“So many women suffer in silence”: A thematic analysis of women’s written accounts of coping with endometriosis

RUNNING HEAD: EXPERIENCES OF ENDOMETRIOSIS

Abstract

Objective: To understand women's experiences of coping with endometriosis, and impact on their lives.

Design: Women accessed an online questionnaire through a UK-based endometriosis charity website.

Methods: Thirty-four women, aged 22-56 years, with self-reported medically-diagnosed endometriosis, 30 of whom were White, responded to open-ended questions, analysed using inductive thematic analysis.

Results: Participants spoke about their lives being a constant struggle, where they tried to maintain their personal and working lives whilst dealing with long-term pain. Women had to "battle" for an accurate diagnosis, and had limited faith in health professionals. Coping strategies included avoidance of social events to conserve energy (self-pacing), and avoiding taking painkillers to retain alertness. Women did not feel able to be honest with family and friends about their symptoms, and felt socially isolated and misunderstood.

Conclusions: Implications for health professionals are discussed, including the need for earlier diagnosis and taking women's symptoms more seriously at referral; understanding the need to conserve energy in the context of long-term pain; that not taking pain medication may be an active choice to retain alertness; and that avoiding being honest with friends and family and subsequent feelings of isolation may be common experiences relevant to designing treatment programmes.

Key words: endometriosis, thematic analysis, women's health, pain, non-adherence

“So many women suffer in silence”: A thematic analysis of women’s written accounts of coping with endometriosis

Endometriosis is a relatively common condition in which tissue similar to the uterine lining is found outside the uterus. Clinical studies suggest that it affects about one in ten women of reproductive age (Viganò et al., 2004; Endometriosis UK, 2017). Symptoms include heavy and/or painful periods, pelvic pain, fatigue, and bowel and bladder problems, and long term effects include infertility and chronic pain; treatments involve painkillers, hormone treatments, and surgery to remove small patches of cells, or in some cases the entire uterus (American College of Obstetricians and Gynaecologists, 2010; National Health Service, 2017). This study investigates women’s accounts of coping with endometriosis from the perspectives of women who have experienced this condition themselves.

Some studies of the psychological impacts of endometriosis have found that the condition impacts negatively on women’s wellbeing and quality of life. In a large-scale international study by DeGraaff et al (2013), where 931 women in 10 countries completed measures of work and social well-being, health quality of life, endometriosis symptoms and education, endometriosis had a significant impact on work in 51% of the women sampled, and relationships in 50% of the sample. The authors concluded that women suffer from frequent symptoms, in particular chronic pain and dyspareunia (pain during or after sexual intercourse), resulting in significantly reduced quality of life.

Other quantitative studies have suggested that, although dysmenorrhoea (painful periods) has a significant impact on quality of life in women with endometriosis, chronic pelvic pain and dyspareunia did not have any significant impact on quality of life in women with endometriosis (Altinbas, Teklin, Dilbaz & Dilbaz, 2015), and have proposed that impacts on quality of life of endometriosis are equivalent to other long term medical conditions (Friedl et al., 2014). However, these findings are widely disputed, and whether or not women experience painful symptoms may be crucial in determining quality of life. Facchin et al. (2015) investigated the psychological impact of having asymptomatic endometriosis versus endometriosis with pelvic pain in 110 women with surgically diagnosed endometriosis, 78 of whom had pelvic pain, and 61 healthy controls. They found that women with endometriosis who experienced pelvic pain had significantly poorer quality of life and mental health compared with those with asymptomatic endometriosis and the healthy controls.

Although interesting, quantitative work does not enable women to expand on and explain their answers, and the format necessarily restricts what women are able to share about their condition. Qualitative work enables exploration of women's experiences from their own perspectives in some depth. Existing qualitative studies have used focus groups and interviews to investigate impact on women's lives, finding reduced self-reported quality of life and wellbeing in women with endometriosis. Facchin et al. (2017) interviewed 74 Italian women with endometriosis, and argued that participants recounted difficulties with doctors, friends, and families who normalised or trivialised their pain, diagnostic delays which represented a major source of distress, and significant negative impacts on quality of life. Moradi et al. (2014) ran focus groups with 35 Australian women aged 17-53 with a history of 2 to 40 years living with endometriosis to investigate impact on women's lives. They found that endometriosis impacted negatively on a number of aspects of women's lives, including marital/sexual relationships, social life, and physical and psychological factors, supporting quantitative work by authors such as De Graaff et al. (2014). Culley et al. (2017) and Hudson, Culley and Law (2016) also argue that endometriosis can have a significant negative impact on the male partners of women with endometriosis, including self-reports of helplessness and frustration, and significant disruptions to their relationships with their partners with endometriosis.

In a review of 42 qualitative and quantitative papers from the UK, Australia, Brazil and the USA investigating the psychological impact of endometriosis on women's lives, Culley et al. (2013) conclude that endometriosis has significant negative social and psychological impacts. This is also supported by a more recent systematic review of 18 qualitative papers utilising focus groups and interviews by Young, Fisher and Kirkman (2015). They found that results from focus group and interview studies suggested that endometriosis has a significant negative impact on women's lives.

In the Young et al. (2015) review, all studies used either focus groups or interviews, with Whelan (2007) using both focus groups and an open-ended online questionnaire. One of the problems in using focus groups or interviews to understand impacts of endometriosis on women's lives is that these methods may restrict disclosure; even in the most non-directive interviews or focus groups, people are speaking face-to-face which may lead to perceived pressure to present particular kinds of socially-acceptable accounts (see Willig, 2013). For instance, women may be reticent about sharing stories that present them as 'bad'/non-adherent patients (Kelly & May, 1982; Witry, LaFever & Gu, 2017) when they are interviewed face-to-face by psychology researchers who may be perceived in health-professional-type roles.

Open-ended online questionnaires such as used by Whelan (2007) have many advantages (Hewson, 2017; Lee, Fielding & Blank, 2017), and we have found them particularly useful when working with women with other long term conditions such as cancer (e.g. Authors, 2017). Online open-ended questionnaires can be very useful when researchers are interested in understanding the lived experiences of participants (Terry & Braun, 2017). These kinds of questionnaires allow space to expand answers, and offer anonymity relative to interviews or focus groups which, though not completely removing pressures for socially desirable responses, can promote increased disclosure (Jowett, Peel & Shaw, 2011). People are also able to answer questions in their own time which enables careful reflection and can be a significant advantage when working with people with painful or long-term conditions, who can pace their answers to avoid fatigue (Purtell & Gibson, 2012). All these factors make online methods potentially very useful when trying to understand women's experiences of endometriosis.

The Present Study

In order to plan treatment and support women appropriately, it is important to understand women's own experiences of endometriosis, and how they cope with this long term condition. This qualitative study aimed to understand women's experiences of endometriosis and its impact on their lives and relationships. For the reasons outlined above, we used open-ended online questionnaires, ensuring anonymity and enabling women to answer questions at their own pace, and in as much depth as they wished.

This work uses a similar methodology to Whelan (2007) who accessed views of 18 geographically diverse women with endometriosis in an open-ended online questionnaire. However, the present study will focus on women's experiences and coping mechanisms rather than knowledge of the condition, and will access a larger sample of women. Also, the current work will focus only on UK women, all of whom are likely to have accessed health care services within the UK, so are a more homogeneous sample than Whelan's more geographically diverse group.

Method

Design

A qualitative approach was adopted, focusing on the experiences of women who self-reported as having medically diagnosed endometriosis. To encourage disclosure and ensure that women felt comfortable discussing their experiences, we asked them to complete a series of open-ended questions anonymously through an online questionnaire, providing detailed insight into their experiences. Data were collected using *Qualtrics* software.

Recruitment

To ensure that we accessed the views of a relatively wide range of women who had experienced endometriosis, women were invited through a UK-based national endometriosis charity. This network is open to any woman who has self-reported medically-diagnosed endometriosis. A message was posted on the main website by the site's administrator, informing members that the research team were recruiting participants to complete an online questionnaire focusing on the experiences of living with endometriosis and its effect on wellbeing. Women were advised that the study had received ethical approval, and were given a weblink for the research where they could access information on the study, consent form, and the open-ended questionnaire.

Participants

Thirty-four, English-speaking women who reported that they had medically diagnosed endometriosis were recruited. Thirty women self-identified as White, one as Multiple Ethnic Group White and Black Caribbean, one as Persian, one Asian, and one Black British. Ages ranged between 22-56 years, and women had been diagnosed with endometriosis between one week and 22 years before completing the study. Women had experienced symptoms of endometriosis for between 1.5-30 years at the time of the study.

Materials

The questions were constructed using previous literature on endometriosis as a guide. Due to the exploratory nature of the research, questions were broad to allow women to share their thoughts and experiences. Questions included the effects of endometriosis on daily life, the impact(s) of endometriosis on relationships (partners, friends, family), work, social life and the experience of living with endometriosis (see Appendix 1).

Procedure

Ethical approval was granted through [blinded for review] ethics committee. The initial post from the website administrator gave participants a link to an anonymous *Qualtrics* questionnaire. All women gave their informed consent to taking part in the study, including the use of anonymised quotes in reports, through ticking a box on the online questionnaire to confirm agreement. At the end of the questionnaire, women were also given the contact details (telephone and e-mail) of the second author to enable follow-up if they had any queries or wanted more information about the study, as well as information on websites that could provide further information and support on endometriosis.

Data Analysis

All women responded to all questions, providing between one and 22 lines of text in answer to each question. Braun and Clarke's (2006) thematic analysis approach was employed to identify themes, capturing women's understandings, and allowing an in depth analysis of the data. Pseudonyms were assigned to participants and data were described, summarised, and then interpreted in relation to broader implications. All three authors familiarised themselves with the data by reading responses several times, whilst taking notes. Points of interest were noted whilst reading and re-reading the transcripts. Each author then produced an initial set of codes and a thematic map presenting themes and sub-themes. The first author then integrated elements of the three models into one thematic map and accounts were re-read to ensure that coding was checked, and that nothing had been overlooked. Themes were reconsidered following initial review of this paper, and further changes were made by the first author. The second and third authors cross-checked the final set of themes and were involved fully in their interpretation and write-up for dissemination, and all themes and quotes were agreed by all three authors.

In this research, we adopted a critical realist perspective (Madill *et al.* 2000); we recognise that it is possible to acquire an insight into people's experiences through their accounts, but also that we as researchers have a role in constructing knowledge, so we were mindful to be reflexive throughout the process of data collection and analysis. For this reason, all authors engaged in reflexive analysis throughout the process of analysing the data, following Willig (2013).

Results

Inductive thematic analysis revealed five themes, two of which had two sub-themes each, evidenced across the participant group. In the quotes below, women are identified by pseudonyms to retain anonymity, indicating age and length of time living with symptoms of endometriosis in parentheses to provide context.

Theme 1: A constant struggle with pain and fatigue

Women described their lives as a constant struggle with pain and fatigue. All women reported that pain was the most disruptive aspect of endometriosis, affecting both work and social events; long- term pain stopped them working, engaging in social events, exercising, doing housework, and affected relationships with colleagues and family:

> Pain can stop me going to work or going out. Stops me from exercise enjoying my children. Needing pain relief daily to get on with my day to day. Struggle to do housework wash and dress myself. Maintain my relationship with husband and children. Affects my work and relationships with colleagues (Sandra, aged 38, 6 years).

Pain was severe, and caused nausea and sometimes vomiting "pelvic pain, vomiting, sometimes fainting with pain" (Wanda, aged 56, 23 years). Deepa (aged 22, 8 years) described the pain as "excruciating" and "non-stop" as well as "a twisting, throbbing, stabbing, suffocating, nauseating, shocking and numbing pain" Pain was also described as "debilitating", and felt primarily in the abdomen, back and legs "Every day is painful. Every step is painful. Mostly the pain is in my abdomen but my back and legs also suffer" (Xena, aged 27, 16 years).

Fatigue was also cited as a major struggle for all participants. Many women reported significant impacts on their ability to function normally, to the extent of sometimes being unable to leave the house for several days:

> Some days not even being able to get out of bed. Weeks in a month not having the energy of suffering too much to leave the house or can't as need to be right by a toilet so you avoid any embarrassment of bleeding through your clothes. Not having the strength to cook or make dinner. Zero energy horrendous debilitating pain 3 weeks every month sometimes more. (Catherine, aged 27, 6 years).

Theme 2: The "battle" for an accurate diagnosis

a) Delays in referral

Most women did not receive an accurate diagnosis immediately on referral to health care providers, and delays in diagnosis ranged from four months to 25 years. Many were frustrated by lack of support from health professionals who made them feel that they were "overreacting" (Beth, aged 36, 3 years), making a "fuss over nothing" (Yvonne, aged 32, 20 years). All participants had experienced a "battle" to get diagnosed, and had felt frustrated and isolated as a result. Deepa (aged 22, 8 years) talks about feeling "isolation" and "hopelessness", Nina (aged 26, 12 years) talks about feeling "so alone", and Olena (aged 42, 15 years) says "It has changed my life forever... and sadly not for the better... I feel so isolated and alone... I wish more people understood endometriosis".

Women had lost faith in health professionals, and felt "let down" by the health care system in general:

> Only gone [sic] let down I feel by the system for there to be so little help and understanding for women who suffer with endo. It's so sad to know how many of us there are and how little help there is (Xena, aged 27, 16 years).

Women felt that their symptoms were not taken seriously by health professionals, and that they were not believed, even when they stressed the severity of their symptoms:

> For me my GP not believing there was anything wrong with me for a long time was very hard. I didn't feel listened to (Barbara, aged 33, 3.5 years).

Many women had been told that they ‘just’ had painful periods, and it was only after extreme persistence and repeat medical trips over a number of years that they finally received the correct tests and a clear diagnosis:

> I was fourteen when I was told I just had 'painful periods'...every month I was having heavy bleeds and pain that shot up into my bottom that would make me freeze if sat or walking. This carried on until I was about 18 when I was finding sexual intercourse with my partner back then incredibly painful. I ended up going to and from the doctors but nobody seemed to know what was up until one particular doctor finally took me seriously and referred me to both the gynaecologists and another team to look at my bowel and intestines. It was when I was 23, nine years later that things finally started to move with people looking into my condition. (Nina, aged 26, 12 years).

Once diagnosed, many women were angry that their diagnosis had been delayed for so long. For instance, Evelyn (aged 36, 22 years) says “These things make me feel angry, frustrated and disappointed” and Olena:

> It's going to sound insane but first feeling was relief! That after 10 years I was not "imagining" this pain! Then fear, then anger as to why it took so long to get diagnosed... (Olena, aged 42, 15 years).

b) **Poor support following diagnosis**

Many women were also dissatisfied with how the final diagnosis of endometriosis was delivered. Many reported being drowsy as they were often told when they were in recovery after laparoscopy [keyhole surgery] making it difficult to formulate appropriate questions about the condition. Also, the diagnosis was often unexpected, and they did not understand the prognosis, leaving them feeling uninformed and vulnerable. At diagnosis, Jayne was relieved that she now had “a name to my condition” and that she no longer had to “cope in silence” but was dissatisfied with the long time between her diagnosis and follow-up appointment, and the fact that she was given her diagnosis when just out of surgery, so had no one with her, leaving her feeling vulnerable and alone; she described this as a “rushed, lonely and cold experience” (Jayne, aged 30, 15 years). Participants stressed the importance of GPs and other health professionals having a better understanding of endometriosis, and presented themselves as having had to become experts in their condition due to lack of support from health professionals, mainly using the internet to access information. For instance, Nina had become sufficiently expert in her condition through her own research and previous experience to know that she was not being treated optimally, and emphasised the need for better education around endometriosis for health professionals:

> I really just feel it needs to be shared more. I have had doctors who are gyne registrars try injecting me with things that I know I shouldn’t be injected with or that is the wrong medication from just my own research or knowing my own medical procedure. [Nina, aged 26, 12 years]

Theme 3: Self-pacing to conserve energy

a) Avoiding social events

One coping strategy was to try to conserve depleted energy levels though avoiding social events. This had led to perceptions of social isolation, where women felt they had lost friends who had become frustrated because of frequent cancellations and changes of plans. Women had lied to friends about reasons for changed plans, not feeling able to tell them the true reason for fear of negative judgement:

> I have lost a number of friendships because I have been unable to be consistent and stick to plans and also am not keen on going out so much because of the difficulties I then have with added pain and fatigue so I avoid social situations a lot. For example: one of my friends is getting married and a hen do is being organised for 3 days and 2 nights. I have said I can't go for all of it because I can't get time off work on the Friday. **This is a lie**. I can get time off but I have taken it on the Monday following the event because I know I won't manage to go away for the weekend and do a full week at work afterwards (Xena, aged 27, 16 years).

Catherine (aged 27, 6 years) said that avoiding social contact when unwell had led to problems both in her marriage “affects my marriage”, and her friends “I have no friends now as couldn’t see them as too unwell now they don't bother trying”. Felicia (aged 40, 20 years) had felt isolated and as though she was dealing with her condition alone, even though her friends tried to understand saying “My friends were understanding but it still felt like dealing with such pain alone because they couldn't understand”.

b) Managing negative impacts on work

Women stressed the importance of pacing themselves to prioritise ability to work, and many reported that breaks from work such as weekends and holidays were spent recovering so as to be able to function on working days. Xena (aged 27, 16 years) reported that “by the end of the week I am in bits and have to rest the whole weekend to even feel partly prepared for the next week”. Georgia also describes having to use her days off from work to recover her energy:

> Often have no energy, so on my days off, I often spend this recovering which is difficult as I would like to be more active, I often find it difficult to make plans as I am unsure as to how I will feel day to day. If I need to take painkillers or am in particularly bad pain it effects my concentration. I also find it difficult to eat sometimes or even go out when I have bowel and urinary symptoms (Georgia, aged 24, 4 years).

Most women reported that they had to avoid work when symptoms were particularly bad, and some had taken part-time work and additional leave because of their symptoms. Only two (Ursula and Hannah) said that impact on work had been limited. Ursula (aged 39, 25 years) said there had only been two or three occasions where she had taken time off due to symptoms, and reported that she usually “takes anti-inflammatories” and “just gets on with things”. Hannah had adjusted her working patterns to work around the limitations caused by her condition:

> I rarely take time off work as I refuse to let the endometriosis take over so I put on my TENS machine or take pain killers or just cope with it. I am a midwife so working in that

> environment my managers are very supportive and understanding, it is generally so busy it tends to take my mind off the pain then I just crash at the end of the day. I have found I struggle doing night shifts as it makes my symptoms worse so I don't do many night shifts. If I have every had to take a day off it has been no problem (Hannah, aged 26, 13 years).

Theme 4: Avoiding painkillers to retain alertness

Women struggled to stay alert when taking pain medication; this made them feel drowsy and not sufficiently alert to function effectively. Hannah (aged 26, 13 years) said that when she took her painkillers she was “so drowsy I cannot get out of bed or off the sofa”. Vera found that painkillers affected alertness, and appetite:

> I'm high or drowsy for most of the day and can't get enough sleep at night! I can't drink alcohol due to the painkillers. I have to take time off work when the pain gets too bad. I'm losing weight due to the painkillers and loss of appetite (Vera, aged 34, 4 years).

Zita also reported struggling to concentrate after taking pain medication:

> I am a nurse and my work needs me to focus on patient needs this can be hard when I am in pain and I can't concentrate due to strong painkillers I take (Zita, age 37, 9 years).

Women reported that they sometimes had to avoid work because they would not be sufficiently alert to work whilst taking pain medication, and had avoided taking pain medication to avoid feeling drowsy at work:

> My painkillers are strong and can’t drive or work when taking them.. so I try to not take them.. even though I’m in pain (Isabelle, aged 25, 9 years)

Theme 5: Hiding symptoms for fear of negative judgement

Women concealed symptoms from friends, family and work colleagues, and reported feeling that others did not perceive endometriosis to be a legitimate illness. Participants had experienced lack of understanding and empathy from friends, family and colleagues, and were concerned not to be labelled as a “hypochondriac” or as unable to handle “normal’ period pains. For instance, Zita (aged 37, 9 years) “not a lot of people understand, they just think I can't handle period pains”, and Hannah:

> I sometimes I think I'm being a hypochondriac and get very worried and anxious I hate the thought of people thinking of me as being ill or weak so I try to hide my symptoms as much as possible and keep a lot to myself (Hannah, aged 26, 13 years).

As women expected negative reactions, they concealed symptoms from friends and colleagues, and this put additional strain on women’s intimate relationships, leading to increased feelings of guilt and isolation. For instance:

> As time has gone on, I have managed to hide these symptoms and get on with things, but it’s my husband who then has to put up with me on the weekends not able to function and in tears due to a feeling of being overwhelmed with everything, from working, and socialising. And I find myself arguing with him for no apparent reason (Carol, aged 36, 9 years).

Discussion

Summary of themes

Women presented similar stories of struggling to cope with debilitating pain and fatigue, leaving them feeling vulnerable and isolated. Participants were frustrated by delayed diagnosis and lack of clear information on prognosis, and management at initial diagnosis. Perceived lack of support from health professionals, friends and family left them trying to control their energy levels through avoidance of social events, and sometimes being unable to work due to pain and fatigue. Women reported hiding their symptoms from friends and family, lying about reasons for not attending social events for fear of being considered to be “overreacting” and not able to cope with period pains, and occasionally being unable to work due to pain or side-effects of painkillers. Pain medication caused problems with concentration, fatigue and drowsiness, making them unable to work effectively or socialise.

Links to previous work

Results support previous quantitative and qualitative work that has suggested significant negative impacts of pain and fatigue on quality of life in women with endometriosis (e.g. Culley et al., 2013; DeGraaff et al., 2014; Facchin et al., 2015; Moradi et al., 2014; Whelan, 2007; Young et al., 2015). Women's accounts did not support work by Altinbas et al. (2015) who suggested that pain caused by endometriosis does not affect quality of women's lives; on the contrary, women's accounts showed that dealing with chronic pain was a constant struggle, and pain and fatigue impacted on women's lives on a day to day basis. Results support data from reviews by Young et al. (2015) and Zarbo et al. (2018) which showed that pain is the key negative experience reported by women with endometriosis. This pain and associated fatigue impacted on all domains of life, including employment and social life, supporting Facchin et al.'s (2015) suggestion that endometriosis with pelvic pain causes significant negative impacts on quality of life in women experiencing these symptoms. None of the women in the current study reported asymptomatic endometriosis; all women reported severe, debilitating pain that impacted on the rest of their lives.

Delayed diagnosis (between four months and 25 years) was reported in the current study, supporting focus group work from Moradi et al. (2015), interviews by Denny (2004) and Facchin et al. (2017), and reviews by Culley et al. (2013), and Young et al. (2015), showing that this "battle" for diagnosis is common across a range of geographical areas and health services. Moradi's Australian focus group participants also used a "fight" metaphor. This could be seen as a positive story around taking control and being active in determining the eventual outcomes of being diagnosed, but for the women in the present study the "battle" was linked with anger, frustration, and perceived betrayal by health professionals.

Delays, repeated misdiagnoses, and having their severe symptoms trivialised as "just period pains" meant that women had lost their faith in health professionals, and then sometimes ignored medical advice in favour of advice from support websites, or their own weighing up of costs and benefits relating to medical treatment. Women presented themselves as experts in endometriosis, and more expert than the health professionals to whom they were referred, supporting work from Seear (2009a) on development of patient expertise in women with this condition. Women in the present study had developed expertise, often from a very low base where they had known very little about the condition at diagnosis, to become experts in their endometriosis, symptom management, gauging use of painkillers, and managing energy levels through pacing themselves so that they were able to achieve the goals they needed to achieve, de-prioritising alternative goals. Although this prioritisation sometimes led to social isolation, it enabled them to function more-or-less normally at work while concealing their symptoms from colleagues, friends and family. Seear (2009a) notes the costs of developing this expertise which she conceptualises as "third shift" work performed in addition to paid and unpaid work.

Self-pacing to conserve energy was one way that women attempted to take control over the challenges presented by their condition. Women reported careful restructuring of their work and social time to make their lives bearable. Results support suggestions from quantitative work by De Graaff et al. (2014) and qualitative work by Moradi et al. (2014) that endometriosis has a significant impact on women's perceived ability to work (thirty-two women in the present study reported some impact, either caused by pain or impacts of painkillers), and relationships with friends, family and partners, and that long term pain and fatigue resulted in significantly reduced quality of life, including having to conserve energy by resting and avoiding social contact when in pain or under the influence of painkillers.

Women reported concerns over taking painkillers, and sometimes chose not to take these, supporting work by other authors who suggest that decisions not to take prescribed medication may sometimes be the result of careful weighing up of costs (in this case, fatigue and inability to concentrate) against the benefits (pain relief), rather than forgetfulness

(Donovan & Blake, 1992; Witry, LaFever, & Gu, 2017). Results support Seear's (2009b) suggestion, from interviews with 20 women with endometriosis, where apparent "non-compliance" with medical advice was actually the result of what she calls "a form of rational expertise" which she says is equivalent to medical expertise, and based on factors such as avoiding potential risks associated with compliance. In the present study, as in Seear's (2009b) interviews, women presented accounts where they demonstrated significant expertise in managing their condition. This self-knowledge and expertise, along with lack of faith in health professionals' knowledge of endometriosis, meant that participants carefully weighed up the benefits and costs of taking painkillers, and sometimes decided to forgo the pain relief in favour of retaining the alertness required to work or fulfil other responsibilities. Although women may be willing to discuss this apparent "non-compliance" in anonymous on-line questionnaires, they may be reticent about having similar discussions with health care providers, because of already fraught relationships between participants and health care professionals, fears of additional stigma, and concerns about being judged as not doing enough to help themselves.

Women hid symptoms from friends, family and colleagues, and sometimes did not feel able to be honest with friends and family about their health, often minimising and concealing their symptoms, and sometimes lying about reasons for failing to attend social events. This was a conscious strategy for exerting some control within a context where pain was sometimes uncontrollable, "nonstop", and "excruciating", but where they did not feel confident that those close to them would understand fully the extent of their pain and their need to pace themselves. These findings are new, and further work could investigate these issues further.

Strengths and Limitations

Strengths of this study are the large number of women whose opinions we accessed, and the good degree of information from each woman. Participants were detailed in their responses and shared a lot of information, possibly related to the relative anonymity of the online methodology which seemed to enhance freedom of expression, supporting Hewson (2017). There were also limitations inherent in our work. Women were mostly White, so we do not know how far their responses would generalise to other women with endometriosis. Also, they were all accessed through one endometriosis website which may have restricted scope of experiences expressed here (De Graaff et al., 2015; Moradi et al., 2014); in particular, women accessing an endometriosis support website may have more severe symptoms than other women with endometriosis, and may be more proactive in their healthcare. Further research could examine this through selection of a wider group of women.

Reflexive Analysis

As researchers, we have tried to present women's accounts fairly, although we acknowledge that we were engaged emotionally in these women's accounts. The first author is a health psychologist with experience of talking to women about their bodies and health, but no direct experience of endometriosis. The second author is a critical psychologist and has a personal diagnosis of endometriosis and research interests in women's psychology. The third author is a social psychologist with an interest in women's health, but no direct experience of endometriosis. The analysis we have produced hopefully benefits from these different perspectives on endometriosis.

Key Implications for Health Professionals

The primary implication for health professionals is the importance of early diagnosis. Supporting Denny (2004), Culley et al. (2013), Moradi et al. (2014), Whelan (2007) and Young et al. (2015), all participants had experienced significant time between experiencing symptoms and getting a diagnosis of endometriosis which had led them to feel misunderstood, not listened to, and as though their experiences and reports of severe pain were not taken seriously. Women also felt that initial diagnosis should be handled more sensitively. This diagnosis often came as a shock and left them feeling unprepared and vulnerable, particularly as they were often given the diagnosis when they were in recovery after laparoscopy surgery. Women may have found it helpful to have a family member of friend with them to listen to any advice given at diagnosis. Women who had received leaflets on endometriosis to take away with them directly after diagnosis had found these outdated and unhelpful and would prefer to have had an earlier follow-up appointment to get direct, tailored advice from a knowledgeable healthcare professional. Women would also have found it helpful to be informed about support groups at diagnosis.

The psychological implications of endometriosis may include feelings of isolation, the need to conserve energy, and guilt at letting people down by being unable to function adequately in social and work situations. These feelings need to be acknowledged and addressed along with a discussion of ways to control pain and other physical symptoms of endometriosis. Also, non-adherence to pain medication may be an active choice for some women, in order to avoid feeling too “drowsy” to concentrate at work or social events, and there also needs to be greater awareness on behalf of health care professionals of the negative impact of medication side effects on daily lives of women with endometriosis. Alternatives and adjuncts such as cognitive behavioural therapy and relaxation techniques should be discussed as soon as possible after diagnosis so that women are aware of the full range of alternatives and adjuncts to medication.

Conclusions

Women who completed our open-ended online questionnaires shared similar experiences of endometriosis, and wrote about the many challenges they faced in trying to maintain an appearance of normality in their personal and working lives whilst dealing with long-term, often very severe, pain and fatigue. Earlier diagnosis may have reduced frustration and resultant isolation and feelings of hopelessness, and it is crucial that GPs and other health professionals are trained to be able to differentiate endometriosis from other kinds of pain, and also to take women's symptoms seriously at referral. Health care professionals working with women with endometriosis should also be aware that women may feel that they have to develop their own coping strategies, due to perceptions of being misunderstood and feeling isolated. These coping strategies may involve avoiding taking painkillers to enable them to stay alert when necessary, self-pacing to conserve energy, avoiding social events, changing work patterns, and hiding symptoms from colleagues, friends and family. It is therefore important that health professionals discuss the full range of possibilities for treatment, in addition to painkillers, as well as possible strategies for communicating honestly with friends and family about their condition, when designing treatment programmes for women with endometriosis.

References

Altinbas, S.K., Tekin, Y.B., Dilbaz, B. & Dilbaz, S. (2015). Evaluation of quality of life in fertile Turkish women with severe endometriosis, *Journal of Obstetrics and Gynaecology, 35*, 49-52. DOI: 10.3109/01443615.2014.930110

American College of Obstetricians and Gynecologists (2010). Management of endometriosis. ACOG Practice Bulletin No. 114. *Obstetrics and Gynecology, 116*(1): 225-236. DOI: 10.1097/AOG.0b013e3181e8b073

Authors (2017) [blinded for review]

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77 - 101. DOI: 10.1191/1478088706qp063oa

Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M., & Raine-Fenning, N. (2013). The social and psychological impact of endometriosis on women's lives: A critical narrative review. *Human Reproduction Update, 19 (*6), 625-639. DOI: 10.1093/humupd/dmt027

Culley, L., Law, C., Hudson, N., Mitchell, H., Raine-Fenning, N., & Denny, E. (2017). A qualitative study of the impact of endometriosis on male partners. *Human Reproduction,* 32(8),1667-73. DOI: 10.1093/humrep/dex221

De Graaff, A.A., Hooghe, T.M., Dunselman, G.A.J., Dirksen, C.D., Hummelshoj, L., WERF EndoCost Consortium, & Simoens, S. (2013). The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Human Reproduction, 28* (10), 2677-2685. DOI: 10.1093/humrep/det284

Denny, E. (2004). Women's experience of endometriosis. *Journal of Advanced Nursing, 46* (6), 641–648. DOI: 10.1111/j.1365-2648.2004.03055.x

Donovan, J.L. & Blake, D.R. (1992) Patient non-compliance: Deviance or reasoned decision-making? *Social Science and Medicine 34*, 507–13. DOI: 10.1016/0277-9536(92)90206-6

Endometriosis UK (2017). Endometriosis facts and figures. Retrieved 15 August 2017 from https://www.endometriosis-uk.org/endometriosis-facts-and-figures.

Facchin, F., Barbara, G., Saita, E., Mosconi, P., Roberto, A., Fedele, L. & Vercellini, P. (2015). Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference, *Journal of Psychosomatic Obstetrics & Gynecology*, *36* (4), 135-141. DOI: 10.3109/0167482X.2015.1074173

Facchin, F, Saita, E, Barbara, G, Dridi, D, Vercellini, P. (2017). “Free butterflies will come out of these deep wounds”: A grounded theory of how endometriosis affects women’s psychological health. *Journal of Health Psychology*. DOI: 10.1177/1359105316688952

Friedl, F., Riedl, D., Fessler, S., Wildt, L., Walter, M., Richter, R., Schubler, G., & Bottcher, B. (2015). Impact of endometriosis on quality of life, anxiety and depression: an Austrian perspective. *Archives of Gynaecology and Obstetrics, 292*, 1393-1399. DOI: 10.1007/s00404-015-3789-8

Hewson, C. (2017). Research design and tools for online research. In N.G. Fielding, R. M. Lee, and G. Blank (eds.).*The Sage Handbook of Online Research Methods* (2nd edition) (57-75). London: Sage. DOI: 10.4135/9781473957992

Hudson, N., Culley, L., & Law, C. (2016). “We needed to change the mission statement of the marriage”: Biographical disruptions, appraisals and revisions among couples living with endometriosis. *Sociology of Health & Illness, 38,* 721–735. DOI: 10.1111/1467-9566.12392

Jowett, A., Peel, E., & Shaw, R. (2011). Online interviewing in psychology: Reflections on the process. Qualitative Research in Psychology, 8(4), 354-369. DOI: 0.1080/14780887.2010.500352

Kelly, M.P. & May, D. (1982). Good and bad patients: a review of the literature and a theoretical critique. *Journal of Advanced Nursing, 7*(2), 47-56. DOI: 10.1111/j.1365-2648.1982.tb00222.x

Lee, R.M., Fielding, N.G., & Blank, G. (2017). Online research methods in the social sciences: An editorial introduction. In N.G. Fielding, R.M.Lee, and G.Blank (eds.).*The Sage Handbook of Online Research Methods* (2nd edition) (3-16). London: Sage. DOI: 10.4135/9781473957992

Madill, A., Jordon, A., and Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91 (1), 1-20. DOI: 10.1348/000712600161646

Moradi, M., Parker, M., Sneddon, A., Lopez, V., & Ellwood, D. (2014). Impact of endometriosis on women's lives: A qualitative study. *BMC Women's Health, 14*, 123. DOI: 10.1186/1472-6874-14-123

National Health Services (2017). Endometriosis. Retrieved 4 June 2017 from http://www.nhs.uk/Conditions/Endometriosis/Pages/Introduction.aspx#symptoms

Purtell, R. & Gibson, A. (2012). How to make health and social care research radical and really really useful. In C.E. Lloyd and T.Heller (eds.). *Long-term Conditions: Challenges in Health and Social Care* (69-80). London: Sage. DOI: 10.4135/9781446288757.n8

Seear, K. (2009a). The third shift: Health, work and expertise among women with endometriosis. *Health Sociology Review, 18* (2), 194-206. DOI: 10.5172/hesr.18.2.194

Seear, K.(2009b). “Nobody really knows what it is or how to treat it”: Why women with endometriosis do not comply with healthcare advice”. *Health, Risk and Society, 11* (4), 367-385. DOI: 10.1080/13698570903013649

Terry, G., & Braun, V. (2017). Qualitative survey methods. In V. Braun, V. Clarke & D. Gray (eds.). *Collecting qualitative data: A practical guide to textual, media and virtual techniques* (15-44). Cambridge: Cambridge University Press. DOI: doi.org/10.1017/9781107295094

Viganò P, Parazzini F, Somigliana E, & Vercellini, P. (2004). Endometriosis: Epidemiology and aetiological factors. *Best Practice & Research in Clinical Obstetrics & Gynaecology*, 18, 177–200. DOI: 10.1016/S1521-6934(04)00008-2

Willig, C. (2013). *Introducing Qualitative Research in Psychology (3rd edition).* Maidenhead: Open University Press. DOI: 10.1036/9780335244508

Whelan, E. (2007). ‘No one agrees except for those of us who have it’: endometriosis patients as an epistemological community. *Sociology of Health and Illness, 29*, 957–982. DOI: 10.1111/j.1467-9566.2007.01024.x

Witry, M.J., LaFever, M. & Gu, X. (2017). A narrative review of medication adherence educational interventions for Health Professions students. *American Journal of Pharmaceutical Education, 81*(5), 95. DOI: 10.5688/ajpe81595

Young, K., Fisher, J. & Kirkman, M. (2015). Women's experiences of endometriosis: a systematic review and synthesis of qualitative research. *Journal of Family Planning and Reproductive Health Care*, 41(3), 225-234. DOI: 10.1136/jfprhc-2013-100853

Zarbo, C., Brugnera, A., Frigerio, L., Malandrino, C., Rabboni, M., Bondi, E., & Compare, A. (2018). Behavioral, cognitive, and emotional coping strategies of women with endometriosis: a critical narrative review. *Archives of Women’s Mental Health, 21* (1), 1-13. DOI: 10.1007/s00737-017-0779-9

Appendix 1

Open-ended Questionnaire

Please answer the following questions in as much detail as you would like. You do not have to answer any questions that might upset you; please tick the ‘prefer not to answer box’ next to any such questions. Please think about your thoughts, your feelings and your body when answering the questions.

1. Please describe in your own words when and how you found out that you had endometriosis.
2. How long had you had symptoms by the time you were diagnosed?
3. Can you describe your thoughts, feelings and emotions when you received the diagnosis of endometriosis?
4. Please describe in your own words the physical, psychological and emotional symptoms that you experience.
5. What effect does having endometriosis have on your day to day life? Please give examples.
6. Has the condition had any impact on your relationships with partners? Please describe any impacts or effects (both positive and negative).
7. Has it impacted the relationships with your family in any way? Please describe any impacts or effects (both positive and negative).
8. Has having endometriosis had any impact on your relationships with friends? Please describe any impacts or effects (both positive and negative).
9. Has having endometriosis impacted on your social life, and if so how? Please give examples.

10. Would you say the condition has impacted on your work? If yes, please say how, if no please explain why.
11. What are the most significant effects for you of living with endometriosis?
12. Has living with endometriosis had any effect on how you see or perceive yourself and your body? If yes, please say how, if no please explain why.
13. Is there anything else you would like to tell us about your experiences of having endometriosis? Please use the space below to say as much as you like.