.

Even studies that use generic instruments do not always include control groups and may not take account of medical confounders such as disease severity and co-morbidities. Very few quantitative studies account for social variables such as educational level, socio-economic status and ethnicity. While such studies helpfully challenge theories that position endometriosis as a lifestyle or psychosomatic disease, and make visible the correlations between extent of disease, symptoms and QoL, they are limited in their ability to uncover the subjective experiences of living with the condition and the meanings it has for women with endometriosis and those around them. Such issues are found to be highly relevant in qualitative papers.

Qualitative research suggests that the experience of endometriosis and its treatment varies considerably across the life course. Experiences fluctuate according to women's ages, social circumstances and biographical priorities and are dependent on a range of socio-demographic characteristics. Such studies highlight that women may have conflicting and contradictory understandings and meanings of endometriosis and that the impact of endometriosis is multifaceted and complex. Qualitative work has also highlighted the way in which women may adopt a range

of strategies to respond to and resist the impact of endometriosis. However, while these studies produce rich data, they often include small sample sizes and their generalizability is limited as a result.

Both quantitative and qualitative studies may include skewed samples, e.g. more severe and long-term cases due to recruitment methods focused primarily on secondary care clinics or support groups. In addition, few studies link endometriosis to wider theories of gender, disability, stigma or inequality of access and virtually nothing is known about how social class, educational status, age or ethnicity impacts on the experience of endometriosis. Women with endometriosis often have a combination of symptoms and whilst it is difficult to assess the individual significance of chronic pelvic pain, deep dyspareunia and severe dysmenorrhoea in a woman experiencing all three of these symptoms, very few studies have tried to quantify, either objectively or subjectively, the relative importance of each.

## Suggestions for future research

Prospective and retrospective longitudinal cohort studies would enable us to more adequately capture the changing and dynamic nature of the impact of endometriosis on people's lives. This is particularly relevant given the impact of this condition on life-course markers such as child-bearing, relationships and career progression and its inherent association with both menarche and menopause. Future QoL research should consider utilizing endometriosis-specific instruments, such as the EHP-30 and EHP-5, which have been developed as a result of qualitative research with women.

Researchers should consider the use of mixed methods to explore the impact of endometriosis to draw on the combined strengths of qualitative and quantitative research (Plano Clark, 2010; Tashakkori and Teddlie, 2010). While there are difficulties in bringing together approaches from different paradigms (Bryman, 2006), there are many advantages in taking a broader, more holistic and more comprehensive biopsychosocial approach to understanding the impact of endometriosis.

A wider range of people should be recruited into studies of all kinds, which may mean adapting recruitment sites and methods, and there is a need to report more fully on the socio-demographic characteristics of participants. Since factors relating to the organization and financing of healthcare systems impact on access to services, availability of treatment regimes, the provision of information and forms of support for endometriosis patients, further comparative, cross-country research would be helpful in identifying areas of good practice in supporting women.

Some authors have suggested the experience of endometriosis is qualitatively different for adolescents (Cox *et al.*, 2003a; Manderson *et al.*, 2008; Markovic *et al.*, 2008). However, there has been little research focusing specifically on the social and psychological impact of endometriosis on adolescents (although there has been some research into the impact of chronic pain on adolescents) (see Forgeron, 2011). Given the potential impact of endometriosis on mental wellbeing, social life and educational achievement during formative years, such research would be of value.

The impact of endometriosis on relationships between women and their partners, and the impact of endometriosis on partners themselves, has been underexplored and warrants further investigation. Similarly, the impacts on children of women with endometriosis and on the wider family have been paid scant attention and should be considered in future research.

Importantly, research is needed which can assist the development of interventions to tackle the negative social and psychological impact of endometriosis and its treatment. Such interventions should be collaboratively developed with patients, partners and support/information groups, tailored to the needs of specific groups of patients and robustly evaluated (Crawford *et al.*, 2002).

Finally, a review into women's experiences of care and support would be of value in identifying problematic experiences and in collating recommendations for how care can be improved.

## Conclusion

This review has identified a large number of studies which address the psychological and social impact of endometriosis on women's lives, with the majority identifying a significant impact across several domains. The review has discussed some of the methodological limitations of existing studies and identified significant gaps in the literature. We recommend further research which utilizes mixed methods approaches and endometriosis-specific instruments to explore the impact of endometriosis in more diverse populations. In particular, there is an urgent need to develop and evaluate interventions for supporting women and their partners living with this chronic and often debilitating condition.

## Authors' roles

L.C. conceived the study, and participated in study design, collection and analysis of data, and drafting and revising of manuscript and critical discussion. C.L. participated in study design, collection and analysis of data, and drafting and revising of manuscript and critical discussion. N.H. and H.M. participated in study design, collection and analysis of data, and drafting and revising of manuscript and critical discussion. E.D., M.B. and N.R.F. participated in collection and analysis of data, and drafting and revising of manuscript and critical discussion.

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## References

- Arruda MS, Petta CA, Abrão MS, Benetti-Pinto CL. Time elapsed from onset of symptoms to diagnosis in a cohort study of Brazilian women. *Hum Reprod* 2003; **4**:756–759.
- Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril* 2006; **5**:1296–1301.
- Bernuit D, Ebert AD, Halis G, Strothmann A, Gerlinger C, Geppert K, Faustmann T. Female perspectives on endometriosis: findings from the uterine bleeding and pain women's research study. *J Endometriosis* 2011; **2**:73–85.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; **2**:77–101.
- Bryman A. Integrating quantitative and qualitative research: how is it done? *Qual Res* 2006; **1**:97–113.
- Butt F, Chesla C. Relational patterns of couples living with chronic pelvic pain from endometriosis. *Qual Health Res* 2007; **5**:571–585.
- Chene G, Jaffeux P, Lasnier C, Cuvelier BA, Tamburro S, Matsuzaki S, Jardon K, Mage G, Pouly J, Canis M. Quality of life of women with endometriosis: comparison between epiphenomenon and severe disease. *J Endometriosis* 2012; **2**:77–84.

- Christian A. The relationship between women's symptoms of endometriosis and self-esteem. *J Obstet Gynecol Neonatal Nurs* 1993;**4**:370–376.
- Cox H, Ski C, Wood R, Sheahan M. Endometriosis, an unknown entity: the consumer's perspective. *Int J Consum Stud* 2003a;**3**:200–209.
- Cox H, Henderson L, Andersen N, Cagliarini G, Ski C. Focus group study of endometriosis: struggle, loss and the medical merry-go-round. *Int J Nurs Pract* 2003b;**1**:2–9.
- Cox H, Henderson L, Wood R, Cagliarini G. Learning to take charge: women's experiences of living with endometriosis. *Complement Ther Nurs Midwifery* 2003c;**2**:62–68.
- Crawford M, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, Tyrer P. Systematic review of involving patients in the planning and development of health care. *Br Med J* 2002;**325**:1263–1265.
- Damewood M, Kresch AJ, Metzger D, Begany T. Current approaches to endometriosis. *Patient Care* 1997;**31**:34–43.
- Dancet EAF, Nelen WLDM, Sermeus W, De Leeuw L, Kremer JAM, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. *Hum Reprod Update* 2010;**5**:467–487.
- Dancet EAF, Ameye L, Sermeus W, Welkenhuysen M, Nelen WLDM, Tully L, De Bie B, Veit J, Vedsted-Hansen H, Zondervan KT et al. The ENDOCARE questionnaire (ECQ): a valid and reliable instrument to measure the patient-centeredness of endometriosis care in Europe. *Hum Reprod* 2011;**11**:2988–2999.
- Dancet EAF, Apers S, Kluivers KB, Kremer JAM, Sermeus W, Devriendt C, Nelen WLDM, D'Hooghe TM. The ENDOCARE questionnaire guides European endometriosis clinics to improve the patient-centeredness of their care. *Hum Reprod* 2012;**11**:3168–3178.
- De Nardi P, Ferrari S. *Deep Pelvic Endometriosis: A Multidisciplinary Approach*. Milan: Springer, 2011.
- Denny E. Women's experience of endometriosis. *J Adv Nurs* 2004a;**6**:641–648.
- Denny E. 'You are one of the unlucky ones': delay in the diagnosis of endometriosis. *Divers Health Social Care* 2004b;**1**:39–44.
- Denny E. 'I never know from one day to another how I will feel': pain and uncertainty in women with endometriosis. *Qual Health Res* 2009;**7**:985–995.
- Denny E, Mann CH. Endometriosis-associated dyspareunia: the impact on women's lives. *J Fam Plan Reprod H* 2007;**3**:189–193.
- Denny E, Mann CH. Endometriosis and the primary care consultation. *Eur J Obstet Gynecol Reprod Biol* 2008;**1**:111–115.
- Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Po* 2005;**1**:45–53.
- Dixon-Woods M, Cavers D, Shona A, Annandale E, Arthur A, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006;**6**:35.
- Emad MC. At WITSENDO: communal embodiment through storytelling in women's experiences with endometriosis. *Women Stud Int Forum* 2006;**2**:197–207.
- Eriksen HL, Gunnarsen KF, Sørensen JA, Munk T, Nielsen T, Knudsen UB. Psychological aspects of endometriosis: differences between patients with or without pain on four psychological variables. *Eur J Obstet Gynecol Reprod Biol* 2008;**1**:100–105.
- Eskenazi B, Warner ML. Epidemiology of endometriosis. *Obstet Gynecol Clin North Am* 1997;**24**:235–258.
- European Society of Human Reproduction and Embryology. Guideline on the management of women with endometriosis, 2013. <http://www.eshre.eu/ESHRE/English/Guidelines-Legal/Guidelines/Guidelines-in-development/page.aspx/1518> (28 March 2013, date last accessed).
- Fagervold B, Jenssen M, Hummelshoj L, Moen M. Life after a diagnosis with endometriosis: a 15 years follow-up study. *Acta Obstet Gyn Scan* 2009;**8**:914–919.
- Fernandez I, Reid C, Dziurawiec S. Living with endometriosis: the perspective of male partners. *J Psychosom Res* 2006;**4**:433–438.
- Ferrero S, Esposito F, Abbamonte LH, Anserini P, Remorgida V, Ragni N. Quality of sex life in women with endometriosis and deep dyspareunia. *Fertil Steril* 2005;**3**:573–579.
- Forgeron PA. My friends don't really understand me: examining close friendships of adolescents with chronic pain, Dalhousie University, 2011. <http://dalspace.library.dal.ca/handle/10222/14085> (24 April 2013, date last accessed).
- Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, Laboy J, Flores I. Patients' report on how endometriosis affects health, work, and daily life. *Fertil Steril* 2010;**7**:2424–2428.
- Fourquet J, Báez L, Figueroa M, Iriarte RI, Flores I. Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril* 2011;**1**:107–112.
- Gao X, Yeh Y, Outley J, Simon J, Botteman M, Spalding J. Health-related quality of life burden of women with endometriosis: a literature review. *Curr Med Res Opin* 2006;**9**:1787–1797.
- Gilmour J, Huntington A, Wilson H. The impact of endometriosis on work and social participation. *Int J Nurs Pract* 2008;**6**:443–448.
- Huntington A, Gilmour J. A life shaped by pain: women and endometriosis. *J Clin Nurs* 2005;**9**:1124–1132.
- Jia S, Leng J, Shi J, Sun P, Lang J. Health-related quality of life in women with endometriosis: a systematic review. *J Ovarian Res* 2012;**5**:29.
- Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obst Gyn* 2004;**2**:123–133.
- Kennedy S, Bergqvist A, Chapron C, D'Hooghe T, Dunselman G, Greb R, Hummelshoj L, Prentice A, Saridogan E. ESHRE guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005;**20**:2698–2704.
- Kumar A, Gupta V, Maurya A. Mental health and quality of life of chronic pelvic pain and endometriosis patients. *J Project Psychol Ment Health* 2010;**2**:153–157.
- Laws S. *Issues of Blood: the Politics of Menstruation*. Hampshire: Macmillan, 1990.
- Lemaire G. More than just menstrual cramps: symptoms and uncertainty among women with endometriosis. *J Obstet Gynecol Neonatal Nurs* 2004;**1**:71–79.
- Lorençatto C, Petta C, Navarro M, Bahamondes L, Matos A. Depression in women with endometriosis with and without chronic pelvic pain. *Acta Obstet Gyn Scan* 2006;**1**:88–92.
- Low WY, Edelmann RJ, Sutton C. A psychological profile of endometriosis patients in comparison to patients with pelvic pain of other origins. *J Psychosom Res* 1993;**2**:111–116.
- Manderson L, Warren N, Markovic M. Circuit breaking: pathway of treatment seeking for women with endometriosis in Australia. *Qual Health Res* 2008;**4**:522–534.
- Markovic M, Manderson L, Warren N. Endurance and contest: women's narratives of endometriosis. *Health* 2008;**3**:349–367.
- Marques A, Bahamondes L, Aldrighi JM, Petta CA. Quality of life in Brazilian women with endometriosis assessed through a medical outcome questionnaire. *J Reprod Med Obstet Gynecol* 2004;**2**:115–120.
- Mathias SD, Kuppermann M, Liberman RF, Lipschutz RC, Steege JF. Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. *Obstet Gynecol* 1996;**3**:321–327.
- Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. *Fertil Steril* 2009;**1**:68–74.
- Moher D, Liberati A, Tetzlaff J, Altman D. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med* 2009;**4**:264–269.
- Neal DM, McKenzie PJ. Putting the pieces together: endometriosis blogs, cognitive authority, and collaborative information behaviour. *J Med Libr Assoc* 2011;**2**:127–134.
- Nnoaham KE, Hummelshoj L, Webster P, d'Hooghe T, de Cicco Nardone F, de Cicco Nardone C, Jenkinson C, Kennedy S, Zondervan K. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011;**2**:366–373.
- Petrelluzzi KF, Garcia MC, Petta CA, Grassi-Kassisse DM, Spadari-Bratfisch RC. Salivary cortisol concentrations, stress and quality of life in women with endometriosis and chronic pelvic pain. *Stress* 2008;**5**:390–397.
- Peveler R, Edwards J, Daddow J, Thomas E. Psychosocial factors and chronic pelvic pain: a comparison of women with endometriosis and with unexplained pain. *J Psychosom Res* 1996;**3**:305–315.
- Plano Clark VL. The adoption and practice of mixed methods: US trends in federally funded health-related research. *Qual Inq* 2010;**6**:428–440.
- Popay J, Roberst H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S. Guidance on the conduct of narrative synthesis in systematic reviews, 2006. <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.178.3100&rep=rep1&type=pdf> (6 February 2012, date last accessed).
- Roth RS, Punch MR, Bachman JE. Psychological factors in chronic pelvic pain due to endometriosis: a comparative study. *Gynecol Obstet Inves* 2011;**1**:15–19.
- Scott JL, Halford WK, Ward BG. United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynecological cancer. *J Consult Clin Psych* 2004;**6**:1122–1135.

- Seear K. The etiquette of endometriosis: stigmatisation, menstrual concealment and the diagnostic delay. *Soc Sci Med* 2009a;**8**:1220–1227.
- Seear K. The third shift: health, work and expertise among women with endometriosis. *Health Social Rev* 2009b;**2**:194–206.
- Seear K. 'Nobody really knows what it is or how to treat it': why women with endometriosis do not comply with healthcare advice. *Health Risk Soc* 2009c;**4**:367–385.
- Sepulcri RD, do Amaral VF. Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. *Eur J Obstet Gyn R B* 2009;**1**:53–56.
- Shepherd J, Harden A, Rees R, Brunton G, Garcia J, Oliver S, Oakley A. Young people and healthy eating: a systematic review of research on barriers and facilitators. *Health Educ Res* 2006;**2**:239–257.
- Siedentopf F, Tariverdian N, Rütcke M, Kantenich H, Arck PC. Immune status, psychosocial distress and reduced quality of life in infertile patients with endometriosis. *Am J Reprod Immunol* 2008;**5**:449–461.
- Simoens S, Dunselman G, Dirksen C, Hummelshoj L, Bokor A, Brandes I, Brodzsky V, Canis M, Colombo G, DeLaire T et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;**5**:1292–1299.
- Souza CA, Oliveira LM, Scheffel C, Genro VK, Rosa V, Chaves MF, Filho J. Quality of life associated to chronic pelvic pain is independent of endometriosis diagnosis: a crosssectional survey. *Health Qual Life Out* 2011;**1**:41–45.
- Tashakkori A, Teddlie C. *SAGE Handbook of Mixed Methods in Social & Behavioral Research*, 2nd edn, Thousand Oaks, CA: Sage Publications, 2010.
- Tripoli TM, Sato H, Sartori MG, de Araujo FF, Girão M, Schor E. Evaluation of quality of life and sexual satisfaction in women suffering from chronic pelvic pain with or without endometriosis. *J Sex Med* 2011;**2**:497–503.
- Waller KG, Shaw RW. Endometriosis, pelvic pain, and psychological functioning. *Fertil Steril* 1995;**4**:796–800.
- Ward V, House A, Hamer S. Developing a framework for transferring knowledge into action: a thematic analysis of the literature. *J Health Serv Res Policy* 2009;**3**:156–164.
- Whelan E. 'No one agrees except for those of us who have it': endometriosis patients as an epistemological community. *Social Health Illn* 2007;**7**:957–982.
- Whitney ML. Importance of lay organizations for coping with endometriosis. *J Reprod Med* 1998;**3**(Suppl.):331–334.
- World Endometriosis Society and the World Endometriosis Research Foundation. Facts about endometriosis, 2012. <http://endometriosis.org/resources/articles/facts-about-endometriosis/> (6 February 2012, date last accessed).