Women’s experiences of endometriosis: Qualitative explorations of psychological support, and interactions with healthcare professionals

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical Psychology in the Faculty of Biology, Medicine and Health

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Fiona N Varney

School of Health Sciences, Division of Psychology and Mental Health
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Abstract

This thesis explored women’s experiences of endometriosis, using qualitative methodologies. The thesis is comprised of three papers: 1) a systematic review and thematic synthesis, 2) an empirical study, and 3) a critical reflection of the research process.

Paper one is a systematic review and thematic synthesis of the experiences of women with endometriosis, with regards to their interactions with healthcare professionals. Nineteen papers, describing fifteen primary studies, were identified during the systematic search, as meeting inclusion criteria for the synthesis. Three main themes were generated during analysis: 1) hopes dashed: expecting solutions and finding none, 2) a new relationship with, and view of, healthcare professionals, and 3) finding their way in a new patient role. The importance of women and healthcare professionals working together to manage endometriosis in a collaborative relationship is identified and discussed. In light of these findings, recommendations are suggested to improve the care for women with endometriosis, within physical health care settings.

Paper two is an empirical study of the experiences of women with endometriosis, with regards to accessing and receiving emotional and psychological support, to enable them to live well with the condition. Fifteen women took part in semi-structured interviews, which were subsequently analysed using thematic analysis. Three main themes were generated: 1) A community who can relate: the value of true understanding, 2) being heard and acknowledged: attempted acts of empathy, and 3) a taboo condition: a long way to go. The findings allowed a number of recommendations to be made, which may go some way towards enabling the emotional and mental health needs of women with endometriosis to be met, in the future.

Paper three is a critical commentary of the research process, with regards to papers one and two. Key decisions are explored and justified, challenges are described, and strengths and limitations of the research are identified. The relevance and contribution of the research are also considered, and personal reflections of the author are offered.
Declaration

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Acknowledgements

I would like to thank my research supervisors Dr Joanna Brooks and Professor Gillian Haddock, whose support, encouragement, and expertise were a key component in enabling this thesis to come to fruition. Thank you also to Dr Kenneth Ma, and the staff at Endometriosis UK, without whom, recruitment of participants would have certainly been much more difficult. To all study participants, I am so grateful for you kindly giving your time, and for expressing your enthusiasm, for this research.

I would to thank my friends and family, for the support and encouragement they have given me throughout this process. My gratitude here is especially extended to my fellow trainee clinical psychologists, and close friends, who have remained supportive, helpful, and understanding, even when they were preoccupied with their own research. A special thank you to my wonderful friend, Natalie. Without you, this research may not even have happened, and your input was invaluable.

Finally, I would like to thank my fiancé Jonathan. No one has felt the impact of my training highs and lows more than you, and yet throughout the whole of my career you have remained endlessly positive and full of faith for what I could achieve. I could not have done this without you.
Paper 1

How women with endometriosis experience their interactions with healthcare professionals: A systematic review and thematic synthesis

Varney, F.\textsuperscript{a,b}, Haddock, G.\textsuperscript{a,b,c}, & Brooks, J.\textsuperscript{a}

\textsuperscript{a} School of Health Sciences, University of Manchester, UK
\textsuperscript{b} Greater Manchester Mental Health NHS Foundation Trust, UK
\textsuperscript{c} Manchester Academic Health Sciences Centre, UK

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The following paper has been prepared for submission to the Journal Social Science and Medicine. Author guidelines can be found in Appendix 1.
Abstract

Interactions with healthcare professionals can impact patient outcomes. Empathic interactions can lead to reductions in patient anxiety and pain, and can facilitate condition self-management, whereas less empathic interactions, or those that reflect uncertainty, can raise patient distress. Women with endometriosis come into contact with healthcare professionals repeatedly, and have also been shown to have poor physical and mental health outcomes. Qualitative research has highlighted some of the difficulties these women encounter within their healthcare interactions. This systematic review and thematic synthesis of qualitative literature exploring women’s experiences of their interactions with healthcare professionals, was conducted in order to go some way towards improving endometriosis care. Five electronic databases were searched systematically, and nineteen papers, describing fifteen qualitative studies, met criteria for inclusion in the review. Three main themes were identified during analysis: 1) hopes dashed: expecting solutions and finding none, 2) a new relationship with, and view of, healthcare professionals, and 3) finding their way in a new patient role. The findings highlighted that the most beneficial healthcare relationship for women with endometriosis was one where they could work in collaboration with professionals, however this relationship was uncommon. Healthcare professionals would benefit from further training in endometriosis and in responding empathically to patient concerns, in order to improve care for women, and lessen the personal and economic burden of this condition.

Keywords: Endometriosis; healthcare professionals; thematic synthesis
Introduction

Endometriosis is a long-term physical health condition affecting approximately 10% of women of reproductive age, worldwide (Hogg & Vyas, 2018; Viganò, Parazzini, Somigliana, & Vercellini, 2004). For women with the condition, endometrial tissue, which is tissue similar to the tissue lining the uterus, also grows in other places of the body, such as the bowel, bladder, fallopian tubes and ovaries (Giudice, 2010). Every month during menstruation, this excess tissue sheds, and, as it has no way of leaving the body, deposits form over time, creating endometriosis symptoms (Endometriosis UK, 2019b). The symptoms of endometriosis vary in severity, but can include chronic pelvic pain, heavy menstrual bleeding, bowel and bladder problems, dyspareunia, and infertility (National Health Service [NHS], 2019).

Women with endometriosis often experience a diagnostic delay. The time between symptom onset and diagnosis takes on average between 4-11 years, depending on the country of diagnosis, with the average delay in the UK being 7.5 years (Agarwal et al., 2019; Endometriosis UK, 2019a). There are many reasons for this delay. First, women themselves may be unaware of the existence of endometriosis. When they tell others of their symptoms, these are often trivialised or dismissed by family, friends and healthcare professionals (Agarwal et al., 2019; Ballard, Lowton, & Wright, 2006; Culley et al., 2013) who may also be unaware of, or lack knowledge about, the condition (Shah, Moravek, Vahratian, Dalton, & Lebovic, 2010; van der Zanden & Nap, 2016). Both sufferers and healthcare professionals may also have difficulty in distinguishing between normal and abnormal symptoms, for example, the level of pain a woman must experience, before this is classed as abnormal, may be unclear (Ballard et al., 2006; Culley et al., 2013). Symptoms can also be misdiagnosed as indicative of
another condition, such as irritable bowel syndrome (IBS; Ballard et al., 2006; Culley et al., 2013). The ‘gold-standard’ method of diagnosing endometriosis is currently laparoscopic surgery. Other methods of diagnosis include detecting the presence of the endometrial tissue on magnetic resonance imaging (MRI) and computed tomography (CT) scans (Hogg & Vyas, 2018; National Institute for Health and Care Excellence [NICE], 2017; NHS 2019).

Endometriosis cannot be cured, and is predominantly medically or surgically managed. Medical treatments include hormonal treatments (e.g. contraceptive pills), pain medication, and medication to induce a reversible menopause. Women may be offered surgery to excise deposits, with the hope of reducing symptoms or improving fertility, or surgery to remove the womb (Hogg & Vyas, 2018). A trial-and-error approach to management may be experienced by women with endometriosis, with many requiring multiple excision surgeries, or different hormonal or pain management treatments, until they experience symptomatic relief, or a treatment with tolerable side effects (Culley et al., 2013; Denny, 2004b; Dunselman et al., 2014; Young, Fisher, & Kirkman, 2015). This relief may be short lived, and, upon the return of their symptoms, women may seek the expertise of healthcare professionals for an alternative approach (Dunselman et al., 2014; Giudice, 2010). Alternatively, women may not experience any relief from their symptoms (Becker, Gattrell, Gude, & Singh, 2017), and yet may continue to seek the advice of healthcare staff, over a number of years. During both the time of seeking a diagnosis, and in the post-diagnostic period, whilst trying to manage symptoms or improve fertility, it is clear women with endometriosis come into contact with healthcare professionals repeatedly.
The importance of the relationship between healthcare professionals and patients has long been emphasised, with those such as Hippocrates in 400 BC (1923) and Balint (1955) implying that, regardless of the patient’s condition, the way the doctor interacts with and responds to the patient can be just as important as the treatment given (Di Blasi, Harkeness, Ernst, Georgiou, & Kleijnen, 2001). Di Blasi et al. (2001) put these hypotheses to the test by conducting a systematic review of randomised controlled trials, to study the effects of healthcare professional and patient relationships, on patient outcomes, such as health service use, anxiety, and subjective health status. The reviewed studies included patients with a variety of conditions, including pain, and those with ambiguous symptoms; both issues women with endometriosis may present to their healthcare provider with. Di Blasi et al. (2001) found when healthcare professionals formed positive, warm and friendly relationships with their patients, the outcomes were more positive and effective, than for those professionals whose consultations were more formal, impersonal, or reflected uncertainty. Two separate reviews looking at healthcare professional’s communications with patients experiencing pain (Mistiaen et al., 2016), and patients with a variety of presenting issues such as chronic pain, irritable bowel syndrome, gynaecological problems and undiagnosed symptoms (Howick et al., 2018), similarly found when healthcare professionals are empathic, and provide positive messages that give patients encouragement, there are small, but significant, improvements in pain and anxiety. Such reviews show that, by delivering information to patients, and providing empathy, this can lead to an improvement in symptoms, and reduced distress (Howick et al., 2018; Mistiaen et al., 2016). Many symptoms described in these reviews, are also ones faced by women with endometriosis, for example, ambiguous symptoms including gastrointestinal symptoms, chronic pain, anxiety and uncertainty. It is perhaps the case that the findings reported in the reviews described above would therefore also apply to women with endometriosis in
their healthcare interactions, whereby more empathic and informative consultations may reduce women’s pain, anxiety and uncertainty.

O’Hara, Rowe, and Fisher (2019) reviewed evidence of healthcare interactions as part of a wider review into self-management strategies in women with endometriosis. They found that when women had support from professionals, this enabled women to feel more in control of their condition, thereby facilitating self-management (O’Hara et al., 2019). Conversely, when women encountered professionals who had poor communication skills and low empathy, this led to feelings of neglect, reduced self-esteem, and acted as a barrier to self-management (O’Hara et al., 2019). Thus, the literature demonstrates that for endometriosis patients, or those experiencing chronic pain, undiagnosed symptoms, and gastrointestinal difficulties, as endometriosis patients do also (NHS, 2019), interactions with healthcare professionals may play an important role in producing good outcomes for those patients, especially with respect to reduced pain experiences, reduced distress, anxiety and uncertainty. Such outcomes may also have positive longer-term effects for patients, especially in situations where they are then able to take control over their condition, and manage aspects of it themselves (O’Hara et al., 2019).

Women with endometriosis are at risk of experiencing a range of poor outcomes, beyond the physical symptoms associated with the condition. They can experience mental health and emotional difficulties, such as depression, anxiety, and stress (Chaman-Ara, Bahrami, & Bahrami, 2017a; Pope, Sharma, Sharma & Mazmanian, 2015), reduced quality of life (Chaman-Ara, Bahrami, Moosazadeh, & Bahrami, 2017b), and a significant impact of their symptoms on their work and social lives, and relationships (Bahrami, Chaman-Ara, & Bahrami, 2017; Culley et al., 2013). These
experiences are consistent with the wider literature into the impact of living with a long-
term physical health condition. Those with such conditions have been shown to be at
risk of experiencing anxiety, depression, and other mental health difficulties (de Ridder,
Geenen, Kuijer, & van Middendorp, 2008). Patients’ responses to and coping
mechanisms for managing these emotions can play a large role in determining how well
those with long-term physical health conditions are able to adjust to the changes to their
lives (de Ridder et al., 2008). Approximately 30% of patients will struggle to adjust, and
are more likely to come into contact with mental health services (Dobbie & Mellor,
2008). There are many reasons why women with endometriosis may specifically
experience such difficulties, and struggle to adjust. For example, symptoms such as
chronic pain may impact on their everyday life (Culley et al., 2013), they may
experience uncertainty related to the recurrence of their symptoms, or their fertility
status (Lemaire, 2004), and they may experience a lack of understanding and belief
about symptoms from family, friends and work colleagues (Gilmour, Huntington, &
Wilson, 2008), as previous research shows the general public has limited knowledge
and understanding of the condition (Shah et al., 2010). However, given the literature
surrounding the potential impact of healthcare interactions on the health and wellbeing
outcomes of patients, there may be possibilities the interactions women with
endometriosis have with their healthcare providers may also influence them. These
interactions may influence how women manage their condition, their experience of
symptoms, and how they feel, ultimately contributing to some of the mental health and
emotional difficulties women with endometriosis experience.

Qualitative studies into the experiences of women with endometriosis often highlight
some of the difficulties, and some of the positive interactions women perceive they have
with healthcare services and professionals, even in instances where healthcare
interactions were not the focus or aim of the original study (Cox, Henderson, Andersen, Cagliarini, & Ski, 2003a; Jones, Jenkinson, & Kennedy, 2004). As these healthcare experiences are a recurring theme within the qualitative literature, other qualitative studies have focused entirely on women’s experiences with healthcare services and practitioners (Denny & Mann, 2008; Grunström, Alehagan, Kjølhede, & Berterö, 2018). So far, however, no review exists that has a sole focus of bringing together the findings of these separate studies, to analyse and summarise the experiences of women with endometriosis in their healthcare interactions. By conducting such a review, useful findings may emerge to show what it is that women perceive healthcare professionals do, and say, that women with endometriosis find particularly helpful or unhelpful, in helping them adjust to and manage their condition. Such findings may guide healthcare professionals in their encounters with women in the future, in order to improve the overall care experience of women with endometriosis, their treatment outcomes, and quality of life. Clinical health psychologists are often part of medical multidisciplinary teams, and have a role to play in helping those with long-term physical health conditions adjust to, and manage, their health and any distress associated with it (Belar & Geisser, 1995; British Psychological Society [BPS], 2008). They are also trained to support other members of the team to deliver low-intensity psychological interventions, including empathic listening skills, and tailoring communication, to indirectly impact upon patient wellbeing and adjustment (Belar & Geisser, 1995; BPS, 2008). The results of this review may then be important to guide endometriosis services to identify if such multidisciplinary teams would be useful, and if so, how a clinical health psychologist could be well placed to support both patients and medical healthcare professionals, in their interactions and delivery of care. Therefore, the aim of this research was to conduct a systematic review and meta-synthesis of qualitative studies, in order to fill this gap in the literature, and provide a clear analysis and summary of the healthcare
interaction experiences of women with endometriosis. Given that this review will focus on women’s perceptions of their experiences, independent of the views of healthcare professionals, then this should be held in mind when interpreting the findings and conclusions drawn.

**Method**

The review was pre-registered on the PROSPERO international prospective register of systematic reviews (CRD 42019154005).

**Inclusion/Exclusion Criteria**

For inclusion in the review, papers were required to be published in the English language, and in peer-reviewed journals. They were required to fully or partially report on the experiences of adult women with endometriosis, regarding their interactions with healthcare professionals and services. Only papers that published qualitative results, or mixed-method results, where the qualitative results were substantial and could be separated, were included.

Papers including participants under the age of 18, those seeking a diagnosis of endometriosis, or other participants in combination with those with endometriosis (such as partners or medical professionals), were excluded, unless the data of the experiences of adult women with endometriosis could be separated.
Search Strategy

Searches were conducted on electronic databases, from the start of their records, up to 12\textsuperscript{th} July 2019. The databases used were deemed to be the most appropriate for identifying relevant literature, and were, PsychINFO, Embase, Medline, Cinahl Plus, and Web of Science. Search terms were formulated and structured using the ‘Context, How, Issues Population’ (CHIP; Shaw, 2010; Williams & Shaw, 2016) tool. Searches were combined as follows: Context AND How AND Issues AND Population. Full search terms can be seen in Appendix 2.

The titles and/or abstracts of all search results were screened against the inclusion/exclusion criteria. An independent reviewer screened 40\% (N=557) of these for reliability purposes, and 98.6\% agreement was reached. An interrater reliability analysis using Cohen’s Kappa statistic was performed to determine consistency among the raters. There was moderate agreement between the two raters’ judgements, $\kappa = .771$ (95\% CI, .618 to .924), $p < .001$. The disagreements were discussed amongst the authors. Of the titles and abstracts where there was disagreement (N=8), six of these were subsequently included in the full text screen. The full texts of all potentially eligible articles were read, to determine if they were to be included in the review. The reference lists of included papers were searched by hand, to identify other potentially eligible articles. The independent reviewer screened 100\% (N=33) of these papers. This reviewer disagreed with 6\% (N=2) of decisions made regarding papers to include. The interrater reliability analysis showed there was strong agreement between the two raters’ judgements, $\kappa = .878$ (95\% CI, .715 to 1.00), $p < .001$. The disagreements were discussed among the authors, and a consensus resulted in one of these two papers being included in the final review.
Quality Assessment

The quality of each included paper was assessed using a modified version of the Critical Appraisal Skills Programme (CASP) tool for qualitative research (CASP, 2018; Long, Brooks, Harvie, Maxwell, & French, 2019). The original version of the CASP for qualitative research allows researchers to consider quality within the following ten dimensions: clear aims, appropriateness of qualitative methodology, research design, recruitment strategy, data collection, researcher and participant relationship, ethical issues, data analysis, clear findings, and the value of the research (CASP, 2018). The modified version selected was created by Long et al. (2019) to address the problem, that the original CASP tool does not have a question relating to the theoretical, epistemological or ontological stance of the study being appraised. It is considered good practice for qualitative researchers to reflect upon this, and to clearly report their approach to inquiry (Levitt et al., 2018; Long et al., 2019). As a result, an additional appraisal question was added which was ‘are the study’s theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?’. This resulted in an 11-criterion appraisal tool where the presence or absence of a characteristic was recorded as ‘yes’, ‘no’ or ‘can’t tell’. In addition, a response option of ‘somewhat’ was also added (Long et al., 2019). This was to allow for recording whether a criterion had been partially addressed, and therefore did not warrant a ‘no’ response, but had not been addressed sufficiently to warrant a ‘yes’ response.

Although some studies were represented by more than one included paper, the first author assessed the quality of each, separately (see Appendix 3 for example CASP). No standardised guidelines exist that state exactly how critical appraisal should be approached within a qualitative meta-synthesis, with debate surrounding the issue, and
choice largely being left to reviewers (Carroll & Booth, 2015). Therefore, no guidance exists as to the proportion of papers that should be externally appraised, and the decision was made that more than one third of papers would be reasonable to check for the consistency of quality decisions made. This was a percentage similar to other systematic reviews and thematic syntheses into psychological aspects of health conditions (e.g. Long et al., 2019; Travis, Ashley, Pownall, & O'Connor, 2020). Given the uneven number of included papers, the nearest number of whole papers to be screened, to be over 33%, was 7 papers. The independent reviewer therefore assessed the quality of 37% (N=7) papers, in order to check the consistency of quality decisions made, and any disagreements were discussed between raters, and amongst all study authors, and were resolved through a consensus-building process (see Appendix 4 for example CASP). In the critical appraisal of qualitative studies, the degree of concordance between raters is not as important as the discussion generated (Barbour, 2001; Noyes et al., 2019), hence no reliability statistics were calculated here. All studies were included in the analysis, regardless of their quality, however greater weight was given in the synthesis to those studies deemed to be of higher quality. There is no consensus on how to use the CASP tool for the purposes of weighting, for example, the appropriateness of using categories such as ‘high’, ‘medium’ and ‘low’ quality. Therefore papers were not given a score, or classification during appraisal, but quality weighting was based on consideration of the CASP responses, and papers were ordered from highest to lowest quality, based on the ratings they were given.

**Data Extraction**

The following data were extracted from the included studies: author; year of publication; country of study; research aims; design; method of data analysis; number of participants; participant ethnicities; time since diagnosis; results including those
mentioned in the abstract, results or findings section, and discussion; results included in figures or tables; and direct quotes from participants.

**Analysis**

Study characteristics, such as number of participants, were grouped together using descriptive statistics. Data were analysed using thematic synthesis, and Thomas and Harden’s (2008) guidelines were followed. Thematic synthesis was selected for analysis due to its appropriate use in reviews seeking to inform policy and practice, as the current review did (Thomas & Harden, 2008). The epistemological stance taken was a critical realist perspective, in line with the thematic synthesis approach (Barnett-Page & Thomas, 2009). The data synthesised included all data extracted from the results, such as the primary study authors’ interpretations, participant quotes, and any additional findings reported in the abstracts or discussions of included papers. The full set of included papers was read several times by the first author, prior to undertaking the initial analysis. The analysis was informed by dialectical pluralism (Johnson, 2017). This approach enables the results of studies with differing ontological and epistemological stances, to be combined into a new whole (Johnson, 2017).

Data analysis was split into three stages. Stage one involved each line of text being coded inductively, according to its meaning and content. Original participant quotations were coded first, followed by authors’ interpretations of primary study data, which were reported as findings. Studies deemed to be of higher quality were coded first. During stage two of data analysis, the codes were examined for conceptual and descriptive similarities and differences, so they could be grouped into descriptive themes, which were subsequently assigned a label. Stage three involved generating analytical themes, which allowed the results to ‘go beyond’ the content of the original studies, in order for
new interpretations and findings to be made. The first author predominantly undertook analysis, however, codes and themes were discussed between all authors, to ensure the results were grounded in the data, and were informed by multiple perspectives.

**Results**

**Search Results**

The search strategy identified 1987 articles. Following removal of duplicates, and screening of titles, abstracts and full papers, against the inclusion and exclusion criteria, a total of 19 papers, describing 15 studies, were eligible for inclusion in the review (Figure 1).
Study Characteristics

Study characteristics can be seen in Table 1. All were published between 2001 and 2018, and were conducted within a range of countries: UK (n = 8), Australia (n = 6), Italy (n = 2), Sweden (n = 2), Brazil (n = 1), Canada (n = 1), Guatemala (n = 1), South

Figure 1: PRISMA flow diagram of study inclusion process
Africa (n = 1), and the USA (n = 1). One study was conducted online across more than one country, giving a total of more than 19 countries of study.

The aim of each of the studies varied. Eight sought to explore and understand the impact and experience of living with endometriosis. Three aimed to explore the experience of women with endometriosis specifically within healthcare settings. Two aimed to understand the impact of the condition on health related quality of life. The remaining studies’ aims were to determine the information and support needs of women with endometriosis (n = 1), to explore women’s use of complimentary therapies (n = 1), to understand the impact of endometriosis on psychological health (n = 1), to determine women’s aspirations for the management of their endometriosis (n = 1), to understand the differences between socio-demographic background and health related phenomena in women with endometriosis (n = 1), and to demonstrate how experience is crucial to members of the endometriosis patient community (n = 1).

Where papers reported on data from the same study (Cox et al., 2003a; Cox, Henderson, Wood, & Cagliarini, 2003b; Denny, 2004a; Denny, 2004b; Denny, 2009; Denny & Mann, 2008; Seear, 2009a; Seear, 2009b) these each had a different focus or research question. Therefore, all were entered into the analysis separately.
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<tr>
<td>Cox, Henderson, Andersen, Cagliarini, &amp; Ski†</td>
<td>2003a</td>
<td>Australia</td>
<td>61 (20-64)</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Focus groups</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Cox, Henderson, Wood, &amp; Cagliarini†</td>
<td>2003b</td>
<td>Australia</td>
<td>61 (20-64)</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Focus groups</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Denny†</td>
<td>2004a</td>
<td>UK</td>
<td>20 (20-47)</td>
<td>Not reported</td>
<td>White British (19); Afro-Caribbean British (1)</td>
<td>Interviews with open-ended questions</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Denny†</td>
<td>2004b</td>
<td>UK</td>
<td>15 (18+)*</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Interviews with open-ended questions</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Denny‡</td>
<td>2009</td>
<td>UK</td>
<td>30 (18+)*</td>
<td>Not reported</td>
<td>White British (27); Afro-Caribbean British (1); Indo Caribbean (1); South American Indian (1)</td>
<td>Semi-structured interviews; Diary data</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Denny &amp; Mann‡</td>
<td>2008</td>
<td>UK</td>
<td>30 (19-44)</td>
<td>Not reported</td>
<td>White British (27); Afro-Caribbean British (1); Indo Caribbean (1); South American Indian (1)</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Facchin, Saita, Barbara, Dridi, &amp; Vercellini</td>
<td>2018</td>
<td>Italy</td>
<td>74 (24-50)</td>
<td>Not reported</td>
<td>Caucasian (74)</td>
<td>Interview with open-ended questions</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
<td>Sample Size</td>
<td>Age Range</td>
<td>Ethnicity</td>
<td>Data Collection Method</td>
<td>Analysis Method</td>
</tr>
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<tr>
<td>Grogan, Turley &amp; Cole</td>
<td>2018</td>
<td>UK</td>
<td>34</td>
<td>(22-56)</td>
<td>White (30); White and Black Caribbean (1); Persian (1); Asian (1); Black British (1)</td>
<td>Open-ended online questionnaire</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Grundström, Alehagen, Kjølhed, &amp; Berterö</td>
<td>2018</td>
<td>Sweden</td>
<td>9</td>
<td>(23-55)</td>
<td>Not reported</td>
<td>Interviews with open-ended questions</td>
<td>Moustaka’s modification of the Stevick-Colaizzi-Keen method</td>
</tr>
<tr>
<td>Hållstam, Stål Nacke, Svensén, &amp; Löfgren</td>
<td>2018</td>
<td>Sweden</td>
<td>13</td>
<td>(24-48)</td>
<td>Not reported</td>
<td>Semi-structured interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Hirsh, Ladipo, Bhal, &amp; Shaw</td>
<td>2001</td>
<td>UK</td>
<td>32</td>
<td>(20-49)</td>
<td>Caucasian (32)</td>
<td>Semi-structured interviews</td>
<td>Not stated</td>
</tr>
<tr>
<td>Jones, Jenkinson, &amp; Kennedy</td>
<td>2004</td>
<td>UK</td>
<td>34</td>
<td>(21-44)</td>
<td>Not reported</td>
<td>Semi-structured interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Markovic, Manderson, &amp; Warren</td>
<td>2008</td>
<td>Australia</td>
<td>30</td>
<td>(20-78)</td>
<td>Not reported</td>
<td>Interviews with open-ended questions</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Roomaney &amp; Kagee</td>
<td>2018</td>
<td>South Africa</td>
<td>25</td>
<td>(25-42)</td>
<td>Not reported</td>
<td>Interviews with open-ended questions</td>
<td>Thematic analysis</td>
</tr>
</tbody>
</table>
Table 1: Main characteristics of included papers

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Country/Location</th>
<th>Sample Size (Age Range)</th>
<th>Age Range</th>
<th>Data Collection Methodology</th>
<th>Data Analysis Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>São Bento &amp; Moreira</td>
<td>2017</td>
<td>Brazil</td>
<td>20 (21-48)</td>
<td>Not reported</td>
<td>Data reported by skin colour as follows: White (15); Brown (4); Black (1)</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Seear</td>
<td>2009a</td>
<td>Australia</td>
<td>20 (24-55)</td>
<td>Not reported</td>
<td>Majority Anglo-Celtic (no other data reported)</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Seear</td>
<td>2009b</td>
<td>Australia</td>
<td>20 (24-55)</td>
<td>Not reported</td>
<td>Majority Anglo-Celtic (no other data reported)</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Whelan</td>
<td>2007</td>
<td>Canada, Guatemala, Italy, UK, US</td>
<td>24 (18+)*</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Focus groups; Grounded theory; Open-ended online survey</td>
</tr>
<tr>
<td>Young, Fisher, &amp; Kirkman</td>
<td>2016</td>
<td>Australia</td>
<td>26 (20-54)</td>
<td>Range 6 months – 18 years (median 3.5 years)</td>
<td>Not reported</td>
<td>Semi-structured interviews</td>
</tr>
</tbody>
</table>

*Age range not specified in article, but participants confirmed to be aged 18+ by author
+ ± Symbols indicate data generated by the same study
Quality Appraisal

The included studies varied in quality (Appendix 5). What authors did well was clearly stating aims and findings, and, for the majority of studies, it was clear a qualitative approach was appropriate for the aims. However, authors rarely considered their role, or potential ways they may have had influence, for example with participants. Most authors did not discuss research methods or analysis in sufficient detail, meaning it was difficult to understand exactly what was done, and few reported the study’s ontological and epistemological stance. These limitations may have been due to restricted word counts for submission, or due to reporting standards and expectations changing over time, as generally the higher quality studies were published most recently. 16 papers were thought to be of sufficient quality to be fully incorporated into the analysis, and were coded in order of quality. Three papers (Cox et al., 2003b; Hirsh, Ladipo, Bhal, & Shaw, 2001; Seear, 2009a) were thought to be of particularly low quality, leading the trustworthiness of their findings to be questioned. These studies were ones where either the aims or appropriateness of qualitative methodology, and the appropriateness of the subsequent research design, were unclear. Subsequently, no new codes were developed from the data extracted from these studies, however the data was used to support the codes already generated from the analysis of the higher quality studies.

Thematic Synthesis

Three analytic themes were generated, which were thought to represent women’s perceptions of their experiences of their interactions with healthcare professionals: (1) *Hopes dashed: expecting solutions and finding none*; (2) *A new relationship with, and view of, healthcare professionals*; (3) *Finding their way in a new patient role*. Analytic themes one and two were comprised of five, shared, descriptive themes: *Healthcare professionals don’t have the knowledge; Healthcare professionals assert their...*
authority; Bluffing and un-tailored help; Not as compassionate as once thought; Wait for them to figure it out. Analytic themes two and three were comprised of two shared descriptive themes: A new collaborative relationship; Women take ownership. One descriptive theme, pervasive damage done, underlay all analytic themes. Each analytic theme is described in detail below. Original participant quotes are demonstrated by quotation marks, and original author interpretations are demonstrated by the use of italics, alongside quotation marks. Appendix 6 displays a thematic map of the findings, including codes.

**Theme 1 - Hopes dashed: Expecting solutions and finding none**

Women appeared to experience their interactions with healthcare professionals as something that did not meet their expectations. They went to appointments expecting solutions and answers to their problems, but their hopes could be dashed when they did not get these.

Previous interactions with healthcare professionals, about different issues and illnesses, might have led women to believe they could get answers and solutions for any problem they took to professionals. However, when women attended appointments regarding endometriosis symptoms, they were surprised to encounter professionals who did not appear to supply them with the information they wanted or needed, illustrated as follows: “almost all participants stated that they had little or no knowledge of endometriosis and relied on information provided by healthcare providers. However, many stated that the information they received was insufficient” (Roomaney & Kagee, 2018, p. 911). What’s more, women perceived that those who they sought expertise from had very little knowledge of endometriosis: “I think one of the worst things, one of
the biggest negatives that I have found with doctors is a lack of knowledge, that they don’t understand the condition” (Seear, 2009a, p.380).

Not encountering the level of expertise, and information they perhaps expected, was one of many issues women faced when attending appointments. This was potentially a time of vulnerability and uncertainty, where women were actively seeking help from those they trusted, however many of their concerns were not met with the level of compassion they would perhaps normally expect from professionals. Instead of receiving answers and information, women could encounter professionals who offered unhelpful judgements, for example, about “how much pain should be experienced by women, given the degree of endometriotic lesions seen” (Denny, 2009, p. 989), overloaded them with information that was not always helpful, and were un-empathic, for example, “distant and nonchalant: they sighed, tapped their fingers on the table, avoided eye contact and responded in a monotone voice, using a discourse that was incomprehensible” (Grundström et al., 2018, p. 208). This potentially maintained women’s vulnerability and uncertainty.

Some responses that women received whilst they were seeking answers were perceived as inappropriate, and not what would be expected from professionals. In some instances, professionals appeared to try and uphold their position as an expert, and imparted information and advice that was not perceived to be correct, although they may have tried to pass it off as such: “the doctors don’t know the answer but want to uphold their ‘pedestal position’ and bluff it” (Whelan, 2007, p. 966). As a result, some women had the experience of being “frequently exposed to conflicting advice from different doctors about how they should approach treatment, such that they lost confidence that doctors were actually ‘experts’ about endometriosis” (Seear, 2009a, p. 380). Women were
sometimes given unhelpful, untailored, and even impractical advice, regarding pregnancy, and managing symptoms: “When I first went to see the gynaecologist, he said go out and have a child. You’re telling an 18-year-old girl who’s single to go out and have a baby, come on, what do you expect me to do? Yeah, the first bloke that comes along, I’ll take him, no worries” (Markovic et al., 2008, p. 358). Some healthcare professionals also trivialised and normalised symptoms as “‘just what girls have to go through’” (Markovic et al., 2008, p. 359). Many women encountered professionals who took a psychological or psychiatric view of their symptoms, as they were perhaps unaware of how endometriosis could manifest, or in some instances even what it was: “some women felt treated like they were insane, especially by doctors” (Facchin et al., 2018, p. 542). Similarly, women sometimes experienced professionals who attributed their symptoms to other conditions, such as IBS, therefore treating these, and not the root problem. Women also encountered professionals who took potentially inappropriate action in response to their concerns. There were situations where professionals asserted their authority, meaning when their priorities were at odds with what patients wanted, they ignored patient requests, were reluctant to make referrals, and generally acted in ways patients did not expect, as Grundström et al. (2018, p. 208) put it: “the women felt at their most insecure when the doctor put the burden on them, by asking “how do you want me to help you?””

Healthcare professionals could sometimes be perceived to completely dismiss women’s concerns, and fail to take them seriously, as Cox et al. (2003a, p. 6) described: “in a number of instances, the women felt that gynaecologists who did not specialise in endometriosis shared the GPs attitude of dismissing their symptoms and trivialising their problems”. In very damaging interactions, women experienced that “professionals go so far as to mock the amount of times women seek the service, fake pain to get away
from school/work. They conclude that women exaggerate” (São Bento & Moreira, 2017, p. 3029). The very places women turned to for help and advice had, in some cases, left them alone, let down, and without faith.

The lack of answers and help potentially led to delays. One key area in which women experienced delays was diagnosis: “Many of the women attributed a delay in receiving a diagnosis in part to the lack of knowledge about endometriosis by their GP” (Denny & Mann, 2008, p. 113). This may have led to a delay in further care and treatment, and a lack of improvement in health. Women also experienced more internal problems caused by endometriosis, as they avoided further interactions with professionals that they felt would be problematic, based on their prior experience: “due to normalisation, many participants ignored their pain or tried to relieve it with a huge amount of over the counter analgesics, to the point of seeking help only when their sufferance was extremely high and endometriosis had already caused damages” (Facchin et al., 2018, p. 540). Unfortunately for women, “the condition induced dependence on healthcare” (Hållstam et al., 2018, p.99). However, as this dependence was perhaps not giving them the answers they needed, and the encounters were not what women were used to, or expected, they had to develop new relationships with their healthcare professionals.

**Theme 2 - A new relationship with, and view of, healthcare professionals**

Given there are not always clear answers, and the medical and scientific communities still lack knowledge of endometriosis (Denny et al., 2018; Dunselman et al., 2014), this meant women had to interact with healthcare professionals, and vice versa, in a different way to what was normal and expected. In general, the study participants were quite understanding about the lack of answers. It was not this that caused distress, anger,
frustration and uncertainty. It was the way the professionals dealt with this, often with whether they believed the woman’s story or not, being key.

Some women started forming new, collaborative relationships with professionals. Receiving a compassionate response where they felt listened to, taken seriously and acknowledged, was integral to this relationship, and had the potential to mitigate the problems women experienced from professionals who were perceived to not know much about endometriosis. As Denny and Mann (2008, p. 114) described: “a lack of up-to-date medical knowledge on the part of GPs was not seen as so much of a problem if she listened to the woman, treated her symptoms sympathetically, and was willing to help her receive appropriate treatment by a referral to a gynaecological specialist.”

When professionals imparted as much information as they could, this allowed the new relationship to thrive, with particularly helpful explanations being demonstrated “using tools such as sketches to illustrate the disease” (Roomaney & Kagee, 2018, p. 912), or links to the woman’s experience “in a way that reflected their reported symptoms and surgical findings” (Young et al., 2016, p. 558). These approaches also positively reinforced to women their condition was in fact medical, which resonated with their own experience, as opposed to being psychological, which for many it had been implied it was. The healthcare professionals could still be uncertain in this new relationship, as, if they acted in line with the patient’s best interests, and with the women as a collaborator, then women did not require them to have all the answers, as shown by Denny and Mann’s participant (2008, p. 113): “To be honest I don’t think he knew very much, but he was very nice and he did go and read all about it. I know that the next time I went he knew a lot more”. When professionals were able to form these new collaborative relationships, it perhaps renewed women’s faith in their competence, and
helped boost the women’s own confidence, as “participation in treatment decisions was empowering” (Hällstam et al., 2018, p. 100).

When professionals were not able to show women they believed them, this could make it difficult to form this collaborative relationship. In these instances, women’s views of healthcare professionals, which may previously have been they were trustworthy experts, were potentially damaged, and women began to see through the professionals’ perceived cover-up of their lack of knowledge. As discussed in theme one, women in these scenarios shifted to beginning to see professionals as uncompassionate and un-empathic, and as trying to maintain a position of authority and unhelpful ‘expertise’, perhaps as a way to cover their own anxieties of not knowing how to help: “I went to see a GP, but not the one who had been sympathetic, it was a newly qualified GP. And I felt she was contradicting everything I had read in endometriosis books. So I had no confidence really” (Denny, 2004a, p.42). As previously discussed, in some instances, women viewed that professionals covered up their perceived lack of knowledge about endometriosis by bluffing, which ultimately led to poor advice, damaging their relationships further: “I was given advice like ‘start exercising or something’. It made me feel as if I was being ridiculed” (Grundström et al., 2018, p. 208). This all perhaps confirmed women’s previously described views of professionals as dismissive individuals who do not take their concerns seriously. Women sometimes now believed they were “alone in a hostile world since the health professionals who could legitimise their symptoms were dismissive of them” (Cox et al., 2003a, p. 5). This lack of belief had potentially damaging consequences for all future healthcare interactions, as women perhaps entered all further appointments with views of scepticism and mistrust. As Seear (2009a, p. 380) described: “the final factor implicated in women’s non-
compliance involved their scepticism and mistrust about medical professionals, and their capability in relation to the condition”.

These beliefs perhaps meant women began to form a whole new relationship with the professionals who were perceived as dismissive and invalidating. These relationships were ones were women began to view themselves as the experts, and ultimately took on a new patient role.

**Theme 3 - Finding their way in a new patient role**

Due to their experiences of being dismissed, and the faith they had lost in healthcare professionals, women now felt alone: “The most useful thing I have learned is that women are alone in the fight of this disease since most doctors are not informed enough” (Whelan, 2007, p. 964). For some women, perhaps those with higher levels of self-confidence and self-esteem, this prompted them to become advocates for themselves, and attempt to become experts in their own condition.

‘Doctor shopping’ was born out of a desire to find someone who would not treat them as others had, or leave them with negative emotional consequences, as illustrated by Cox et al. (2003b, p. 65): “where they were still not listened to, they switched GPs or specialists; they demanded good care and kept searching until they got what they needed”. Attempting to find answers, and more helpful, compassionate support was not easy however, but required “extreme persistence and repeated medical trips over a number of years” (Grogan et al., 2018, p. 1369). Women sometimes had to become assertive, which was done in various ways, for example by gathering evidence of their symptoms and distress, as described by Cox et al. (2003a, p. 7): “One of the things that started women on the road to assertiveness was recording their symptoms, locating
their patterns and realising that their symptoms were cyclical and had a basis in
physiology. Their statements revealed how they first began to believe what they were
feeling and started to realise that they did really know their own bodies and could trust
the judgements that they were making about what was happening to them. This led the
women to start rejecting what they were being told by those who were dismissive of
them.” This demonstrates that seeking and gathering information and knowledge
became another powerful tool for women, and another way in which their behaviour
was influenced, following their interactions with healthcare professionals. This
knowledge and information seeking was a common experience among women, when
they did not feel they were getting the answers or information needed, from healthcare
professionals, as Facchin et al. (2018, p. 542) described: “when the doctor-patient
communication was poor, women were more likely to use the internet to retrieve
information”. For some women, this led to empowerment and a feeling of being the
expert as illustrated by Grogan et al. (2018, p. 1373): “women presented themselves as
experts in endometriosis, and more expert than the health professionals to whom they
were referred”. In some cases however, seeking their own knowledge and information
had negative consequences for women, for example “increased stress and wrong self-
treatment as that material was general and not specifically focused on the individual
case” (Facchin et al., 2018, p. 542). Therefore, although it could empower women, the
self-advocate role was not always one that fully benefitted them.

The other new patient role women could potentially find themselves in, and potentially
the healthier and more adaptive one, was the one previously described in theme two. In
this role, professionals were able to collaborate with women, giving women new
opportunities to develop confidence and skills as a partner in treatment. As Grundström
et al. (2018, p. 208) described: “when the HCPs could guide women towards verbally
expressing their sensations, the women felt their self-esteem growing, as they had received the tools to make their symptoms visible to the HCPs”. This collaborative patient role should ultimately be what women and professionals should aim for. This role could be the one that could repair the perceived pervasive damage done, by dismissive professionals, and could enable women to more productively and safely manage their endometriosis, within healthcare settings.

**Discussion**

**Overview of the Findings**

This systematic review and thematic synthesis identified 19 papers describing 15 qualitative studies that described the perceived experiences of women with endometriosis, in their interactions with healthcare professionals. The studies were of varied quality, however, all were included in the analysis, with 16 of them used to generate codes. Three analytic themes were generated that demonstrated women with endometriosis experienced their interactions with healthcare professionals as something that could dash their hopes, when they expected answers but may find none, as something that could lead them to develop a new view of and relationship with professionals, and as something that could motivate them to take on a new and different patient role.

Women attended their appointments with healthcare professionals potentially expecting to be given answers and solutions to the difficulties they were having with their endometriosis. Instead, what they felt they encountered were professionals who themselves did not know how to help and support them. Due to this perceived lack of
knowledge, women experienced that professionals tried to maintain their expertise, which meant women perceived professionals bluffed about how they could help them. Professionals looked for other causes of the women’s symptoms, including psychological causes, leading to misdiagnosis and repeated interactions with professionals, as symptoms were unresolved. Women were sometimes given unhelpful and inconsistent advice, and information not tailored to them. The majority of women experienced healthcare professionals who, perhaps because they did not know what was happening or exactly how to handle it, were dismissive and trivialising of their claims, normalising them and not taking action to find out more. This often led to delays, for example in diagnosis, meaning women’s health declined further, before answers could be given.

Women felt frustrated, angry and distressed, but it was not the lack of answers per se that determined if they would feel this way. Instead, it was the way the healthcare professionals were perceived to respond to their own potential uncertainties, with belief in the woman and her experiences being key. Women who felt believed by their healthcare provider were able to form collaborative relationships with them. In these relationships, women experienced professionals who explained to them as much as they knew and how this matched women’s own experiences, referred them for extra tests and scans, and worked with women to find solutions. This left women with faith in professionals’ competence, and with confidence and raised self-esteem. These experiences were more rare however, and for the vast majority of women, they began to form views of healthcare professionals as dismissive, uncompassionate, bluffers, and negatively authoritative. This left women seeing through the healthcare professionals’ perceived lack of knowledge, leaving women sceptical and mistrusting, and feeling alone in their fight against endometriosis. These women began to form their own ideas
and understandings of endometriosis, and then began to form a new role with their healthcare providers, one in which they attempted to reverse power roles, and become the experts themselves.

Women became advocates for themselves, and worked in a number of ways to find their way in this new, expert patient, role. They became assertive, and persistent in their efforts to find a professional who would listen and take them seriously, who they ‘shopped around’ for. They armed themselves with information and knowledge from other sources, including the Internet, so they could evidence their claims, and go into healthcare appointments feeling empowered. This new patient role could also be negative, however. The information women sought was not always tailored to them, and would not always improve symptoms. Some women felt stressed and worried about having to find solutions themselves, and that these solutions were not working.

Ultimately, the other new role in which women could collaborate with their healthcare providers, was one that would benefit them most, but was the one most difficult to find, perhaps as it relied on healthcare professionals who were willing to occupy the other side of this relationship.

Underlying many experiences, were that women repeatedly felt that they experienced dismissal and a negative normalisation of their problems. This left women feeling alone and mistrusting of professionals, which influenced their future interactions, and how women wanted to respond and work with healthcare professionals. This influenced the future roles women took on, in their fight for good care for their endometriosis.
Relevance to Existing Literature

Existing literature places importance on the interactions between those with long-term health conditions and their healthcare providers, suggesting these can lead to positive outcomes for the patient, if healthcare providers respond with warmth and empathy (Di Blasi et al., 2001; Howick et al., 2018; Mistiaen et al., 2016). Such positive outcomes include reduced patient anxiety, reduced pain experiences, and reduced uncertainty (Di Blasi et al., 2001; Howick et al., 2018; Mistiaen et al., 2016), and in some cases, more confidence to self-manage their condition (O’Hara et al, 2019). The current review goes some way to suggesting this may also be the case for women with endometriosis. Women who experienced poor interactions with healthcare professionals, such as perceiving that they were dismissed, provided with little to no information, and not referred for further care, suffered emotional and physical health consequences, that lasted even after interactions had ended. These included delays in diagnosis and treatment, and feeling they were alone, and had been let down, and feeling they had no clear guidance about how to proceed. This fit with the findings of Bullo (2018), who noted, when there is a lack of knowledge on the part of the healthcare professionals, this ultimately disempowers women with endometriosis. Conversely, those that experienced helpful, collaborative interactions in which they were believed, listened to, and responded to helpfully, experienced quicker routes to diagnosis, and faster treatment and care. These women also experienced positive emotional consequences, including increased confidence and self-esteem, therefore extending their good outcomes to their emotional wellbeing. Women with endometriosis have been shown to experience poor mental health, and the condition is related to depression, and anxiety (Chaman-Ara et al., 2017a; Chaman-Ara et al., 2017b; Pope et al., 2015). Although the current review did not have a mental health focus, the emotional consequences woman experienced following interactions with healthcare professionals may indicate some overlap, or
precursors to further difficulties with mental health. For example, the women within the studies were left feeling uncertain following their interactions, and intolerance of uncertainty has been shown to be a possible maintaining factor for mental health difficulties such as depression and anxiety (McEvoy & Mahoney, 2012). Women were also left feeling overloaded with information, something shown to have a positive relationship with poor psychological wellbeing, in those who seek health information online (Swar, Hameed, & Reychav, 2017).

The cost to healthcare services for treating and managing endometriosis is high. For example in the UK, the most recent approximation of the cost to the economy was £8.2 billion, which is similar to that of other chronic conditions such as diabetes and rheumatoid arthritis (Simoens et al., 2012). These costs are attributable to time off work, reduced productivity due to symptoms, and treatment costs, but also to emotional difficulties (Simoens et al., 2012). Decreased quality of life has been shown to be the most important predictor of direct health care costs (Simoens et al., 2012). It may be then, that women seek healthcare interactions when they first notice symptoms that something may be wrong. Women may then, as this review demonstrates, encounter professionals who they feel do not help them in the way they need, or supply them with what they perceive as useful information. This potentially leads to emotional distress, and worsened physical health difficulties, leading women to seek healthcare interactions again, for both emotional and physical needs. This cycle may continue for some time, therefore increasing the cost of endometriosis, both actual costs for the economy, and personal for the women. Even for those women who, as this review describes, seek their own information and knowledge, this is not always the right knowledge for them, as it is often generalised, and not suited to their needs, therefore leading them to seek healthcare interactions again in the future. One way of targeting and reducing some of
these difficulties, for both women, the pressurised health care systems, and the economies of the countries treating the women, could therefore be to intervene at the level of the healthcare professionals.

**Implications for Practice and Research**

The findings have implications for the care of women with endometriosis within healthcare services. Guidelines for the care and management of endometriosis currently exist, such as those by NICE (2017) in the UK. Such guidelines recommend services at both community and specialist levels should provide women with information about what endometriosis is, its signs, symptoms, diagnostic process and treatment options. Professionals should also encourage women to keep diaries and records of symptoms to reduce delays in recognition and diagnosis. It is clear from this review that healthcare professionals should offer women clear, consistent, practical and tailored advice for how to manage their endometriosis. However the results of this review suggest these practices are not yet happening in a widespread fashion. It might be that guidelines assume healthcare professionals, especially those at the primary care level, are aware of endometriosis themselves, however this review suggests that perhaps this is not the case. This is in line with prior research where healthcare professionals themselves have reported their training into the condition is limited, and they require more information and knowledge about endometriosis (van der Zanden & Nap, 2016; Young, Fisher & Kirkman, 2017). Alternatively, perhaps healthcare professionals are not conveying the information they do have, in the most beneficial way. Healthcare professionals could be offered more training to help them be aware of and understand endometriosis, and how to recognise and manage it. Alternatively, they could be offered further training to support them in clearly communicating the information they do have about endometriosis, to women. This review found there is perhaps a clear and urgent need for
healthcare professionals to take women’s concerns seriously and at face value. Prior research has showed that many professionals are aware that the condition can have a considerable impact on women’s lives (Young et al., 2017), therefore again perhaps they do not convey this perception to women, who often do not feel their concerns are taken seriously enough. Healthcare professionals could therefore be offered opportunities for further training in empathic listening, communication, and responding skills. Research does also show that despite acknowledging endometriosis can have a considerable impact on women, some clinicians often attribute much of this disruption to menstrual pain, and only discuss the impact on relationships in the context of sexual activity (Young et al., 2017). Some clinicians also still believe that the condition is a result of poor mental health (Young et al., 2017). Therefore, alongside further training into the physicality of endometriosis, these clinicians may benefit from training to help them understand the profound impact endometriosis can have upon women’s physical health, social and working lives, and emotional wellbeing, to help them further understand and empathise with the concerns women present with. As these recommendations for training would potentially have the indirect benefit of reducing some of the emotional distress associated with living with endometriosis, mental health professionals, for example clinical health psychologists, could deliver it. As previously discussed, clinical health psychologists are often placed within medical multidisciplinary teams to not only support patients, but also to provide training to medical colleagues, into topics such as communication, understanding the psychosocial impact of a condition, and empathic responding (Belar & Geisser, 1995; BPS, 2008). It is therefore recommended that endometriosis services could be transformed to include a multidisciplinary team, with a clinical health psychologist as a member. This may benefit medical teams in providing different frameworks for understanding the whole impact of endometriosis, enabling better communication, decision making, and also in
providing support for staff in managing more complex cases (Fleissig, Jenkins, Catt, & Fallowfield, 2006; Ugwumadu et al., 2017). It is recommended that these clinical psychologists could also provide psychosocial interventions to those women that may benefit from it, in helping them to adjust to, and better manage, their endometriosis. As is done within other medical multidisciplinary teams, a stepped care approach could also be implemented (BPS, 2008; Kneebone, 2016). Using this model, a clinical psychologist could support other medical members of the team to deliver low-intensity interventions, such as active listening, providing advice and information for adjustment, and goal setting, to support women with lower levels of emotional distress. Those identified as needing more specialist psychological input, could then be seen by the clinical psychologist, with support and training provided to professionals in recognising which patients would benefit from this the most (Kneebone, 2016; Young et al., 2017). This could all be implemented with the aim of benefitting patients, in having their condition, and their distress, understood and managed by a whole system of professionals, working in conjunction with one another, to facilitate whole system care (Shulman-Green et al., 2012).

The findings suggest avenues for further research. The majority of women’s experiences synthesised made reference to interactions with healthcare professionals at the primary care level, and generally their experiences with doctors within this system, rather than other professionals. It would be important to know of women’s experiences of healthcare professionals within specialised gynaecology services, where they may be more likely to encounter care from a range of professionals including specialist gynaecologists, nurse practitioners, and professionals specialising in pain management (NICE, 2017). Exploring such experiences could go some way to determining if women’s information, care and emotional needs are being met within such services, in a
way they are not being at a primary care level. Although this review combined primary studies conducted both within private and public healthcare systems, to the author’s knowledge, little research exists directly comparing the experiences of women who access these different healthcare domains. It could be one domain meets women’s needs more than the other. If this were the case, it would be important to know the reasons why one system is more beneficial than the other. Such findings could then be used to inform the other system, and improve the healthcare experiences for all women with endometriosis, regardless of the healthcare services they are able to access and afford.

**Strengths and Limitations**

A major strength is this is the first review to solely synthesise qualitative research detailing women’s experiences of their interactions with healthcare professionals, using explicit, systematic and reproducible methods. Existing guidance for conducting a thematic synthesis was followed, and the quality of included papers was thoroughly appraised. A further strength lay in the amount of papers included, and the amount of data synthesised. A number of directions for future practice and research have been identified, therefore the review is of use to both the medical and scientific communities.

The review has some limitations. Only studies published in the English language were included, and only those with participants aged over 18. It may be that young women under the age of 18 with endometriosis have important experiences with healthcare professionals, however it was felt they may have been treated differently due to not being classed as adults within the medical system, hence their experiences were excluded from this review. As shown in Table 1, not all studies reported the ethnicity of their participants, however the majority of studies were conducted in countries with populations from mainly white ethnic backgrounds. Of those studies reporting
participant ethnicity demographics, the majority were white. Therefore the experience of women from other ethnic backgrounds may be largely excluded from this review, and their experiences may be different, perhaps partly due to implicit racial bias of healthcare professionals (Hall et al., 2015). The included studies were of mixed quality, and given the results relied on the published quotes and primary study authors’ interpretations, it is not possible to know how representative these were of the original data sets as a whole. Whilst searching for literature compatible with the study findings, a paper was discovered, that met inclusion criteria for the review, but which had not been found in the systematic searches (Bullo, 2018). This may have limited the findings somewhat, as they did not include a synthesis of all relevant literature on the topic, however, upon reading the paper, its findings appear consistent with the findings of the review, and its inclusion may not have altered the conclusions drawn.¹

**Conclusion**

Women with endometriosis regularly encounter professionals who they perceived as not having much awareness or knowledge about their condition, and thus whom they felt did not know how to help them. They can be supplied with what they perceive to be unhelpful and inconsistent advice and information, or are dismissed and their claims normalised, leading to delays and worsened physical health. Some women meet professionals who believe them, and take helpful action despite their own uncertainty, and thus these women experience a new, positive, collaborative relationship. For many however, their views of healthcare professionals are changed, leading them to view them as uncompassionate, unknoledgeable and unhelpful. These women take

¹ This is discussed further in Paper 3, with additional context provided as to why the searches did not identify the paper, and why the paper was then subsequently not included in the review.
ownership of their endometriosis, attempting to become an expert patient. This can cause undue stress and anxiety however, and ultimately the most beneficial relationship with healthcare professionals is the one where both parties collaborate. In order to foster this type of relationship, and to improve the health and wellbeing of women, healthcare professionals should be offered further training in endometriosis, and how to respond clearly, empathically and usefully to the concerns of women with this condition.
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Women’s experiences of emotional and psychological support for endometriosis: a qualitative study

Varney, F. a, b, Brooks, J. a, Ma, K. c, & Haddock, G. a, b, d

a School of Health Sciences, University of Manchester, UK
b Greater Manchester Mental Health NHS Foundation Trust, UK
c Manchester University Hospitals NHS Foundation Trust, UK
d Manchester Academic Health Sciences Centre, UK

Word Count

Complete text: 10556
Abstract: 149
Main text (excluding abstract, tables, figures, and references): 8823

The following paper has been prepared for submission to the Journal Qualitative Health Research. Author guidelines can be found in Appendix 7. Some formatting requirements have been changed, to ensure compliance with thesis submission requirements.
Abstract

Women with endometriosis experience difficulties with their condition, including delayed diagnosis, impairment in functioning, and ineffective treatments. Subsequently, women are at increased risk of mental health difficulties. Clinicians and researchers have made a case for psychological support to be provided for women with endometriosis, however it is unclear whether women would welcome this support, or, are accessing it already. The aim of the current study was to explore women’s perspectives regarding psychological support. Fifteen women with a diagnosis of endometriosis took part in semi-structured interviews. Results were analysed using thematic analysis, and three main themes were derived. Women feel emotionally supported when others empathise with them, provide information and practical support. Overall however, their psychological needs remain largely unmet. Services need to offer more in the way of psychological support. Awareness of endometriosis needs to increase, and healthcare professionals need further training, to enable them to support women further.

Keywords: endometriosis; psychological support; thematic analysis
Introduction

Endometriosis is a long-term physical health condition, in which the endometrial tissue that lines a woman’s uterus also grows in other places of the body, such as the bowel, bladder and ovaries (Giudice, 2010; National Health Service [NHS], 2019). Each month, during a woman’s menstrual period, this excess tissue sheds and is unable to exit the body (Endometriosis UK, 2019). Deposits form, leading to the symptoms women can experience (Hogg & Vyas, 2018). Symptoms vary in severity, but can include chronic pelvic pain, heavy menstrual bleeding, painful sexual intercourse, bowel and bladder problems, and infertility (NHS, 2019). There is currently no cure for endometriosis and it is estimated that approximately 10% of women of reproductive age worldwide have the condition (Hogg & Vyas, 2018; Viganò, Parazzini, Somigliana, & Vercellini, 2004).

Endometriosis can have detrimental effects across a number of domains in women’s lives. Previous reviews have highlighted that women might experience problems during the process of obtaining a diagnosis, they may be significantly negatively affected by symptoms, especially chronic pain, painful sexual intercourse and infertility, and they may encounter problems with treatments (Culley et al., 2013; Marinho et al., 2018; O’Hara, Rowe, & Fisher, 2019; Young, Fisher, & Kikman, 2015; Zarbo et al., 2018; Zarbo et al., 2019). Each of these areas are considered in turn below, alongside the impact women experience on their work, education, social and family lives, intimate relationships, and their perceptions of themselves.

Diagnosing endometriosis can be difficult. Women may be unaware of the condition, and so assume that their symptoms are attributable to a normal menstrual cycle, thus
preventing them from seeking professional advice (Ballard, Lowton, & Wright, 2006; Culley et al., 2013). When women do seek medical advice, professionals may also be unaware of, or have limited knowledge of, the condition, as research shows clinicians report they do not necessarily have enough information and knowledge, and do not always recognise its symptoms (van der Zanden & Nap, 2016). This can lead to normalisation, misdiagnosis, and delays in further investigations (Agarwal, et al., 2019; Culley et al., 2013; Young et al., 2015). Women can also experience a lack of sympathy and disbelief in their symptoms from medical professionals, colleagues, friends and family, leading women to feel they are ‘going mad’, or their symptoms are ‘all in their head’ (Ballard et al., 2006). Such reactions possibly stem from low public knowledge of the condition, and the limited knowledge professionals report having (Shah et al., 2010; van der Zanden & Nap, 2016). Even when women and professionals suspect endometriosis, a definitive diagnosis is generally only made after ‘gold-standard’ laparoscopic surgery (Hogg & Vyas, 2018), an invasive procedure, which can, as with any surgical procedure, carry risks (Ballard et al., 2006; Chapron et al., 1998). Such difficulties mean women often experience a delay in receiving a diagnosis of endometriosis. Within the UK, women face on average a 7.5-year delay, following the onset of their symptoms, with women worldwide experiencing average delays of 4-11 years (Agarwal et al., 2019; Hogg & Vias, 2018). This is a time of uncertainty, with women reporting they feel their life is on hold, and their symptoms are attributable to serious and life threatening conditions, such as cancer (Ballard et al., 2006). Receiving a diagnosis can be positive, as women know the cause of their symptoms, feel legitimised, and can access appropriate treatments and potential support (Ballard et al., 2006, Culley et al., 2013; Young et al., 2015). However, women also experience shock and disbelief at being told they have an incurable condition, or for asymptomatic women, shock that they even have a condition at all (Culley et al., 2013; Young et al.,
Diagnosis does not end the uncertainty for women, with symptom variability, treatment efficacy, and the future, remaining a concern (Culley et al., 2013; Young et al., 2015).

Endometriosis is predominantly medically and surgically managed. Women may be offered pain-management medication, hormonal treatments, including oral contraceptives, or the induction of a medical menopause, or surgery to remove deposits, or the womb (Hogg & Vyas, 2018; NHS, 2019). For women experiencing fertility issues, they may be offered in vitro fertilisation (IVF) or other interventions to increase the chances of conceiving (NHS, 2019). Treatments may only offer short-term relief from symptoms, with ineffective treatments leading women to feel anger, despair and worry (Culley et al., 2013; Young et al., 2015). Women also report feeling upset and offended by medical professionals who recommend certain lifestyle changes, in lieu of treatments, such as pregnancy or marriage (Young et al., 2015). The physical side effects of treatments, such as acne, and weight gain, can also impact negatively on women’s self-image (Culley et al., 2013). Some women may attempt to self-manage their condition, however, this can lead to them feeling less confident in themselves, and more worried, as they focus more on their endometriosis and its symptoms overall (O’Hara et al., 2019). Self-management can also be a perceived burden, and can impact negatively on women’s finances (Culley et al., 2013; Young et al., 2015).

Many women with endometriosis, therefore, find that their symptoms persist, with some reporting they feel powerless over them (O’Hara et al., 2019). Women report chronic pelvic pain controls them, and forces them to put their life on hold, thereby causing distress (Culley et al., 2013; Young et al., 2015). Pain can impact women in a multitude of ways, including reducing their appetite, disrupting sleep, and making daily activities
such as cooking, cleaning and childcare, difficult (Bernuit et al., 2011; Culley et al., 2013; Fourquet et al., 2010). Pain can also significantly impact work and education opportunities. Women resort to taking days off, are limited in what they can do and how productive they can be when they do attend, and some ultimately feel forced to work or study part time, or cease altogether, impacting their finances and quality of life (Fourquet et al., 2010; Young et al., 2015). Other symptoms associated with the condition including fatigue, sleep deprivation, and gastrointestinal symptoms can also cause women to decrease their social activities, and withdraw from others (Culley et al., 2013; Marinho et al., 2018; Young et al., 2015; Zarbo et al., 2018). Women report their symptoms, and, how others around them relate to these symptoms, lead them to feel weary, angry, and depressed (Young et al., 2015). Women’s experience of painful sexual intercourse also impacts their lives negatively, especially with regards to intimate relationships. Women manage this by avoiding or limiting sexual intercourse, or ‘putting up with it’ in order to have a baby or feel close to their partner (Culley et al., 2013; Young et al., 2015). Such management strategies lead women to feel guilty or inadequate, with strain and friction impacting their relationship, leading to relationship breakdown, and the resulting negative emotional consequences (Culley et al., 2013; Young et al., 2015). For women who navigate these difficulties, infertility can be another issue they face. Actual infertility, or concerns about its occurrence, lead women to feel inadequate, judged as ‘not a real woman’, and worried, with intimate relationships suffering, and relationship breakdown occurring (Culley et al., 2013; Young et al., 2015). Infertile women with endometriosis have also been shown to be more depressed, stressed and anxious, than infertile women without endometriosis (Zarbo et al., 2019).
Given the range of detrimental impacts that women with endometriosis can experience on their lives, it is perhaps unsurprising that they are at risk of emotional and psychological difficulties. Reviews have found women with endometriosis experience higher levels of depression, anxiety and stress when compared to controls or the general population (Culley et al., 2013; Gambadauro, Carli, & Hadlczyky, 2019; Pope, Sharma, Sharma, & Mazmanian, 2015). Women also experience loneliness, hopelessness, worthlessness, and suicidal ideation (Cox, Henderson, Andersen, Cagliarini, & Ski, 2003a; Cox, Ski, Wood, & Sheahan, 2003b; Whelan, 2007). Quality of life is negatively impacted across several domains, including powerlessness and control, social support and emotional wellbeing (Chaman-ara, Bahrami, Moosazadeh, & Bahrami, 2017).

Psychological difficulties such as these can negatively impact women’s symptoms further, with high anxiety and depression leading to an increase in the experience of pain (Laganà et al., 2017), and psychological distress negatively influencing the success of medical interventions (Pope et al., 2015). These experiences, and emotional distress, can be common among those living with long-term physical health conditions (de Ridder, Geenan, Kuijer, & van Middendorp, 2008). How patients respond to and cope with difficult emotions in the context of their condition, can affect how well they are able to adjust to, and manage it (de Ridder et al., 2008). Women with endometriosis face challenges, similar to those with other long-term conditions, that they do need to adjust to and manage, including recognising symptoms, using medication appropriately, dealing with psychological consequences, and interacting with healthcare services and professionals (Schulman-Green et al., 2012). Many of those with long-term conditions are able to successfully adjust to these changes, however approximately 30% of patients will continue to struggle (de Ridder et al., 2008). Those who are struggling are then more likely to come into contact with mental health services (Dobbie & Mellor, 2008). Clinical health psychologists have a role to play in helping these patients to adjust, and
reduce their distress (de Ridder et al., 2008; Dobbie & Mellor, 2008). Addressing emotions, accepting their new reality, and making small changes in their lives in the context of their illness, with the support of a psychologist, can enable patients to do this (de Ridder et al., 2008; Shulman-Green et al., 2012). Due to the role that a psychologist can play in facilitating adjustment and reducing distress for those with long-term physical health conditions, they have long been identified as an important component of multidisciplinary care specifically within physical health care settings (Brown et al., 2002; Wahass, 2005). Not only are clinical health psychologists well placed to support patients, but they can also support medical colleagues to indirectly improve patient outcomes, for instance in the application of low-intensity psychological interventions, and with communication skills (Belar & Geisser, 1995; British Psychological Society [BPS], 2008).

Due to the current predominantly medical and surgical nature of endometriosis management, there have been calls for multidisciplinary care, such as that described above, to be established, to enable the psychosocial impacts and distress of the condition to be addressed. Some authors have suggested services should screen for psychosocial and psychiatric difficulties (Pope et al., 2015), utilise the perspective of clinical psychologists (Fritzer, Tammaa, Heinrich, & Hudelist, 2012; Zarbo et al., 2018), offer talking therapies (Hogg & Vyas, 2018), or provide integrated care and multidisciplinary teams (Dancet et al., 2014; Facchin, Saita, Barbara, Dridi, & Vercellini, 2018; Hallstam, Stålnacke, Svensén, & Löfgren, 2018). This would bring endometriosis care in line with other physical health settings that have successfully implemented clinical health psychology services (BPS, 2008). However, these calls for psychological support come predominantly from researchers and clinicians working within the field and, to date, the literature has not given a voice to women with
endometriosis regarding their experiences of psychological support for the condition. It may be that women feel their emotional and psychological needs are being met, as some studies and reviews report women do receive support from those such as partners and parents (Culley et al., 2013; Dancet et al., 2014). Alternatively, perhaps women may take a negative view of the offer of psychological support as suggesting their symptoms are ‘all in their head’, which may be reminiscent of their journey to diagnosis (Culley et al., 2013).

The current study therefore aimed to qualitatively explore women’s perceptions of their experiences of accessing and receiving psychological and emotional support, to enable them to manage and reduce the psychosocial impact of endometriosis. It was hoped the research would provide women’s own narrative to the literature recommending psychological support for those diagnosed with endometriosis. A better understanding of women’s experiences from their perspective could usefully contribute to recommendations as to what services might be needed, and how these could be structured in the future, to ensure women’s needs are met in a multidisciplinary way. Given that this study will focus on women’s perceptions of their experiences, independent of the views of those whom they may have sought support from, then this should be held in mind when interpreting the findings and conclusions drawn.

**Method**

**Design**

Qualitative methodology was used to elicit the views and experiences of participants, regarding emotional and psychological support for living with endometriosis. Each participant completed a demographic questionnaire, and took part in a single semi-
structured interview. The research was explorative, to gain detailed insight into the women’s experiences. Individual interviews were undertaken to elicit rich, detailed information about participants’ personal experiences and views.

Recruitment

To ensure that views were elicited from a range of women, participants were recruited using purposive sampling, from specialist endometriosis clinics within a UK hospital, and a UK based online support group. To be included in the study, women had to have a medical diagnosis of endometriosis, and sufficient command of the English language. Given that endometriosis is considered a disease of the reproductive years, with symptoms settling after menopause (Johnston, Reid, & Hunter, 2015), participants had to be aged between 18-45 years old, to be included in the study. This enabled recruitment within the premenopausal time frame. Those under age 18 were excluded, due to treatment for adolescents occurring within paediatric hospitals, which may have led to different support experiences. The age range selected was consistent with other research in the field (Denny, 2004; Hallstam et al., 2018; Roomaney & Kagee, 2018).

The first author attended the hospital clinics. Consultant gynaecologists and specialist nurse practitioners identified potential participants who met the inclusion criteria, and offered these women the opportunity to speak to the first author. Those wishing to meet were given a brief description of the study and a participant information sheet (Appendix 8). A group administrator from the charity Endometriosis UK also posted an advertisement for the study in their online social media support group page. This was local to the area in which the research was being conducted. The group was private, and only intended for those who have an endometriosis diagnosis. Interested women approached the first author themselves, at which point they were given the same study information as the women recruited from clinics. All potential participants who
expressed an interest in taking part in an interview arranged this at a date and time convenient for them.

Participants

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<td>26-30</td>
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<td>36-40</td>
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<tr>
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Table 2: Participant demographic information

Fifteen women, aged between 24 and 45 years (mean age 32.5 years) with a medical diagnosis of endometriosis, participated in the study. The demographic characteristics of the participants are presented in Table 2. Five other women had initially agreed to participate, but withdrew prior to their interviews. Not all of these women gave an explanation for withdrawal, but those that did, reported reasons including the time commitment, life events, and endometriosis symptoms preventing them from participating. Of those that participated, seven were
recruited from the hospital clinics, and eight from the online support group. One pilot interview was conducted prior to recruitment, with the purpose of trialling the topic guide. This interview took place between the first author and a friend with a diagnosis of endometriosis. Although it was audio recorded to enable reflection, this pilot interview was not transcribed or included in the data corpus, due to the close relationship between interviewer and interviewee, and the potential for this to impact data analysis. Participant interviews were stopped when it was felt the data corpus held an adequate amount of information power to allow new knowledge to be developed (Malterud, Siersma, & Guassora, 2016).

Materials
A topic guide (Appendix 9) was constructed using previous literature into women’s experiences of endometriosis as a guide. In order to ensure that the data collected was going beyond this previous literature, gaps in knowledge and understanding highlighted in the literature were used as a basis for developing relevant questions. Due to the exploratory nature of the research, the questions were kept open and broad, to allow women to share their experiences and views, however, prompts and probes were included, to give the interviewer the opportunity to elicit more detailed information, where necessary. The demographics questionnaire, invited participants to indicate their age, age at diagnosis, ethnicity, marital status, and occupational status (Appendix 10).

Procedure
NHS ethical approval (REC Reference 19/LO.0443; Appendix 11) was obtained prior to study commencement. All women gave informed consent to take part, including consent for their anonymised quotes to be used (see Appendix 12 for blank consent form). The first author conducted all interviews, as the study was part of wider research.
contributing to her doctorate in clinical psychology. The first author attended teaching and training on the use of qualitative methods in research, and conducting participant interviews. Participants were given a choice of either a telephone, or face-to-face interview in a variety of locations. Seven participants were interviewed in person, at either hospital or university sites. The remaining eight interviews took place over the telephone. Only participants and the first author were present during interviews. Just prior to the interview starting, participants completed the demographic questionnaire. The interviewer then told participants of the reasons she had chosen to conduct research in the area, including its contribution to a doctorate degree, and close relationships with women with endometriosis. Participants were also informed the interviewer was training to be a clinical psychologist, and had worked with clients both in traditional mental health services, and within physical health services as part of multidisciplinary teams providing psychological support to those with physical health conditions. The interviewer answered any questions, and aimed to put participants at ease and establish rapport with them, prior to interview commencement. Participants were informed they could stop the interview and withdraw from the study at any time, and distress management procedures were in place if necessary. All participants were debriefed following their interview. Interviews were audio-recorded and lasted between 42 and 73 minutes (mean 55 minutes). The first author kept a reflective diary throughout the process.

**Analysis**

Inductive reflexive thematic analysis, using Braun and Clarke’s (2006; 2019) approach was utilised. A critical realist stance was taken. The research reflected a potential social problem whereby the needs of women with endometriosis were unmet, and the results could potentially go some way to informing future policy or service structure, both
issues that a critical realist perspective fit with, and which could be appropriately explored using thematic analysis (Fletcher, 2017). Interviews were transcribed by both the first author, and a third-party employee of the University of Manchester, and all identifying participant information was removed (see Appendix 13 for a transcript sample). Transcripts were exported into NVivo software (QSR International Pty Ltd. Version 12, 2018) to facilitate analysis. The first author further familiarised herself with the data by reading and re-reading transcripts, whilst taking initial notes of points of interest, before commencing line-by-line coding (see Appendix 14 for a coding example). Codes were subsequently grouped together into meaningful themes. These were discussed with the other authors on several occasions, leading to the themes being further refined in a way that more accurately reflected the data corpus. Following such revisions, a final thematic map (Appendix 15) was produced. Participants were unable to provide feedback on their transcripts or study findings, due to time constraints. The final thematic map, consisting of three themes, was applied to the data set to ensure it fully captured the data, and the themes generated represented the data appropriately. Participant quotes were selected to illustrate the findings, and the quotes were chosen so they represented the views of all participants.

**Results**

Thematic analysis resulted in three themes, consisting of ten subthemes. The three main themes were as follows: 1. A community who can relate: the value of true understanding; 2. Being heard and acknowledged: attempted acts of empathy; 3. A taboo condition: a long way to go.
Theme 1 - A community who can relate: the value of true understanding

Women in the study described themselves as embedded within a unique community through which they were able to access both information and support. This community was comprised mainly of other women with endometriosis, but also of gynaecologists and specialist nurses who predominantly worked within endometriosis services, friends and family that women lived with who witnessed the effects of the condition on a day-to-day basis, and those with other, often stigmatised, long-term physical health conditions. Women described this community group as able to respond and provide support in ways that other support networks, more removed from the everyday impacts of a little-known and taboo condition, could not. This theme was comprised of three subthemes: Real understanding; contributing to the community; and becoming fully informed.

Real understanding

Women felt that members of their community with particular expertise in endometriosis, whether through lived experience or medical specialism, could uniquely understand and empathise with their experience. This was experienced as helpful by women, and was contrasted with well-intentioned but less helpful support from other sources:

“as much as they might care and they might try and help, they can’t relate to what you’re going through, they can’t….them telling you that it’s gonna get better is very different to someone telling you it’s gonna get better who’s experienced it…and is going through the same thing” (participant one).
Knowing they were not alone in their experience was reassuring and women particularly valued the empathy and support of those experts by experience:

“it’s awful that other people have to go through it, that’s awful but, it’s almost comforting to know that you’re not by yourself, so, and that’s how I felt when I went to see that show, and, people were talking after it and I was like, this is the first time I feel, not, it’s not just me that’s got this, like, because so many other women that are going through the same thing, and going through things mentally, and it’s just nice to be able to, to talk about it with people that get it” (participant eight).

**Contributing to the community**

Being part of this community also enabled two-way support to be provided, with women in the study receiving support, but also finding it emotionally beneficial to be able to help and provide support to others. This could be achieved in a variety of ways, including giving advice, sharing their experience of symptoms, and taking part in research:

“that’s why I said to you about doing things like the research and things like that...if....if you only put one poster up on the board, and somebody looks at it and thinks oh I’ve got that, or I’ve got some of them symptoms, what can I do...that’s beneficial...because you might help somebody who’s only in the early stages of it, and hasn’t gotta go through the possibly infertility, IVF later on” (participant seven).
**Becoming fully informed**

An important role played by this community was providing convincing and trusted information about a poorly understood condition. Feeling sufficiently informed and knowledgeable about endometriosis was helpful for women and benefitted them emotionally and psychologically. Women reported seeking out relevant information by conducting independent research and often found their community of lay experts through these searches. Healthcare professionals more expert in the condition were also described as a helpful source of useful information. Even if this increased knowledge was not necessarily encouraging, being better informed and feeling they knew what to expect and what they had to manage was described by women as reassuring and empowering:

“I spoke to my gynaecologist and she obviously explained like, this might, she said, like I said before, every, everyone’s body’s different, she said you might, you might get nothing now for two years, it might be worse, it might be the same as it was before the operation, you might have to go for surgery and get, er, more surgery in a year, might not have to go for more surgery for six, six years, she’s like, we, we don’t know, and that was horrible to hear, but I was like, I was almost like, well I’ve got, I’ve got an answer so we’ll work with it, at least I know what’s wrong with me, rather than keep going back to the GP and not getting anything” (participant eight)

“once I was diagnosed and then I knew that I had the surgery planned, and then when I knew what the next steps were it became easier...mentally and emotionally it became easier” (participant five).
However, women routinely reported not having access to or not being given this information, and being kept out of medical discussions about their care, which was troubling. As participant one put it: “you can’t be reassured when you don’t know what’s going on”.

Also within this community, being able to gather further information by hearing or reading others’ stories could provide women with emotional benefits, including hope and reassurance, especially so for those women who did not actively post on online forums to seek answers to their own questions, or feel comfortable in sharing their own experience with strangers:

“in this group I, I see all of my symptoms basically, erm, you know, other women are experiencing them as well, so it’s putting everything into context for me, and it’s making me feel a little bit more sane, that, you know, I’m not going crazy” (participant ten).

However, accessing shared experiences and gathering more information was not always reassuring or experienced as helpful. Some women were distressed by the accounts of others struggling with endometriosis. Such accounts could make women feel they were not as unwell as they could be, when compared to others and, could make them concerned their own condition might not improve or could worsen:

“some of the stories are just really harrowing, and it’s just constantly posts about like, you know, I’m in so much pain today, I know you guys will understand, do you have any tips or, so, and kind, I keep (sigh) it’s great that they’re there, and I know that they’re a really useful resource and something
that, you know, could be really helpful, but, it’s also this constant reminder of how horrible this is” (participant eleven).

Therefore, although being part of this unique community could, for the most part, help women to feel they were positively emotionally supported to manage and live well with endometriosis, some of these same networks could increase worry and anxiety and were not always experienced as supportive or reassuring.

**Theme 2 - Being heard and acknowledged: Attempted acts of empathy**

Women reported that a simple but highly valued response from others less expert in endometriosis, to help them feel emotionally supported, was to respond with empathy. As participant eleven pointed out, “I mean that’s free”. There were various ways in which this empathy could be demonstrated, and thus, this theme was comprised of four subthemes: Being present and human; the impact of words; practical empathy; and self-compassion.

**Being present and human**

Women valued being given an open invitation to talk, for example employers demonstrating they were available whenever needed, or specialist nurses having a dedicated endometriosis phone line. When women did make use of these invitations, they often just wanted the other person to provide a listening ear, and to act as a sounding board, allowing them space to process their own experience:

“I talk to my husband a lot to be honest like if I’m just in the car and just venting, and I would just talk to him, but it’s not…it’s someone to listen, it’s...
not someone to tell me it’s gonna be ok and you know supportive in that way, it’s just to listen” (participant fifteen).

What made this listening ear feel more genuine and appreciated was if it was combined with validation and understanding from that person:

“she literally wrote down, she like, told me like, tell me everything you’re worried about, and she drew this map, and then she showed it to me, and she’s like, this is why you’re so tired, and so stressed, so it was, it was really helpful for me, erm, yeah, to have that validation” (participant eleven).

**The impact of words**

Women valued when others simply ‘checked in’, and asked them how they were feeling:

“I think for people who are suffering from long term chronic kind of pain inducing er...condition or any kind of chronic condition really er...they should kind of er...be automatically checked on their emotional status” (participant two).

This seemed especially important for healthcare professionals to do, but sadly something that was often left out of consultations, leaving women feeling emotionally unsupported:

“absolutely nothing from my GPs, I mean I’ve literally, every time I’ve been to my GP I’ve just sat there and cried, and, at no point have I ever felt, like,
there was empathy or an offer of support, or, asking, you know, I don’t know, do you think you might be depressed, have you tried counselling, are you ok, do you, it’s absolutely nothing, non-existent” (participant eleven).

Sometimes networks tried to emotionally support women, by offering well-meaning phrases such as “I hope you get better” (participant fourteen) and “I’m really sorry [you have been diagnosed with endometriosis]” (participant twelve). However, these could miss the mark, and discount the positives finally being diagnosed could bring, or reminded women they never would truly get better, thus leaving women feeling unsupported. Women also encountered scenarios they perceived as actively un-empathic, for example, being judged for cancelling plans or calling in to work sick, and their very painful menstrual cycle being directly likened to that of someone who did not have endometriosis:

“I’ve definitely had times where I’ve had people who I’ve considered close friends who have just been like dismissive, or they’ll like compare their regular period pains to my endometriosis pains, and it’s not something I appreciate at all” (participant nine).

It was clear from the women’s responses they felt empathy was something that did not take another person much effort to provide, but it was lacking from many areas in their life, most notably within healthcare appointments, with GP’s often responding in the least empathic ways.
Practical empathy

Women found it helpful when others made an effort to, and were willing to learn about, endometriosis. Being willing to do this reassured women their experiences would be better understood and gave them greater confidence they would be supported:

“I like it when they [friends] ask about it, erm...it just, it feels like it’s important for them to understand it, which is nice, and I think more people need educating about it and I think the more I talk about it with them then the more they understand it, so the more they’ll have an understanding as to me constantly cancelling things because I can’t go because I’m not feeling very well, so yeah it does it makes it a lot easier” (participant thirteen).

Being given practical help, such as with household chores, childcare, and physical care, was another way in which women felt emotionally supported by their networks of close others. Similarly, these networks being flexible provided psychological benefit, for example, employers facilitating home working, or varied hours, and healthcare services relaxing cancellation policies to account for symptom flare-ups. However, when those same networks tried to fix the problems, or offer advice and solutions, women found this frustrating, patronising and unhelpful in the majority of cases:

“I think that’s probably my frustration the most is when people sort of make a lot of suggestions about what things to try, and some of it is just random and you know it’s a lot to try and try different things all at the same time” (participant fourteen).
**Self-compassion**

It was not just those around them who could support women by being empathic, as women could also be empathic and kind to themselves, as a way of supporting themselves to manage the impact of endometriosis. Women helped themselves by engaging in their own hobbies, or distracting themselves. They also found that adjusting to life with a long-term physical health condition sometimes meant slowing down, and allowing themselves to relax and take time out:

“I’ve found that quite helpful, like being able to switch off, and...erm...yeah just getting a bit of space...what else have I done...I don’t know it’s just, it’s literally about finding space to kind of...you know to say I’m feeling awful today...I’m gonna you know...do something that doesn’t require me to run around or interact too much with other people” (participant four).

**Theme 3 - A taboo condition: A long way to go**

The biggest barrier women came up against, when trying to seek emotional support for their endometriosis, was the perceived taboo of their condition. Perhaps unsurprisingly, women in the study felt others perceived endometriosis, periods, and women’s health as topics that ‘should not’ be discussed. This taboo manifested in several ways, and as such, this theme was comprised of three subthemes: A lack of awareness; services need to change; and too difficult to discuss.

**A lack of awareness**

Women experienced that healthcare professionals, especially GPs, did not have much training into endometriosis, which perhaps stemmed from this taboo topic not being
incorporated as much as needed into medical training programmes. Women felt that, in order to feel physically and emotionally supported, this needed to be addressed:

“If they trained the GPs about this, I think they should give them proper training about this, because people with cancer, they know what they’re going through, I bet if someone with cancer comes to them having this pain, they will give them Oramorph or something strong, because they know how painful it is…we too we’re going through our own pains” (participant six).

This taboo also meant there was not much public awareness of endometriosis, and so women did not feel they were able to get emotional support, as those who they sought it from may not understand what they were going through: “I think because there’s no understanding, or little understanding, there isn’t that support” (participant fifteen).

Services need to change

The other area that was perceived to be of taboo was emotions. The women were perhaps experiencing the effects of a society where emotions and mental health are still somewhat stigmatised and unspoken about. For the women in the study, this meant healthcare professionals not only did not check in with how they were feeling, but they did not offer to refer to psychological services, and get women the support they needed, perhaps for the most likely reason that these services did not exist:

“It just hits you so badly (pause) And then…some of them, they leave you without that support. They just say right OK you’ve got stage 4 endometriosis, and then sort of go and deal with it now” (participant seven).
In cases where it did exist, women came up against many hurdles if they wanted to access support. For example, self-referral processes were complicated, or only a small number of sessions were offered. For those women that were seen by mental-health professionals, outside of endometriosis services, they found appointments were not usually set up to meet their needs, as shown by this participant who mentioned their endometriosis in therapy sessions:

“I have mentioned it occasionally…but it’s cos it’s not really their department, so they don’t really know how to help if that makes sense”

(participant three).

Some women reported that for them, their physical health was their priority, and making progress with this would benefit them emotionally, however, services still had a long way to go to ensure women were getting the physical health care they needed. Other women reported they wanted emotional health and wellbeing to be more of a conversation throughout their care, and they wished more of a holistic approach could be taken, rather than physical aspects being the sole focus of consultations:

“I think with a condition like endometriosis, but with any…chronic pain conditions…you know inevitably the patients will have a….emotional kind of impacts by their physical condition, so I er think it should be an automatic process to then bring the teams together to evaluate, rather than oh yeah this is my side, the physical side, I don’t deal with the emotional side”

(participant two).
They felt conversations about the psychological impact, and the offer of formal support, would be especially helpful at diagnosis. At this point, they could discuss the impact of the lengthy time to diagnosis, and the implications that having a long-term condition could now mean for their lives. Participants that had had experiences of holistic treatment, spoke positively of such experiences.

**Too difficult to discuss**

However, as all of this taboo existed, women felt that being open and honest about their condition or how they were feeling was not easy or comfortable for either themselves or their support networks. They also felt it affected others when they had to provide support, as it was a difficult task, leading some women to feel as if they were a burden:

“I speak to my family about it when it gets so bad and I’m down, then I call my siblings, we have a whatsapp erm group chat so we talk about it, then I call my mum…I don’t like bothering her because she doesn’t like seeing that I’m sick” (participant six)

This then meant some women preferred to keep what they had to say to themselves, and just deal with the physical and emotional aspects of the condition themselves, ultimately meaning their emotional needs went unmet:

“he doesn’t know anything about it…I’ve not ever, ever explained to him like….even when they said that the best thing to do is to have an erm hysterectomy, I didn’t, I couldn’t tell him…I don’t know, like open myself to tell him….he doesn’t know what I’m going through, he doesn’t even know what I have, that’s how bad it is” (participant six).
**Discussion**

Several key findings emerged from this study, in which 15 women diagnosed with endometriosis discussed their experiences of emotional and psychological support for the condition. Women have many networks they can potentially receive support from, including friends, family, healthcare professionals, colleagues, and other women with endometriosis. However, there is variation in the support women can get, and want to get. On the one hand, women do not necessarily want or need explicit emotional or psychological support. There are many practical things both they, and those around them can do, such as managing physical symptoms, and increasing information sharing. However, there are also more explicitly psychological responses that can be helpful. This does not always include formal psychological support, as if women’s support networks provide empathy, a listening ear, and do not try to ‘fix’ symptoms by offering unhelpful solutions, then women can feel emotionally supported. Women do feel however there need to be more conversations about the psychological impact of endometriosis, and therefore more formal psychological measures do need to be in place, to help them feel supported.

**Relevance to Existing Literature**

Many of the study findings are consistent with previous literature. Theme one’s demonstration of the benefits that being part of a community group bring to women with endometriosis fits with Whelan’s (2007) research into women with endometriosis as a community, who benefit each other by providing knowledge, a shared ownership over their condition, and empowerment. The current research however is perhaps the first to highlight some of the drawbacks to being part of such a group. This research shows being part of a community group can heighten self-awareness of the negative
aspects of living with endometriosis, and potentially creates a need for emotional support, rather than acting as a purely positive experience that acts as a form of support. The finding that when women are supported in ways that are not explicitly psychological, this inadvertently mitigates the need for emotional support, is also consistent with other research in the field. Young et al.’s (2015) review showed women want to be given information and knowledge from healthcare professionals, and having this knowledge is beneficial. It also showed when treatments do not work, women feel despair, anger and disappointment, therefore suggesting when women’s physical health is prioritised and they are given physical relief, they will feel more emotionally supported, which was also shown to be what women in the present study wanted. This review also showed women’s wellbeing is negatively affected by how others react to them, for example when they are dismissed and their experiences trivialised (Young et al., 2015). This fits with the findings of the current study and that of theme two, which showed women feel emotionally supported when those around them are able to empathise and provide a listening ear, rather than when they trivialise their experiences, provide unhelpful comparisons, and make women feel invalidated. Theme three’s assertion that periods are a taboo topic fits with research by Seear (2009) and Denny (2004) demonstrating that women feel menstruation is a private experience, which should be hidden from others, creating problems including delayed diagnosis. The present study is novel in its findings that this taboo is also intertwined with wider societal taboo around emotions and mental health, and that these taboos might be preventing access to psychological support, as well as the physical health support mentioned in other studies (Denny, 2004; Seear, 2009).

The findings of the present study echo previous research, calling for an holistic, multidisciplinary approach to endometriosis care, utilising the skills of clinical
psychologists, cognitive-behaviour therapists, and other mental health professionals (Dancet et al., 2014; Facchin et al., 2018; Fritzer et al., 2012; Hällstam et al., 2018; Zarbo et al., 2018). However, what is novel about the present study, in line with the aims, is it is the first known study to demonstrate from the women’s perspective, that a multidisciplinary approach is needed. Participants in the study were, on the whole, supportive of the idea that endometriosis care should include some focus on emotional wellbeing. There was the potential for women to feel that by being offered mental health support, this was an indication their symptoms and experience is psychosomatic, something which many women may have been told whilst seeking a diagnosis (Culley et al., 2013). However, no participant expressed this view. When explicitly asked how they felt about a trainee clinical psychologist, someone who may be more traditionally based within mental health services, being interested in the mental health needs of women with endometriosis, not one participant expressed a negative view, or felt having psychological support for endometriosis could be stigmatising. Participants instead felt the opposite, and expressed it was refreshing for their emotional needs to be considered, with the hope that one day they would be more supported.

If services began checking in on the wellbeing and mental health of women with endometriosis, this would bring them more in line with policies and other research recommending this should be routine practice. The National Institute for Health and Care Excellence (NICE) in the UK issued guidance in 2009 outlining how depression in adults with a long-term physical health problem should be managed. This recommends healthcare professionals should be alert to the possibility of depression in those people with a long-term health condition that can impair their functioning, and these patients should be referred for appropriate psychological treatment (NICE, 2009). The literature demonstrates women with endometriosis can experience impairment in functioning, for
example with chronic pain and other symptoms making it difficult for them to engage in usual activities such as going to work, looking after their children, and socialising (Culley et al., 2013; Fourquet et al., 2010; Young et al., 2015). However, as the participants in the present study demonstrated, women with endometriosis are not appropriately screened for psychosocial difficulties, including depression, and being referred for appropriate treatment and support. Similarly, the influential ‘No health without mental health’ publication (Prince et al., 2007) outlined that certain long-term health conditions can increase the risk of a person experiencing a mental health difficulty. Such long-term conditions included those with symptoms such as chronic pain, and that come alongside stigma, the need for lifestyle changes, and relationship breakdown, all factors that can be present for women with endometriosis (Culley et al., 2013; Denny, 2004; Prince et al., 2007; Seear, 2009; Young et al., 2015). Prince et al. (2007) also outlined that dysmenorrhoea, and dyspareunia, which are common symptoms of endometriosis, are consistently associated with anxiety, depression, and the use of substances and alcohol. This all adds further weight to the need for the emotional needs of women with endometriosis being screened for and treated where necessary. The ‘No health without mental health’ publication outlined that mental health awareness should be integrated into health-care delivery, and holistic models of care should be promoted and integrated into the management protocols for physical health conditions, including reproductive ones (Prince et al., 2007). From the results of the present study, it appears women with endometriosis would welcome this integration.

At its most recent approximation, the cost of endometriosis to the UK economy was £8.2 billion, which is similar to other long-term health conditions including diabetes and rheumatoid arthritis (Simoens et al., 2012). This figure may now be much higher. These costs are attributable to time off work, reduced productivity due to symptoms, and
emotional difficulties such as depression and anxiety, including associated treatment costs (Simoens et al., 2012). If women with endometriosis were able to access formal psychological support, as part of their standard package of care, this economic cost would likely decrease. This would not only be due to reductions in rates of anxiety and depression, but also due to women feeling more able to return to work, and potentially reduce their need for physical health care appointments, as they learn to manage their symptoms in new and beneficial ways, and reduce the effects of endometriosis on their lives.

**Strengths and Limitations**

This is the first study to qualitatively explore women’s experiences of emotional and psychological support to enable them to live well with endometriosis. Previous literature discussing the need for psychological support has focused on the opinions of clinicians and researchers in the field, however this is the first study to explore women’s opinions, and add their voice to the literature around calls for psychological support. As participants were recruited from two separate settings, this may mean there was greater variation in experiences and responses, and so the results have more cautious transferability, than if women were all recruited from one place. The findings were also discussed between the lead author and two supervisors on several occasions, and therefore had input from multiple perspectives.

The study has some limitations. The majority of participants were from white ethnic backgrounds. The results are therefore missing more views from those from minority ethnic backgrounds, where topics such as periods and emotions may be even more stigmatised, and thus experiences of emotional support may be entirely different. Similarly, all participants were in at least part time employment. The views and
experiences of those women who have struggled to remain employed due to endometriosis are therefore missing, and it may be that these women have a greater unmet emotional need, due to their lack of employment opportunities. Finally, as the sample was self-selecting, it may be the women who participated had more adverse experiences where they lacked emotional support, that they wished to share, and so this may skew the results. However, given the range of experiences that women had had, both positive and negative, this may also not be the case.

**Implications for Practice and Research**

Healthcare professionals, especially GPs, could be further trained in endometriosis, including recognising symptoms, and understanding the various ways women with the condition may be impacted, including psychologically. It may be that professional training courses need to spend more time discussing the topic than they do currently, which is consistent with research showing professionals report needing more knowledge and information about the condition (van der Zanden & Nap, 2016; Young, Fisher, & Kirkman, 2017). Healthcare professionals could also benefit from further training in empathically responding to patient concerns, and in how to open up conversations about patients’ mental health. By being further trained in endometriosis, healthcare professionals would then hopefully be in a better position to supply women with information about the condition, for example symptoms, how to manage them, treatment options and the long-term effectiveness of treatments. It is important women get this information, in order to feel emotionally supported and equipped to deal with endometriosis. Prior research shows the general public have limited, or no, knowledge of endometriosis (Shah et al., 2010). Therefore, there needs to be greater public awareness of endometriosis, so the general public have better understanding, and are therefore better able to respond to women’s needs, in empathic and helpful ways. There
have been some moves towards increasing awareness already. For example within the
UK, a parliamentary inquiry has been launched with support from the charity
Endometriosis UK (Endometriosis UK, 2020) and subsequently more public news
outlets have released human interest stories, articles and features discussing
endometriosis and its impact. However, it is clear from the study participants that more
needs done with regards to public awareness, with some suggesting public health
campaigns, and more posters and adverts may be helpful. Above all, healthcare services
need to provide women with more, formal psychological support, tailored to and
specifically aimed at women with endometriosis. Some women suggested this could
take the form of support groups, facilitated by a mental health professional that is linked
to gynaecology clinics. Women also suggested that at clinic appointments, a mental
health professional could be in attendance, to check in on emotional wellbeing and
provide guidance on managing any difficulties. Women also suggested that having
access to a mental health professional, with awareness and understanding of
endometriosis, which they could see on a one-to-one basis, would be beneficial in
helping them to manage their condition. As previously mentioned within the
introduction, clinical health psychologists are professionals well trained and placed to
support patients with medical conditions to adjust to, and manage, the distress caused
by their physical health condition (BPS, 2008; Schulman-Green et al., 2012).
Endometriosis services could therefore benefit from updating their model of care, and
could create multidisciplinary teams that include a clinical psychologist. Clinical health
psychologists can fulfil many roles within such teams, including by consulting with
medical colleagues on complex cases, and by providing teaching and training in using
psychological skills to improve health care (Belar & Geisser, 1995; BPS, 2008). The
aforementioned training that healthcare professionals may benefit from, could be in part
delivered by psychologists working within these teams. It is recommended that a
stepped care approach could be implemented within the team. In this way of working, the psychologists could support the other members of the medical team to deliver low-intensity psychological interventions, including empathic listening, goal setting, and providing advice around adjustment (BPS, 2008; Kneebone, 2016). These staff could also play a role in identifying the women who are struggling to adjust to their endometriosis, and could be trained by the psychologist in identifying when it would be appropriate to refer for more specialist psychological support (Young et al., 2017). At this stage, the clinical psychologist could then provide the psychosocial interventions to the women who would benefit from them the most. A clinical psychologist could therefore usefully work alongside medical professionals within endometriosis services, to tailor their combined knowledge and resources, to deliver whole person care, ultimately aiming to improve women’s physical and mental health, in conjunction, thereby reducing distress, and enabling women to live well with their endometriosis.

Future research could explore the views of a wider range of women with endometriosis, in order to find out at what stages psychological input would be important and needed, for example at diagnosis, before and after surgeries, or around conversations about fertility. This research could be done using survey methods, and could also elicit views from women regarding what support they would view as acceptable, for example support and therapy groups, or one-to-one psychology appointments. Future research could also focus on using different therapeutic interventions with women with endometriosis, for example acceptance and commitment therapy, in order to evaluate their utility and efficacy, as well as their acceptableness to women.
Conclusion

This qualitative study of 15 women diagnosed with endometriosis shows they have emotional and psychological support needs, which are currently largely unmet. Despite women having many networks that they could potentially be supported by, changes should be made within healthcare services, and the public sphere, in order to improve the support women receive. Healthcare professionals need to be better trained in endometriosis, and services should use multidisciplinary teams, in order to meet the holistic needs of this group of women. Public awareness of endometriosis needs to increase, to enable women to access better informal support from their networks of families, friends and colleagues. Much work needs done; however women with endometriosis are receptive to psychological support being integrated into their care, in the future.
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Paper 3

Critical Appraisal

Word Count

Main text (excluding references): 5727
Introduction

This paper critically appraises the research process, in relation to the systematic review, and the empirical study. It considers and explores decisions made, challenges faced, strengths and limitations of the work, and suggestions for future practice and research. Some personal reflections are also included.

Current care for women with endometriosis has been reported to require a review, and, in line with this, a UK government all-party parliamentary group inquiry has been launched (Endometriosis UK, 2019). It is therefore currently a time when research into endometriosis has the potential to influence future policy, practice, and evidence-based healthcare. In line with this, the work presented here aimed to explore and inform the care that is on offer for women with endometriosis. This was explored in terms of women’s experiences of how healthcare professionals interact with them, and the emotional and psychological support that they are able to access, two issues that present themselves frequently in the literature.

Selecting the Research Topic

The identification of endometriosis as a potentially viable area of exploration came from personal experiences. The author has a close friend who received a diagnosis of endometriosis. The author was aware of the symptoms and how debilitating and frustrating these could be, the difficult route to diagnosis, and the impact that endometriosis could have. There were times when the author’s close friend had been negatively impacted by endometriosis, and this brought to light the lack of support
services for women, at least in this individual case, and the potential need for such services to exist.

A brief search of the literature revealed that, for a number of years, researchers and clinicians working in the fields of psychology, gynaecology and endometriosis, had been making recommendations that women with endometriosis should have better access to psychological support. As a result of their ENDOPART study, into the impact of endometriosis on couples within the UK, Culley et al. (2013a) released a summary report outlining several recommendations that concerned the psychological wellbeing of women. These included that specialist nurses should give women the option to speak about the psychosocial impact of living with endometriosis, during specialist clinic appointments, and that National Institute for Health and Care Excellence (NICE) guidelines should be developed that include information about how psychological assessment and intervention can help. They also recommended that a biopsychosocial approach be taken in the management of endometriosis, including a focus on quality of life, stress reduction and coping strategies, and emotional support (Culley et al., 2013a). Others echoed such recommendations, with some suggesting that gynaecology and endometriosis services could screen for the presence of psychological difficulties (Pope, Sharma, Sharma, & Mazmanian, 2015), or that they could form multidisciplinary teams and use the perspectives of mental health professionals, such as clinical psychologists, during endometriosis clinic appointments (Dancet et al., 2014; Facchin, Saita, Barbara, Dridi, & Vercellini, 2018; Hällstam, Stålnecke, Svensén, & Löfgren, 2018).

Despite these recommendations, the author’s observations, based on anecdotal evidence, were that endometriosis services were not yet structured in a way that met women’s psychological needs, however, this was unclearly described within the
literature. It was also possible, that women’s needs were being met by other, traditional mental health services, thus negating the need for specialist endometriosis support services, however the evidence for this is limited. The final possibility was that women with endometriosis would not want dedicated mental health professionals to be involved in their care. This could be because many had been told on their routes to diagnosis that their symptoms were somatic, or “all in their head” (Culley et al., 2013b), and therefore a mental health professional based in their clinic appointments may be taken as confirmation of this fact, or seen as offensive.

The author therefore felt that, for the empirical study described in paper two, it would be important to gain women’s perspectives in this area, and to determine if they were already accessing psychological support to enable them to live well with endometriosis and, if so, where they were getting this, from whom, and what it looked like. Alternatively, if women were not getting this support, the author felt it was important to explore with women what they wanted from services, and what they felt they needed, in terms of psychological support, thus adding women’s voices to the literature, in a way that had not been done previously. This research could ultimately then go some way towards informing the structure of endometriosis services in the future.

Whilst designing the study described in paper two, and reading the endometriosis literature, it became apparent that the results of many qualitative studies reported, in part, upon women’s experiences of healthcare professionals. Some of the described experiences were positive (e.g. Grundström, Alehagen, Kjølhede, & Berterö, 2018), however, others were negative, and further described the impact this had on women’s wellbeing, and experience of services and care (e.g. Grogan, Turley, & Cole, 2018). The results of each of these studies were a potentially useful source of guidance for
healthcare professionals and service managers, who could use such information to inform the care they delivered. However, initial scoping exercises revealed that no review existed that combined the results of these studies, or appraised their quality. This potentially makes it more difficult, or less likely, for those who could be influenced by such results, to access and read them, and therefore change their practice (Thomas & Harden, 2008). The author therefore decided that conducting a systematic review of the qualitative literature looking at women’s experiences of their interactions with healthcare professionals could prove useful, in informing practice in the future. This review could then hopefully, in part, lead to improvements in the service and care delivery for women with endometriosis.

**Paper One: Systematic Review and Thematic Synthesis**

**Systematic Search**

There are a variety of search tools available to researchers, such as SPIDER (sample; phenomenon of interest; design; evaluation; research type), and PICOS (population; intervention, comparison; outcome; study design). However, there are risks that such tools may not identify all relevant studies, and it can be difficult to ensure that a systematic search captures all of the relevant qualitative literature (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014). The CHIP (context; how; issues; population) tool was thought to be an appropriate fit for the current research, because researchers with expertise in qualitative research and synthesis had developed it (Shaw, 2010; Williams & Shaw, 2016). It was therefore thought that it would capture the relevant qualitative literature, more so than other tools that may have been developed for quantitative systematic reviews. The search strategy and tool were discussed with
staff at the University of Manchester library, with knowledge of conducting systematic reviews, and were deemed to be appropriate, and suitable, in addressing the review aim.

**Inclusion Criteria**

Reviews of qualitative studies have become a useful resource in informing policy and evidence-based healthcare (Barnett-Page & Thomas, 2009). It was therefore thought that a review of the qualitative literature, in this instance, could usefully contribute to recommendations for care of women with endometriosis. Although quantitative literature does exist, which provides some insight into interactions between women and their healthcare professionals, it was decided that the qualitative literature would better capture the experiential data that was sought. To ensure that the review was comprehensive, mixed-methods studies were included, with only the qualitative results being synthesised and reported. However, no such studies were identified.

The review included studies conducted in any country. It was felt that restricting the criteria to include only studies conducted in the UK would limit the number of relevant studies, and thus, limit the transferability of the results. Scoping exercises had shown that, despite encountering different healthcare systems, women throughout the world often encountered similar experiences with their endometriosis care (e.g. Whelan, 2007). Including studies from any country allowed the results to become meaningful in informing the policy and practises of any healthcare system, thus having the potential to inform endometriosis care for all women, rather than a subset.

**Quality Appraisal**

The methods for appraising the quality of qualitative research, and indeed if quality should be appraised at all, is contested (Carroll & Booth, 2015). However, some do
recognise its value and importance within a systematic review (Thomas & Harden, 2008; Tong, Flemming, McInnes, Oliver, & Craig, 2012). Quality appraisal is also recognised as a key component of thematic synthesis; the method utilised in this review (Barnett-Page & Thomas, 2008). It was therefore appropriate to appraise the quality of the studies included, and the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies (CASP, 2018) was selected as an appropriate tool. The CASP is thought to be a useful tool for novice researchers, such as the present author (Hannes, Lockwood, & Pearson, 2010). It is also identified, by organisations such as Cochrane (Higgins & Green, 2011) and the NHS (Ring, Ritchie, Mandava, & Jepson, 2011) to be an appropriate and widely used tool. However, it does come with limitations. As mentioned in paper one, the CASP does not require study authors to have reflected upon their epistemological or ontological stance, something that is considered good practice, and a reflection of higher quality research (Levitt et al., 2018; Long, Brooks, Harvie, Maxwell, & French, 2019). In response to this, a modified version of the CASP was used, (Long et al., 2019), which allowed the author to appraise the studies based upon this additional criterion. This modified version also allowed the author to include a ‘somewhat’ response to each item, which was appropriate when studies only partially met criteria. This was supported by literature that suggests that quality appraisal tools can be modified and adapted to suit their purpose (Tong et al., 2012). The CASP also does not indicate how to meaningfully assign a quality rating to a paper. The author therefore used her own guidelines and judgement, based on the individual ‘yes’, ‘no’, ‘somewhat’ and ‘can’t tell’, ratings, assigned to each study, which enabled the studies to be ordered, in terms of quality. This ordering was matched by an external appraiser, and therefore was judged to be a meaningful way of determining the quality of included papers. Similarly, there are no guidelines to indicate when a paper may be of such low quality, that it is advisable not to include it in a qualitative review. The author again
used judgement in this instance, which is described in more detail, in the main text of paper one. Such judgement fit with the method of analysis, with Thomas and Harden detailing in their paper (2008) that it is important that the differing quality of primary studies is considered in some way.

**Analysis**

Multiple methods of qualitative evidence synthesis have been identified (Barnett-Page & Thomas, 2009), each with its own rationale and purpose. Given the range of possible methods available, the author needed to decide on the most appropriate, for the current review. Thomas and Harden’s (2008) thematic synthesis was selected, for a couple of reasons. This method has previously been used in systematic reviews that seek to address questions concerning experiences, as the present review also sought to do (Thomas & Harden, 2008). It is also an appropriate method to use in reviews that seek to inform policy and practice (Thomas & Harden, 2008), which was again in line with the aim of the present review.

**Excluded Papers**

Following completion of the thematic synthesis, and whilst writing the discussion, an additional paper, not found in the systematic searches, was brought to the attention of the author, by one supervisor, who had found the paper whilst providing comments on a draft of the review (Bullo, 2018). Upon reading this paper, it was evident that it met the review inclusion criteria, and had no reason to be excluded. However, the systematic search had not identified this paper. The author consulted with staff at the University of Manchester library, who confirmed that the original search strategy had been sufficient and appropriate. The library staff re-ran the original search. They verified that the paper in question was not identified in the search results, despite being available on the Web.
of Science database, which was one of the databases originally searched. It was hypothesised that the reason this paper was not identified in the original search, was due to the terms used to index it on the database. The paper had been published in the journal Discourse and Communication, and so had been indexed in line with terms relating to communication, which were outside the scope of the current review. Including such terms in the original systematic search would have led to a less specific search, with many inappropriate studies being identified. As already discussed, identifying all relevant primary studies is a particular challenge when doing a qualitative systematic review, and conducting a sensitive search that is comprehensive enough, without being too all-encompassing, is difficult (Methley et al., 2014). Using strategies such as increasing the number of search terms, in an attempt to find more potentially relevant records, is likely to result in poor precision and the need for more time and resource (Shaw et al., 2004). Such strategies may still not even yield all the potentially relevant articles, and so the limit of search terms has to stop somewhere. It has also been identified that for qualitative synthesis, it may not be necessary to find and include every eligible study, as conceptual saturation can still be achieved when the sample is purposive, rather than exhaustive (Doyle, 2003; Thomas & Harden, 2008). At the time the paper was discovered, the analysis had already been completed, and as the thematic synthesis relied on extracted data being analysed in order of study quality, including the paper would very possibly have meant re-doing the analysis. Given the time constraints, it was therefore not thought possible, pragmatic, or appropriate to include the paper at this stage. The findings of the omitted study do appear to be in line with the results of the present review; however, it is still acknowledged that its exclusion is a limitation. Prior to publication, the review protocol will be updated to include the use of search engines during the systematic search, and the search and analysis will be re-done, ensuring inclusion of this paper, at publication.
By repeating these steps prior to publication, this will also ensure that the review is as up to date and relevant as possible. The author acknowledges that the date the original search was conducted (12/07/2019) means the current review may be out of date. A scoping search conducted on 25/03/2020 highlighted that research into endometriosis is rapidly expanding, and so updating the current review, prior to publication, will account for this.

**Reflexivity**

When conducting a thematic synthesis, the stage of generating analytic themes is thought to be the most controversial, as it requires researchers to make their own judgements and conclusions (Thomas & Harden, 2008). During analysis, the author was very aware of her dual role as both a researcher, and a healthcare professional. Many of the results being synthesised, reported negative experiences with healthcare professionals, however, offered little context from the primary study authors, as to why women may have encountered some unhelpful responses. For example, long waits due to pressurised healthcare systems, lack of referrals due to services not existing, and lack of training due to funding issues. At times, the author found it difficult to analyse such results without this context. This had the potential to impact upon the analysis, i.e. for the author to go beyond the data, using personal experience. However, the wider research team was able to provide an important role in reviewing codes and themes. This helped the author to ensure that the review results were grounded in the primary data, and that the final analytic themes were appropriately derived from this data, without using additional context to synthesise the results.
Trustworthiness and Credibility

The author aimed to produce a review that was trustworthy and credible, and a number of steps were taken throughout, to ensure this as far as possible. This was important to do, in order to ensure that the research was being conducted to a set standard, as all research should aim to do (Tong et al., 2012). A protocol was registered prior to study commencement, and adhered to. An independent reviewer screened a portion of titles and abstracts, as well as reading the full texts of all potentially relevant studies, and offered judgement as to whether they should, or should not be, included in the review. This helped to ensure that the author’s own decisions regarding study inclusion, were reliable. At all screening stages, there were high levels of agreement. Quality appraisals were also independently completed for a portion of the included papers, with judgements consistent with that of the author. During analysis, codes and themes were discussed and revised with the wider research team, to ensure they had input from multiple perspectives. The study was also checked for consistency with the ENTREQ (enhancing transparency in reporting the synthesis of qualitative research; Tong et al., 2012) checklist, which can be seen in Appendix 16.

Summary

This systematic review was the first to comprehensively review the endometriosis qualitative literature surrounding women’s experiences of their interactions with healthcare professionals. The credibility of the findings are enhanced due to the rigorous steps taken throughout. A number of useful key recommendations were made, that have the potential to influence policy and practice.
**Paper Two: Empirical Study**

**Designing the Study**

There were a variety of ways in which the aims of the current research could have been met. Quantitative, or mixed-methods, methodology could have been utilised. For example, survey methods could have been used, asking a large number of women of their experiences of psychological support for endometriosis, and statistically analysing the results, potentially combined with qualitatively analysing the results of open questions. Whilst survey methods would generate the views of a large number of women, this would perhaps be most helpful in informing the structure of endometriosis services if women from across the UK were able to access, and take part in the survey. This was beyond the scope of the current research, in terms of time and resource, however could be a potentially interesting avenue of further research. Alternatively, a purely qualitative methodology was also appropriate, with either focus groups or individual interviews being used to elicit views and perspectives. Qualitative methodology using semi-structured, individual participant interviews was chosen. Given the potentially sensitive nature of the topic, it was felt to be more appropriate to interview women individually, than to hold a focus group, despite focus groups being able to generate the views of more participants, and more breadth of data (Stokes & Bergin, 2006). If the latter had been chosen, group processes may have influenced results, which may not have been representative of the participants’ individual views (Stokes & Bergin, 2006). By using qualitative interviews, the current study allowed the author to develop more detailed insight and understanding into women’s individual experiences, than other methods would have allowed.
Recruitment

Although recruiting a representative sample is an issue that lies with quantitative studies, rather than qualitative (Thompson, 1999), the author felt that recruiting participants from just one domain meant the results may have only reflected the views of a subset of women with endometriosis, therefore limiting their transferability. As the results could go some way to informing services, the author felt it was important, and appropriate, to have results informed by the views of a range of women with endometriosis. Therefore, if the results were used by services, they would make changes based on the views of a wider, more representative, subset of women. The author recruited women from both specialist endometriosis treatment clinics, as well as an online support group. It was thought these women might have differed in a few ways. Women under the care of specialist endometriosis centres often have more severe symptoms (NICE, 2017). This could mean their psychological needs and access to support are different from women not under such services, who may be accessing other forms of support, such as online support groups (Shoebotham & Coulson, 2016). On the one hand, women under the care of specialist centres have increased access to specialist gynaecologists and nurses (NICE, 2017), and physical health treatments. This may increase psychological wellbeing as women are accessing help and support, albeit for their physical health, however this may impact positively on their emotions. As part of their care, these women may also be offered more referrals for further specialist care, for example to pain management teams, and fertility specialists, therefore increasing their care, and potentially promoting wellbeing (NICE, 2017). However, by nature of their severe symptoms, these women may be at greater risk of psychological distress, and may not be in receipt of support for this (Facchin et al., 2017). In the present study, it therefore seemed important to capture the experiences of this group of women. However, the author acknowledged these experiences may have been quite different.
from those not under specialist care, and so it also felt important to capture the experiences of women from another domain. An online support was chosen, as it was considered likely to include a large number of women, with a large variety in experience. Recruiting from two domains also had the potential benefit of speeding up the recruitment process, which was useful within the time constraints of the research.

**Topic Guide Development and Experience of Interviews**

The topic guide was designed to be fairly broad, utilising open questions to enable women to speak more freely about a range of issues that might have been relevant to them. Prompts and probes were included to enable the author to maintain the focus of the research. The guide was developed deductively; using issues prominent in previous research, to inform prompts and probes, for example negative experiences with healthcare professionals (e.g. Culley et al., 2013b). The author was able to test out the utility of the topic guide, prior to participant interviews, by conducting a pilot interview with her friend with endometriosis. This interview enabled useful reflection upon the questions being asked, and led to some changes being made to the guide, for example adding additional probes for areas that seemed pertinent. The pilot interview also offered the author an invaluable opportunity to move from being a clinician, which she regularly was within her role as a trainee clinical psychologist, to becoming a researcher. Distinctions have been drawn between these two roles, with the role of researcher thought to require a more neutral, fact-finding style, versus the more empathic style of a clinician (Targum, 2011). This shift was difficult to do in practice. The author acknowledges that holding this dual-role may have impacted the interviews somewhat, as there may have been times when questions were asked that were more ‘clinical’ than ‘research’ based. However, the author attempted to avoid this, and so she listened to the recording of each interview to enable reflection on the questions asked,
and ensure that questions asked in subsequent interviews were fitting for the research purposes.

The topic guide was revised, following the first three participant interviews. Within these interviews, the author found it difficult to maintain the focus of the interviews, and the participants often reverted to discussing the physical nature of their endometriosis, as opposed to any psychological difficulties they had had, and the support they had received for these. The author reflected that there might have been several reasons for this. Firstly, the participants may have only ever been exposed to the medical model within their healthcare experiences, as opposed to more of a biopsychosocial one, which has been proposed to be useful for women with endometriosis (Culley et al., 2013a). Women may therefore have never had the opportunity to develop a psychological language or understanding of their difficulties, meaning it was difficult for them to talk about issues in this way. In line with this, women may also have been unaware that psychological services could exist, and so were unable to reflect on this as missing from their experience. Similarly, women may have rarely been asked about their emotional experience, and so again, were unable to reflect that this is something that they felt was missing from their care, as it was not something that they expected to happen. Women’s expectations may have been that services only dealt with and acknowledged physical difficulties, and so they may not have seen lack of psychological support as a problem. On the other hand, however, many women with endometriosis have experienced many years of other people, including healthcare professionals, not believing that their symptoms exist, being told that their symptoms are somatic, and ‘in their head’ (e.g. Culley et al., 2013a). Given that the research interviews may have been the first time that these women were able to share their stories, they may have been keen to demonstrate the physicality of their
illness, and prove that their symptoms were real. Therefore, they may have avoided discussing the psychological impact of their difficulties, to avoid any risk that they would encounter a lack of belief on the part of the author. Following these observations, and reflections with supervisors, the author then ensured that, in subsequent interviews, she gave the participants ample opportunity to tell their whole story, before attempting to shift the interview closer towards experiences of psychological support. Following this change, the author noticed an increase in the amount of relevant information that was generated during interviews. The author also added a question to the topic guide, to find out from participants their views on being interviewed by a trainee clinical psychologist, with the hope that this would elicit views regarding stigma, or concerns about lack of belief. Again, this added value to the data collected, and generated useful information, which is included in the main text of paper two. Whilst making these changes to the topic guide and interviews, the author also reflected that in these instances, holding the dual role of clinician and researcher may have added value and proved beneficial. By using some of the therapeutic skills that she would normally use within her clinical role, such as empathy and reflective listening skills, this may have created a safer space for participants to share their story, and ultimately feel comfortable enough to open up and speak about more sensitive issues, such as their psychological wellbeing and experiences of support.

Data Analysis

The data was analysed inductively, using Braun and Clarke’s reflexive thematic analysis (2006; 2019). This data analysis method was chosen for reasons that made it a more appropriate method, above others, including interpretative phenomenological analysis. This version of thematic analysis offers a theoretically flexible approach (Braun & Clarke, 2006), meaning the researcher was able to adopt a critical realist
stance. This stance was chosen as it can be used to help researchers explore and explain social problems, and offer suggestions for policies to address such problems, issues that were relevant to the topic of the present research (Fletcher, 2017). Thematic analysis is also a useful approach for those conducting applied research, which the present research, with its focus on offering solutions for a problem facing women with endometriosis, arguably is (Braun & Clarke, 2014).

Data collection was stopped after 15 participants, when it was felt that the data provided enough information power, for analysis (Malterud, Siersma, & Guassora, 2016). Although much qualitative research mentions the concept of ‘reaching saturation’, this was not used for the present research. Saturation is a concept with origins in Grounded Theory, and so was not felt to be appropriate here (Malterud et al., 2016). Although the author originally aimed to transcribe all participant interviews herself, an important step in thematic analysis (Braun & Clarke, 2006), time constraints of the research meant that some (N=4) transcripts were analysed by a third party member of the University of Manchester, with previous experience of transcription. A confidentiality agreement was formalised and adhered to, in line with ethical procedures. Consistent with the steps outlined for a reflexive thematic analysis approach (Braun & Clarke, 2006), the author spent additional time reading and familiarising herself with these transcripts, also spending time ensuring they were consistent and accurate, and in line with the original audio recordings.

Prior to undertaking data analysis, the author had attended teaching and training on the use of thematic analysis. Within one workshop, whilst transcribing sample text, the author noted the difficulty of moving from a role as a clinician, who may seek to formulate the material, to an inductive researcher, who seeks to remain close to the data,
and remain data-driven. Having a wider research team with whom codes and themes could be discussed, was therefore even more valuable and important in the context of the current research, and helped the author to ensure the results were data-driven, and informed by input from multiple perspectives.

Due to the time constraints of the research, the author found herself conducting two qualitative data analyses in close succession of one another, with paper one’s thematic synthesis being closely followed by paper two’s thematic analysis. The author acknowledges that there were some overlapping findings within each paper, especially regarding the support that is on offer from healthcare professionals, and how they respond empathically to women with endometriosis. Whilst analysing the data from paper two, it could have posed a challenge to the author, to remain true to the data set, and remain data-driven, rather than being influenced by the results of paper one. Again, having a wider research team with whom the results could be discussed enabled any overlapping codes or themes to be discussed. This ensured that different perspectives were offered to enable the author to identify patterns in the data-set that might have been otherwise missed, or hidden by any assumptions formed from the analysis in paper one.

**Reflexivity, Trustworthiness and Credibility**

The author aimed to be reflexive throughout the research, however was aware of some of the reporting difficulties, including constricted work counts, and lack of consensus over what should be reported (Newton, Rothlingova, Gutteridge, Lemarchand, & Raphael, 2012). Whilst writing up the research, the researcher used the Consolidated Criteria for Reporting Qualitative Research Checklist (COREQ; Tong, Sainsbury, & Craig, 2007), as a guide for what to report (Appendix 17).
During initial research design, the author had planned, and sought ethical approval, for respondent validation. The author intended to hold a focus group, where participants could comment on the codes and themes, and offer further opinions regarding the truthfulness of these for them. Unfortunately, this was not possible, due to the time constraints of the research. The author acknowledges that this is a limitation of the research, whereby the results are potentially more influenced by the beliefs of the researcher, than of the participants, and consulting with participants would have added useful and alternative insight and perspectives, enhancing the credibility of the research (Birt, Scott, Cavers, Campbell, & Walter, 2016). However, the discussion of the results with the wider research team mitigated this limitation slightly, by ensuring that multiple perspectives informed the results.

Conducting the systematic review in paper one emphasised to the author the importance of producing a study of high quality. It was clear that higher quality studies produced a greater sense of trustworthiness and credibility in the results, and that they could go further towards informing syntheses. The author therefore appraised her own study using the same version of the CASP used in paper one, in order to ensure that she was also producing high quality research. This appraisal showed that paper two met the CASP criteria outlined, and could be said to be of high quality (Appendix 18).

**Summary**

This empirical study is the first to explore women’s experiences of emotional and psychological support, for endometriosis. The research was considered to have been conducted to a high standard, therefore enhancing the credibility of the findings. The
research has useful implications for policy and practice, and recommendations were made within the main text of paper two, outlining these.

**Implications and Relevance of the Research**

The results from the systematic review, and the empirical study, outlined within this body of work, advance our understanding of how best to support women with endometriosis. Both pieces of work indicate that there needs to be further training for healthcare professionals, both regarding endometriosis and its presentation, and with regards to empathic responding. Additionally, both papers highlight the importance of healthcare professionals providing women with clear, consistent, relevant information, to help them manage their endometriosis. Whilst the results of paper one highlight some of the distress that women with endometriosis can face, following their interactions with healthcare providers, paper two further explores the wider psychological distress that women face, and the lack of formal, evidence-based support that they can get for this.

The research is timely. Certainly within the UK, there has been much more public awareness of endometriosis, leading to the formulation of an all-party-parliamentary group inquiry, and an increase in published research, with the aim that services and care will be improved. The current body of research shows how clinical psychologists may contribute to these improvements and changes. With their ability to assess and understand psychological distress, and the complex role that living with a long-term physical health condition can add to this, clinical psychologists may be uniquely placed to support endometriosis patients, relieving distress and promoting psychological wellbeing. Similarly, clinical psychologists are not trained to solely offer therapies, and so may also have a role in supporting medical colleagues to empathically respond to
women, within the context of their healthcare consultations. Via publication and dissemination of the research, the results could inform policies and practice, and go some way to ensuring that women with endometriosis are more supported in the future.

**Dissemination Plans**

The author is committed to disseminating the research presented in both papers. Paper one has been prepared for submission to the journal ‘Social Science and Medicine’, and paper two has been prepared for submission to the journal ‘Qualitative Health Research’. The author aims to proceed with the submission of each paper, following any changes required, including the new searches and analysis for paper one. Summaries of paper two will be prepared and disseminated to participants, and will also be sent to Endometriosis UK, for publication on their website. The author will also seek to identify a relevant conference, where the research can be submitted for presentation.
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## Appendix 2: Systematic Search Terms

<table>
<thead>
<tr>
<th>CHIP Tool</th>
<th>Focus</th>
<th>Search Terms</th>
</tr>
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<tbody>
<tr>
<td>Context</td>
<td>Interactions with healthcare professionals</td>
<td>doctor* OR nurse* OR staff* OR provid* OR clinic* OR physician* OR profess* OR service* OR assistant* OR HCP OR healthcare profession* OR consulta* OR gynaecologist* OR obstetrician* OR HCA OR healthcare assistant OR hospital* OR GP OR general practitioner* OR surgeon* OR healthcare provider* OR medic* AND interact* OR communicat* OR discuss* OR appointment* OR convers* OR dialog* OR talk* OR chat* OR discourse OR support* OR encount* OR relationship*</td>
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<tr>
<td>How</td>
<td>Qualitative studies</td>
<td>interview* OR focus group* OR case stud* OR qualitative OR mixed method* OR thematic* OR TA OR IPA OR phenomenolog* OR grounded theory OR conversation analysis* OR observ* OR narrati* OR discourse analys*</td>
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<td>Issues</td>
<td>Experiences</td>
<td>view* OR experience* OR opinion* OR attitude* OR perce* OR belie* OR feel* OR know* OR understand*</td>
</tr>
<tr>
<td>Population</td>
<td>Women with endometriosis</td>
<td>endometriosis OR endometrioma</td>
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</table>
Appendix 3: Example of CASP Completed by Author

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

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Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

HINT: Consider

- what was the goal of the research?
- why it was thought important?
- its relevance.

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<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
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</table>

Comments: Clear statement at end of introduction. Follows on from introduction, clearly justifies itself.

2. Is a qualitative methodology appropriate?

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.
- Is qualitative research the right methodology for addressing the research goal?

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<tr>
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</table>

Comments: Aims to understand experience, which is appropriate for qualitative methods.

Is it worth continuing? Yes
3. Was the research design appropriate to address the aims of the research?

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use).

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<tr>
<th>Yes</th>
<th>Somewhat</th>
<th>X</th>
<th>No</th>
<th>Can’t Tell</th>
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Comments: Have stated they are using thematic analysis, which is appropriate, and the sampling method, and data collection method fit in with this and are appropriate. But they have not stated from what perspective they are coming from, therefore a ‘somewhat’ rating is most appropriate.

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider

- If the researcher has explained how the participants were selected.
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study.
- If there are any discussions around recruitment (e.g. why some people chose not to take part).

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<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
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</table>

Comments: They have explained why they recruited the participants they did, and all about the sample that they wished to attract. They haven’t discussed drop out, but participants approached them, and they would have no way of knowing why those that didn’t take part, didn’t take part. They’ve explained why the participants were the right ones for the knowledge in the study.
5. Was the data collected in a way that addressed the research issue?

HINT: Consider

- If the setting for the data collection (e.g. clinic, charity) has been justified.
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen.
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide).
- If methods were modified during the study. If so, has the researcher explained how and why (if applicable).
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data.

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<th>Can’t Tell</th>
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</table>

Comments: Setting has been very clearly justified, i.e. it helps them to recruit participants of varied demographic backgrounds. It’s clear that it was collected through interviews. They have given some indication of what was discussed in these interviews. They have justified their use of interviews. It doesn’t appear that methods were modified. The form of data is clear. There is no discussion of data saturation. For this reason, and because the topic guide could be more explicit / included, I am giving it a somewhat rating.

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location.
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design (if applicable).

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<th>Can’t Tell</th>
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</table>

Comments: No consideration given to the relationship between the researchers and the participants.
Section B: What are the results?

7. Have ethical issues been taken into consideration?

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.
- If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study).
- If approval has been sought from the ethics committee.

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</table>

Comments: They have mentioned ethical review and removing identifiable info, but nothing else. No indication of how they handled effects of the study on participants, or what was explained to participants about the study. It is clear the ethics have been considered, but more detail would have been preferable. Therefore giving a somewhat rating.

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process.
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process.
- If sufficient data are presented to support the findings.
- To what extent contradictory data are taken into account.
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.

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</table>

Comments: Analysis is somewhat in depth – could have done with more description. The researchers haven’t examined their own role within the analysis. There’s no statement on how the quotes were chosen. There does seem to be sufficient data to support the findings, and contradictory data have been taken into account, therefore a somewhat rating is appropriate.
9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?

HINT: Consider

- If the findings are explicit.
- If there is adequate discussion of the evidence both for and against the researcher’s arguments (for = linking to existing research, against = study limitations generally).
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst).
- If the findings are discussed in relation to the original research question.

<table>
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Comments: There are clear statements of the findings. They are discussed with reference to other literature, and the limitations of the study are used to show that there are some arguments against their findings. They have discussed that there was more than one analyst for credibility of their findings. The findings are all discussed with reference to the original research question. Therefore this is being assigned a yes response.

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature).
- If they identify new areas where research is necessary.
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.

Comments: Have addressed all of these hints, therefore giving a yes rating.
11. Are the study’s theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?

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HINT: Consider

- Is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described
- Is there evidence of problematic assumptions about the chosen method of data analysis? E.g. assuming techniques or concepts from another method (e.g. grounded theory) apply to chosen method (e.g. thematic analysis) without discussion or justification
- Is there evidence of conceptual clashes / confusion in the paper? E.g. claiming a constructionist approach but then treating participants’ accounts as a transparent reporting of their experience and behaviour

Comments: They have not explicitly stated the theoretical framework that they are using for their thematic analysis, and so it is difficult to say if the paper is written in a consistent manner with these. Therefore a ‘can’t tell’ rating is appropriate.
Appendix 4: Example of CASP Completed by Independent Reviewer

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

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Paper for appraisal and reference: Endometriosis and fertility: women’s accounts of healthcare. (Reviewed by SH)

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

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<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: A statement of aims is included within the abstract and concluding paragraph of the introduction.

2. Is a qualitative methodology appropriate?

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: The author sought to understand women’s experiences of endometriosis.

Is it worth continuing? Yes
3. Was the research design appropriate to address the aims of the research?

HINT: Consider

• if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

<table>
<thead>
<tr>
<th>Yes</th>
<th>Somewhat</th>
<th>X</th>
<th>No</th>
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</tr>
</thead>
</table>

Comments: The author refers to utilising a thematic analysis but the specific perspective is unclear. There is no discussion around why the author chose to use a thematic analysis or even a qualitative approach.

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider

• If the researcher has explained how the participants were selected
• If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
• If there are any discussions around recruitment (e.g. why some people chose not to take part)

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
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</thead>
</table>

Comments: The author explains how and where participants were recruited. They explain the purposive recruitment method in detail. However, there is no statement about recruitment success (e.g. any drop outs and why).
5. Was the data collected in a way that addressed the research issue?

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

<table>
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<tr>
<th>Yes</th>
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<th>X</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: The author states that they completed ‘in-depth interviews’ with a interview guide. They discuss that this was used to capture women’s experiences and to allow participants to discuss what they deemed to be important. Interviews were audio recorded. There is no discussion of data saturation.

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

<table>
<thead>
<tr>
<th>Yes</th>
<th>Somewhat</th>
<th>No</th>
<th>X</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: The authors have not considered their relationship with participants.
Section B: What are the results?

7. Have ethical issues been taken into consideration?

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

<table>
<thead>
<tr>
<th>Yes</th>
<th>Somewhat</th>
<th>X</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: The authors have mentioned some elements relevant to ethical issues, for example that it underwent review, and that they have ensured anonymity. However, more description could be given.

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

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<th>No</th>
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</thead>
</table>

Comments: The authors have included sufficient data to support their findings. However, the paper would be strengthened by further detail about the analysis process, including how quotes were chosen, how the themes were derived, and the authors’ roles.
9. Is there a clear statement of findings?

HINT: Consider

• If the findings are explicit
• If there is adequate discussion of the evidence both for and against the researcher’s arguments
• If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
• If the findings are discussed in relation to the original research question

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
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</thead>
</table>

Comments: The authors have clearly and explicitly stated the findings, and have discussed these sufficiently. They have discussed the use of more than one analyst, and the original research question and aims are re-addressed.

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

• If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
• If they identify new areas where research is necessary
• If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: These areas have all been addressed within the article.
11. Are the study’s theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?

| Yes | Somewhat | No | Can’t Tell | X |

HINT: Consider

- Is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described
- Is there evidence of problematic assumptions about the chosen method of data analysis? E.g. assuming techniques or concepts from another method (e.g. grounded theory) apply to chosen method (e.g. thematic analysis) without discussion or justification
- Is there evidence of conceptual clashes / confusion in the paper? E.g. claiming a constructionist approach but then treating participants’ accounts as a transparent reporting of their experience and behaviour

Comments: The authors did not originally explicitly state the theoretical framework, therefore the reader cannot discern if these are consistent throughout the article.
Appendix 5: Quality Appraisal of Included Studies

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Clear statement of aims</th>
<th>Qualitative methodology appropriate</th>
<th>Appropriate design</th>
<th>Appropriate recruitment strategy</th>
<th>Data collection addressed research issues</th>
<th>Relationships considered</th>
<th>Ethical issues considered</th>
<th>Rigorous data analysis</th>
<th>Clear statement of findings</th>
<th>Valuable research</th>
<th>Clear theoretical underpinnings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grogan et al. (2018)*</td>
<td>Yes</td>
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<tr>
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<tr>
<td>Denny (2009)*</td>
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<td>Yes</td>
<td>Yes</td>
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<td>Seear (2009b)</td>
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<td>Sáo Bento &amp; Moreira (2017)</td>
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<td>Denny &amp; Mann (2008)</td>
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<td>Can’t tell</td>
<td>Can’t tell</td>
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</tbody>
</table>

* Independently quality appraised by external reviewer
Appendix 6: Thematic Map of Thematic Synthesis Results

### Analytic Theme 1)
**Hopes dashed:**
Expecting solutions and finding none

#### Descriptive Theme: HCPs don’t have the knowledge
*Codes: They lack knowledge; Poor information supplied*

#### Descriptive Theme: HCPs assert their authority
*Codes: Patient requests ignored; Reluctance to refer; Drs priorities at odds with patient; Not acting as expected*

#### Descriptive Theme: Bluffing and un-tailored help
*Codes: Inconsistent advice & information; Information & advice not tailored; Unhelpful/impractical advice; Blindsided by psychological; Negative normalisation; Unhelpful emphasis on pregnancy*

#### Descriptive Theme: Not as compassionate as once thought
*Codes: Lacking in empathy; Unhelpful judgements; Left with uncertainty; Left exposed & vulnerable; Overloaded*

#### Descriptive Theme: Wait for them to figure it out
*Codes: Dependent on Drs; Delays; Worsened physical health*

### Analytic Theme 2)
**A new relationship with, and view of healthcare professionals**

#### Descriptive Theme: A new collaborative relationship
*Codes: They provide clear information & evidence; Feeling legitimised; Acknowledging the whole person; Faith in Drs competence; Feeling supported; They are quick & proactive; They listen & take concerns seriously; Confidence boosting*

### Analytic Theme 3)
**Finding their way in a new patient role**

#### Descriptive Theme: Women take ownership
*Codes: Resort to Dr shopping; Need to be assertive; Need to self educate; Need to be persistent; Women become the experts*

#### Descriptive Theme: Pervasive damage done
*Codes: In this alone; Sceptical & mistrusting; They are dismissive; Let down & faith lost; Concerns not taken seriously; Lasting emotional impact*
Appendix 7: Qualitative Health Research Author Guidelines


Manuscript Submission Guidelines: Qualitative Health Research This Journal is a member of the Committee on Publication Ethics. This Journal recommends that authors follow the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals formulated by the International Committee of Medical Journal Editors (ICMJE).

Please read the guidelines below then visit the Journal’s submission site https://mc.manuscriptcentral.com/qhr to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned. Remember you can log in to the submission site at any time to check on the progress of your paper through the peer review process.

Only manuscripts of sufficient quality that meet the aims and scope of Qualitative Health Research will be reviewed.

There are no fees payable to submit or publish in this journal. As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere. Please see our guidelines on prior publication and note that Qualitative Health Research may accept submissions of papers that have been posted on pre-print servers; please alert the Editorial Office when submitting (contact details are at the end of these guidelines) and include the DOI for the preprint in the designated field in the manuscript submission system. Authors should not post an updated version of their paper on the preprint server while it is being peer reviewed for possible publication in the journal. If the article is accepted for publication, the author may re-use their work according to the journal's author archiving policy. If your paper is accepted, you must include a link on your preprint to the final version of your paper.

1. What do we publish?
   1.1 Aims & Scope
   1.2 Article types
   1.3 Writing your paper
2. Editorial policies
   2.1 Peer review policy 2.2 Authorship
   2.3 Acknowledgements 2.4 Funding
   2.5 Declaration of conflicting interests 2.6 Research ethics and patient consent 2.7 Clinical trials
   2.8 Reporting guidelines
   2.9 Research Data
3. Publishing policies
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   3.2 Contributor’s publishing agreement
   3.3 Open access and author archiving
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   4.1 Formatting
   4.2 Artwork, figures and other graphics
   4.3 Supplemental material
   4.4 Reference style
   4.5 English language editing services 4.6 Review Criteria
5. Submitting your manuscript
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   5.2 Information required for completing your submission 5.3 Permissions
6. On acceptance and publication 6.1 SAGE Production
   6.2 Online First publication
   6.3 Access to your published article 6.4 Promoting your article
7. Further information
1. What do we publish?

1.1 Aims & Scope
Before submitting your manuscript to *Qualitative Health Research*, please ensure you have read the *Aims & Scope*.

1.2 Article types
Each issue of *Qualitative Health Research* provides readers with a wealth of information — commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.2.1 What types of articles will QHR accept? 
*QHR* asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

- Read the Mission Statement on main *QHR* webpage.
- Search the *QHR* journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- *QHR* accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.
- *QHR* is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in *QHR* provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.
- *QHR* does NOT publish pilot studies.

**Look Out for These Regular Special Features**

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

1.3 Writing your paper
The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable
For information and guidance on how to make your article more discoverable, visit our Gateway page on How to Help Readers Find Your Article Online

2. Editorial policies

2.1 Peer review policy
*Qualitative Health Research* strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are initially reviewed by the Editors and only those papers that meet the scientific and...
editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

*QHR* adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Ensure your manuscript does not contain any author identifying information. Please refer to the editorial on blinding found in the Nov 2014 issue: [http://qhr.sagepub.com/content/24/11/1467.full](http://qhr.sagepub.com/content/24/11/1467.full).

*QHR* maintains a transparent review system, meaning that all reviews, once received, are then forwarded to the author(s) as well as to ALL reviewers.

Peer review takes an average of 6–8 weeks, depending on reviewer response. As part of the submission process you may provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted
- You will also be asked to nominate peers who you do not wish to review your manuscript (opposed reviewers).

Please note that the Editors are not obliged to invite/reject any recommended/opposed reviewers to assess your manuscript.

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The Editor or members of the Editorial Board may occasionally submit their own manuscripts for possible publication in the journal. In these cases, the peer review process will be managed by alternative members of the Board and the submitting Editor/Board member will have no involvement in the decision-making process.

### 2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all those who:

1. (i) Made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data,
2. (ii) Drafted the article or revised it critically for important intellectual content,
3. (iii) Approved the version to be published,
4. (iv) Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship. Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

### 2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please do not upload or include the acknowledgments during the initial submission and review. IF your article is going to be accepted, you will be instructed to “unblind” the manuscript, and then you may add this section to your document.

### 2.3.1 Writing assistance

Individuals who provided writing assistance, e.g. from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose
any writing assistance – including the individual’s name, company and level of input – and identify the entity that paid for this assistance. It is not necessary to disclose use of language polishing services.

2.4 Funding

*Qualitative Health Research* requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of *Qualitative Health Research* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a ‘Declaration of Conflicting Interests’ statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that ‘The Author(s) declare(s) that there is no conflict of interest’. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the *World Medical Association Declaration of Helsinki*. Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals:

- All papers reporting animal and/or human studies **must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval.** Please ensure that you blinded the name and institution of the review committee until such time as your article has been accepted. The Editor will request authors to replace the name and add the approval number once the article review has been completed.

- **For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.** Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient’s actual written informed consent with your article, as this in itself breaches the patient’s confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient’s hospital record. Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

2.7 Clinical trials

*Qualitative Health Research* conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline. Other resources can be found at NLM’s Research Reporting Guidelines and Initiatives.

2.9. Research Data

At SAGE we are committed to facilitating openness, transparency and reproducibility of research. Where relevant, The Journal **encourages** authors to share their research data in a suitable public repository subject to ethical considerations and where data is included, to add a data accessibility statement in their manuscript file. Authors should also follow data citation principles. For more information please visit the SAGE Author Gateway, which includes information about SAGE’s partnership with the data repository Figshare.

3. Publishing Policies
3.1 Publication ethics
SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to
the Committee on Publication Ethics’ International Standards for Authors and view the Publication
Ethics page on the SAGE Author Gateway

3.1.1 Plagiarism
Qualitative Health Research and SAGE take issues of copyright infringement, plagiarism or other
breaches of best practice in publication very seriously. We seek to protect the rights of our authors and
we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect
the reputation of the journal against malpractice. Submitted articles may be checked with duplication-
checking software. Where an article, for example, is found to have plagiarized other work or included
third-party copyright material without permission or with insufficient acknowledgement, or where the
authorship of the article is contested, we reserve the right to take action including, but not limited to:
publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the
head of department or dean of the author’s institution and/or relevant academic bodies or societies; or
taking appropriate legal action.

3.1.2 Prior publication
If material has been previously published it is not generally acceptable for publication in a SAGE journal.
However, there are certain circumstances where previously published material can be considered for
publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor
at the address given below.

3.2 Contributor’s publishing agreement
Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor’s
Publishing Agreement. SAGE’s Journal Contributor’s Publishing Agreement is an exclusive licence
agreement which means that the author retains copyright in the work but grants SAGE the sole and
exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an
assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright
in the work will be assigned from the author to the society. For more information please visit the
SAGE Author Gateway

3.4 Open access and author archiving
Qualitative Health Research offers optional open access publishing via the SAGE Choice programme. For
more information please visit the SAGE Choice website. For information on funding body compliance,
and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author
Gateway.

4. Preparing your manuscript
4.1 Article Format (see previously published articles in QHR for style):
- Title page: Title should be succinct; list all authors and their affiliation; keywords. Please upload
  the title page separately from the main document.
- Blinding: Do not include any author identifying information in your manuscript, including
  author’s own citations. Do not include acknowledgements until your article is accepted and
  unblinded.
- Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it
  should be on its own page.
- Length: QHR does not have a word or page count limit. Manuscripts should be as tight as
  possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional,
  will be considered.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a
  group, not listed as individuals. Do not link quotations to particular individuals unless essential
  (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including
  othergeographical
  areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate
  page.
  Additional Editor’s Preferences:
- Please do not refer to your manuscript as a “paper;” you are submitting an “article.”
• The word “data” is plural.

4.2 Word processing formats
Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics
• Figures: Should clarify text.
• Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
• Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e. INSERT TABLE 1 HERE).
• Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR’s Managing Editor.
  o TIFF, JPEG, or common picture formats accepted. The preferred format for graphs and line art is EPS.
  o Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
  o Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
• Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.
Appendix 8: Participant Information Sheet

Participants Information Sheet

Women’s experiences of receiving psychological support for endometriosis: A qualitative study

This Participant Information Sheet should be read in conjunction with The University privacy notice (http://documents.manchester.ac.uk/display.aspx?docid=37095)

WHO WILL CONDUCT THE RESEARCH?

The research will be conducted by Fiona Varney, a Trainee Clinical Psychologist from the Doctorate in Clinical Psychology programme at The University of Manchester. Dr Joanna Brooks, and Professor Gillian Haddock, from the University of Manchester, are supervising her project. Fiona will conduct this research in collaboration with Manchester University NHS Foundation Trust, and Endometriosis UK (registered charity 1035810).

Thank you for taking the time to read this.

SUMMARY

This study involves completing a questionnaire and taking part in a one-hour long, audio recorded, individual interview. Taking part in the interviews may bring up strong emotions for some people. You will have to provide certain personal information (e.g. name, age), which will be collected and stored in accordance with GDPR and University of Manchester policies. Participants can be entered into a prize draw to win a £25 Amazon Voucher.
WHAT IS THE PURPOSE OF THE RESEARCH?

We would like to find out about women’s experiences of accessing and receiving emotional and / or psychological support for living with endometriosis. We would like to find out what women with endometriosis feel they need from health services, in order for their emotional and psychological needs to be met. We hope the results will be beneficial for informing services and the care that women receive, in the future.

WHY HAVE I BEEN CHOSEN?

You have been chosen to take part because you have a diagnosis of endometriosis.

WHAT WOULD I BE ASKED TO DO IF I TOOK PART?

You will be asked to read and sign a consent form. You will be asked to complete a short questionnaire asking for demographic information such as your age. You will then be invited to take part in an hour-long, individual interview to talk about your experiences of receiving emotional and/or psychological support for endometriosis.

WHAT RISKS MIGHT I EXPERIENCE IF I TOOK PART?

There is a possibility that talking about your experiences of emotional and/or psychological support for endometriosis may bring up strong emotions. The researcher will be mindful of this and will proceed only if you wish to. Participating also means a time commitment of taking part in an interview for one hour.

WHAT WILL HAPPEN TO MY PERSONAL INFORMATION?

In order to undertake the research project we will need to collect the following personal information/data about you:

- Name
- Age
- Contact details (address, email address, phone number)
- Marital status
- Occupational status
- Ethnicity

The individual interview you participate in will be audio recorded (i.e. voice only). This audio information will then be transcribed (written out word-for-word) and analysed to form the study results.

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our Privacy Notice for Research Participants http://documents.manchester.ac.uk/display.aspx?docid=37095
The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following way:

The study team at the University of Manchester will have access to your personal identifiable information, that is data which could identify you, but they will anonymise it as soon as practical. However, your consent forms and contact details will be retained. Hard copies will be kept in a locked, storage cabinet on the University of Manchester site, until the end of the research study. Your contact details will also be digitised as soon as they are collected from you. Digital copies will be kept electronically, separate from other study data (e.g. transcripts) and will be retained for 5 years after the study has ended. Consent forms will not be digitised.

In line with Lone Working policies at the University of Manchester, personal details such as your name and address may be shared with individuals outside of the research team, in an emergency.

All data collected from you during the study, including audio recordings, will be transferred to the University of Manchester site, as soon as practical after your interview. The audio recordings will be transferred to a password-protected electronic file, and deleted from the recording device. The audio recording will be transcribed (written out word-for-word). Following transcription, the audio recording will be deleted. The transcripts will also be retained for 5 years after the study has ended.

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our privacy notice for research http://documents.manchester.ac.uk/display.aspx?docid=37095 and if you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights. You also have a right to complain to the Information Commissioner’s Office, (https://ico.org.uk/concerns) Tel 0303 123 1113

WILL MY PARTICIPATION IN THE STUDY BE CONFIDENTIAL?

Your participation in the study will be kept confidential to the study team and those with access to your personal information, as listed above. Audio recordings will be transcribed by either Fiona Varney or by the Clinical Psychology Doctorate departmental secretary, who is employed at The University of Manchester. As a student and an employee of the University, the researcher, and the secretary are professionally bound by University policies on confidentiality and data protection. The departmental secretary will be asked to sign a copy of a Confidentiality Agreement, prior to transcription. All personal information will be removed from the transcripts. Transcripts will be assigned a participant ID that will only be known to the research team. Transcription will take place on University of Manchester premises.
Confidentiality may be broken if you tell us anything that makes us think that you or anyone else is at risk of harm. We will have to share this information, for example, with your Consultant Gynaecologist or the relevant authorities. Individuals from the University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data but all individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

**WHAT HAPPENS IF I DO NOT WANT TO TAKE PART OR IF I CHANGE MY MIND?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised and forms part of the dataset, as we will not be able to identify your specific data. This does not affect your data protection rights.

In order to participate in the study it is essential that the interview is audio recorded. If you do not wish for the interview to be audio recorded, then you cannot take part in the study. It is important that you feel comfortable with the recording process at all times. You are free to ask for the recording to be stopped at any time, however this will stop the interview.

**WILL MY DATA BE USED FOR FUTURE RESEARCH?**

When you agree to take part in a research study, the information about you may be provided to researchers running other research studies in this organisation. The future research should not be incompatible with this research project and will concern endometriosis. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research (https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/).

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you regarding any other matter or to affect your care. It will not be used to make decisions about future services available to you.

**WILL I BE PAID FOR PARTICIPATING IN THE RESEARCH?**

You will be offered the choice to be entered into a prize draw, to win one of two £25 Amazon shopping vouchers, as compensation for your time. If you travel to your interview you will also be reimbursed for your travel expenses, up to the cost of £6.

**WHAT IS THE DURATION OF THE RESEARCH?**

The consent form and demographic questionnaire will take approximately 10 minutes to complete. The interview will last one hour.

**WHERE WILL THE RESEARCH BE CONDUCTED?**

The interview will be arranged for a time and date that is convenient for you, and will take place at a convenient and confidential location. This might be your home, the University of
Manchester, or St Mary’s Hospital in Manchester. Alternatively, the interview may take place over the telephone.

**WILL THE OUTCOMES OF THE RESEARCH BE PUBLISHED?**

The research team hope the findings will be published in an academic journal. As the research forms part of Fiona Varney’s doctoral work, the findings from the study will be shared in line with the doctoral programme requirements, for example at departmental conferences. The findings may be published on the Endometriosis UK website. We will also share the results with other women, health care professionals and researchers at conferences. In all cases, any information you provide will be anonymous and used in such a way so it will not identify a particular participant. A summary of the findings will be written for participants. If you would like a copy of this summary, please tell us and we will ensure that you will receive it when the study has finished. We will need to retain your contact details in order to send this to you.

**WHO HAS REVIEWED THE RESEARCH PROJECT?**

The project has been reviewed by an independent group of people in the NHS, from the Proportionate Review Sub-committee of the London – West London & GTAC Research Ethics Committee.

**WHAT IF I WANT TO MAKE A COMPLAINT?**

**Minor complaints**
If you have a minor complaint then you need to contact the researcher(s) in the first instance. Contact details are provided at the end of this form.

**Formal Complaints**
If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact
The Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

Alternatively you can contact the Patient Advice and Liaison Service (PALS) team, based within Manchester University NHS Foundation Trust, if you became aware of the study through this NHS Trust. You can contact the PALS team by emailing: pals@mft.nhs.uk, or by telephoning 0161 276 8686.
WHAT DO I DO NOW?

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s):

CONTACT DETAILS

Dr Joanna Brooks
Lecturer in Psychology
The University of Manchester
School of Health Sciences
Division of Psychology and Mental Health
1.19 Coupland Building 1
Coupland Street
Manchester
M13 9PL
Tel: 0161 275 2582
Email: joanna.brooks@manchester.ac.uk

Fiona Varney
Trainee Clinical Psychologist,
The University of Manchester
School of Health Sciences
Division of Psychology and Mental Health,
2nd Floor Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 07379 764 855
Email: fiona.varney@postgrad.manchester.ac.uk

Thank you for considering taking part in this study
Appendix 9: Topic Guide

Topic Guide

The following is a guide to the topics that are likely to be covered in the interviews with participants, in order to explore their experiences of psychological and / or emotional support for endometriosis. Some topics may emerge spontaneously, and so the order of the questions and the exact content may vary as the interview develops. The topic guide is flexible, and will be adapted throughout the cycle of the research, therefore the topics below may not be covered in all interviews, and topics not listed below may be discussed.

1. Introduction

The Chief Investigator / Interviewer will explain to participants her own reasons for conducting the research.

The Chief Investigator / Interviewer will remind participants that the interview is approximately one hour in length, and that participants are free to end the interview at any point without having to give a reason. The Chief Investigator / Interviewer will remind participants that if they do this, they will have 2 weeks to get in contact in order to remove any data already contributed, and after this time all data collected will be analysed, unless otherwise specified.

2. Experience of Endometriosis

*E.g. “Could you start by telling me about your history / journey with endometriosis.”*

Probe for:
- Journey to diagnosis and experience of diagnosis itself
- Impact endometriosis has had on their life
- How they have managed the impact

*E.g. “And how has that affected how you feel / impacted you emotionally, for example can you tell me about any experiences of feeling low in mood, anxious, or panicked for example, because of your endometriosis”*
Probe for:
- Emotional impact that endometriosis has had on their life
- How they manage the emotional impact

3. Accessing and Receiving Support

*E.g.* “And when you felt that way (e.g. low, anxious etc.) because of your endometriosis, who or where did you get support from, to help you feel better”

Probe for:
- Support from healthcare professionals / NHS services e.g. GP, gynaecology team, mental health professionals
- Support from friends and family
- Support from support groups e.g. EndometriosisUK support groups
- What did the support look like e.g. emotional support (e.g. counselling, CBT, other therapies etc.)

*E.g.* “And did that emotional support help you / make you feel better?”

*E.g.* “How easy was it to get that support for how you were feeling?”

Probe for:
- Positive experiences with health care professionals / NHS services
- Others’ awareness of endometriosis and its impact

*E.g.* “Could you tell me what has been helpful about the emotional support you have received?”

Probe for:
- Others’ understanding the difficulties that endometriosis can bring
- Others’ awareness of endometriosis
- Changes in quality of life following support
- Positive experiences of healthcare professionals / NHS services
- Instances of being offered different kinds of support to meet all needs, e.g. practical and emotional support
- Support offered at ‘right’ / helpful time

*E.g.* “Could you tell me about anything that made it difficult to get support for how you were feeling, due to your endometriosis”

Probe for:
- Others’ views regarding endometriosis
- Negative experiences of healthcare professionals / NHS services
• Any instances where they have been excluded from accessing services (e.g. if physical health condition excludes them from accessing some forms of emotional/psychological support)
• Anything that has stopped them from accessing any particular kinds of support

E.g. “Could you tell me about anything that has been unhelpful about the support you have received to help with your feelings?”

Probe for:
• Negative experiences of healthcare professionals / NHS services
• Support only offered for short periods of time
• Support not taking into account the impact endometriosis might have on emotional / psychological health
• Support not offered at ‘right’ / helpful time

E.g. “Do you wish you had been able to access any different kind of support to help you with how you were feeling due to your endometriosis?”

Probe for:
• Why they would have wanted different support other than the support they got
• What would this other support have looked like / where would they have got it from

4. Healthcare Professionals / NHS Services

E.g. “Could you tell me if you think there is anything missing from the support that is on offer from Healthcare Professionals?”

E.g. “What would you change about NHS services, or the support offered by Healthcare Professionals, to ensure women are supported emotionally or psychologically, if anything?”

E.g. “As I explained I am training to be a clinical psychologist, someone who traditionally would work in mental health services. How does it feel to know that someone like me is interested in endometriosis, and asking questions about the emotional and psychological support you have received?”

5. Summary

E.g. “Do you have any further comments that you would like to make?”

E.g. “Is there anything that I have not asked you, which you feel is important in your experiences of emotional and psychological support for living with endometriosis?”
“Do you have any questions?”

6. Debrief

Chief Investigator / Interviewer will discuss participant’s experience of the interview with them e.g. “How did you find that”?

Chief Investigator / Interviewer will ascertain the mood state of the participant, to ensure that they leave the interview safely.
Appendix 10: Demographic Questionnaire

Demographic Questionnaire

Project Title:
Women’s experiences of receiving psychological support for endometriosis: A qualitative study

Chief Investigator:
Fiona Varney

This questionnaire is designed to gather some more information about you. Please ask the Chief Investigator if you would like anything explained further.

Please indicate your:

<table>
<thead>
<tr>
<th>Age:</th>
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<tbody>
<tr>
<td>White British</td>
</tr>
<tr>
<td>White Irish</td>
</tr>
<tr>
<td>Any other White background</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
</tr>
<tr>
<td>White and Black African</td>
</tr>
<tr>
<td>Any other mixed background</td>
</tr>
<tr>
<td>Black or Black British African</td>
</tr>
<tr>
<td>Chinese</td>
</tr>
<tr>
<td>Prefer not to say</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity (please circle):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian or Asian British Indian</td>
</tr>
<tr>
<td>Asian or Asian British Pakistani</td>
</tr>
<tr>
<td>Asian or Asian British Bangladeshi</td>
</tr>
<tr>
<td>Any other Asian background</td>
</tr>
<tr>
<td>White and Asian</td>
</tr>
<tr>
<td>Black or Black British Caribbean</td>
</tr>
<tr>
<td>Any other Black background</td>
</tr>
<tr>
<td>Any other ethnic group</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status:</th>
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</table>

<table>
<thead>
<tr>
<th>Occupation (please circle):</th>
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<tbody>
<tr>
<td>Employed full time</td>
</tr>
<tr>
<td>Employed part time</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
<tr>
<td>Age when Endometriosis diagnosed:</td>
</tr>
<tr>
<td>----------------------------------</td>
</tr>
<tr>
<td>Student</td>
</tr>
<tr>
<td>Other (please specify)</td>
</tr>
<tr>
<td>Prefer not to say</td>
</tr>
</tbody>
</table>

Thank you for taking the time to complete this questionnaire.

To be completed by the Chief Investigator:

<table>
<thead>
<tr>
<th>Participant ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Interview</td>
</tr>
</tbody>
</table>

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Appendix 11: Letters of Ethical Approval and HRA Approval

16 April 2019

Ms Fiona Varney
2.01 2nd Floor Zochonis Building
Brunswick Street
Manchester
M13 9PL

Dear Ms Varney

Study title: Women’s experiences of receiving psychological support for endometriosis: A qualitative study
REC reference: 19/LO/0443
Protocol number: NHS001507
IRAS project ID: 255451

Thank you for your response to the Committee’s letter of 8 March 2019. I confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in the letter dated 08 March 2019.

Documents received

The documents received were as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<tbody>
<tr>
<td>Participant consent form [Written consent form]</td>
<td>V3.0</td>
<td>15 April 2019</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [Participant Information Sheet]</td>
<td>V5.0</td>
<td>15 April 2019</td>
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Approved documents

The final list of approved documentation for the study is therefore as follows:

<table>
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<tbody>
<tr>
<td>Copies of advertisement materials for research participants [Advert</td>
<td>V2.0</td>
<td>10 February 2019</td>
</tr>
<tr>
<td>to recruit participants from Facebook]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Copies of advertisement materials for research participants [Poster</td>
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<td>04 January 2019</td>
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<tr>
<td>for NHS waiting room]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)</td>
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<td>12 February 2019</td>
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<tr>
<td>[Sponsor Insurance Letter]</td>
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<td>Interview schedules or topic guides for participants [Topic guide]</td>
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<td>04 January 2019</td>
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<td>21 February 2019</td>
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<td></td>
<td>12 February 2019</td>
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<tr>
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<td>07 January 2019</td>
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<tr>
<td>endometriosis database]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-validated questionnaire [Demographic questionnaire]</td>
<td>V1.0</td>
<td>04 January 2019</td>
</tr>
<tr>
<td>Participant consent form [Consent to contact form / form to record</td>
<td>V1.0</td>
<td>04 January 2019</td>
</tr>
<tr>
<td>contact details]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant consent form [Consent form to send summary and prize</td>
<td>V1.0</td>
<td>04 January 2019</td>
</tr>
<tr>
<td>results]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant consent form [Written consent form]</td>
<td>V3.0</td>
<td>15 April 2019</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [Participant Information Sheet]</td>
<td>V5.0</td>
<td>15 April 2019</td>
</tr>
<tr>
<td>Referee's report or other scientific critique report [Scientific review</td>
<td></td>
<td>04 January 2019</td>
</tr>
<tr>
<td>letter]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research protocol or project proposal [Research protocol]</td>
<td>V2.0</td>
<td>10 February 2019</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (CI) [Chief Investigator CV]</td>
<td></td>
<td>09 February 2019</td>
</tr>
<tr>
<td>Summary CV for student [Chief Investigator CV]</td>
<td></td>
<td>09 February 2019</td>
</tr>
<tr>
<td>Summary CV for supervisor (student research) [Supervisor CV]</td>
<td></td>
<td>04 January 2019</td>
</tr>
<tr>
<td>Summary CV for supervisor (student research) [Supervisor CV]</td>
<td></td>
<td>04 January 2019</td>
</tr>
<tr>
<td>Summary of any applicable exclusions to sponsor insurance (non-NHS</td>
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<td>12 February 2019</td>
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<td>sponsors only) [Sponsor insurance]</td>
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<tr>
<td>Summary of any applicable exclusions to sponsor insurance (non-NHS</td>
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<td>12 February 2019</td>
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<tr>
<td>sponsors only) [Sponsor insurance]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summary of any applicable exclusions to sponsor insurance (non-NHS</td>
<td>V1.0</td>
<td>12 February 2019</td>
</tr>
<tr>
<td>sponsors only) [Sponsor insurance]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summary, synopsis or diagram (flowchart) of protocol in non-technical</td>
<td>V2.0</td>
<td>10 February 2019</td>
</tr>
<tr>
<td>language [Distress and risk protocol]</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

19/LO/0443 Please quote this number on all correspondence

Yours sincerely

Elaine Hutchings
REC Manager

E-mail: NRESCommittee.London-WestLondon@nhs.net

Copy to: Dr Lynne Webster, Manchester University NHS Foundation Trust
         Lead Nation HRA_Approval@nhs.net
Ms Fiona Varney
201 2nd Floor Zochonis Building
Brunswick Street
Manchester
M13 9PL

16 April 2019

Dear Ms Varney

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: Women's experiences of receiving psychological support for endometriosis: A qualitative study
IRAS project ID: 255451
Protocol number: NHS001507
REC reference: 19/LO/0443
Sponsor University of Manchester

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.
Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**
The document “After Ethical Review – guidance for sponsors and investigators”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study
The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **255451**. Please quote this on all correspondence.

Yours sincerely,

Natalie Wilson
Approvals Specialist

Email: [NRESCommittee.London-WestLondon@nhs.net](mailto:NRESCommittee.London-WestLondon@nhs.net)

*Copy to:*  *Ms Lynne Macrae, University of Manchester, Sponsor contact*
Appendix 12: Blank Consent Form

Women’s experiences of psychological support for endometriosis: A qualitative study

If you are happy to participate please complete and sign the consent form below

<table>
<thead>
<tr>
<th>Activities</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  I confirm that I have read the attached information sheet (Version 5.0, Date 15/04/2019) for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.</td>
<td></td>
</tr>
<tr>
<td>2  I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself. I understand that will not be possible to remove my data from the project once it has been anonymised and forms part of the dataset.</td>
<td></td>
</tr>
<tr>
<td>I agree to take part on this basis</td>
<td></td>
</tr>
<tr>
<td>3  I agree to the interviews being audio recorded.</td>
<td></td>
</tr>
<tr>
<td>4  I agree that any data collected may be published in anonymous form in academic books, reports or journals, or may be presented at conferences</td>
<td></td>
</tr>
<tr>
<td>5  (OPTIONAL) I agree that the researchers may retain my contact details in order to provide me with a summary of the findings for this study</td>
<td></td>
</tr>
<tr>
<td>6  I understand that there may be instances where during the course of the interview information is revealed which means that the researchers will be obliged to break confidentiality and this has been explained in more detail in the information sheet.</td>
<td></td>
</tr>
<tr>
<td>7  I agree that any personal or anonymised data collected may be shared with other researchers (including at other institutions) for the purposes of future research</td>
<td></td>
</tr>
<tr>
<td>8  I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data collected from me.</td>
<td></td>
</tr>
<tr>
<td>9  I agree that any anonymised data collected may be shared with other</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>10</td>
<td>I agree that the researchers may contact me in the future about other research projects</td>
</tr>
<tr>
<td>11</td>
<td>I agree to take part in this study</td>
</tr>
</tbody>
</table>

**Data Protection**

The personal information we collect and use to conduct this research will be processed in accordance with data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants (http://documents.manchester.ac.uk/display.aspx?docid=37095)

______________________                 _____________________  
Name of Participant                     Signature                 Date

______________________                 _____________________  
Name of person taking consent            Signature                 Date

One copy of this consent form will be kept by the participant. One copy of this consent form will be kept by the research team.
Appendix 13: Sample of an Anonymised Interview Transcript

116. R: and I guess obviously you saw the advert on the Facebook page for the support group, can you tell me a little about that and kind of what you use that for and what kind of support you get from that group?

118. P12: so I don't post in the group, I don't think I've ever posted in the group, I tend to kind of, I just kind of read the posts as they come across my newsfeed, partially to kind of understand, cos obviously I've, I'm not properly in the system yet...I'm still in limbo between being referred from general gynaecology to an actual endometriosis hosp...like endometriosis centre, so I kind of use it as a little bit of like real time research into how it actually is to be in that system, and also I kind of read it as I'm not alone here, there are other people that are going through similar things

125. R: and do you find that kind of being able to do that research and being able to realise that there are other people going through that similar thing, how does that make you feel, is that I mean, this might seem like a silly question, is this quite a positive thing for you?

129. P12: sometimes positive, sometimes it's a little negative, so positive because I feel like I'm not alone, there are other people going through this, but negative because there are other people going through this, and because there are so many women, it's like one in 10 women, and there's still so few doctors and hospitals that are equipped to deal with this particular condition, and it makes me quite angry that these women, you know I see posts from women you are like oh I went to A&E again because I was in so much pain, and they just, they just gave me some ibuprofen and told me to walk it off, and things like that, erm...it just, you know (pause) the medical system in general is so...if I find, I find it quite dismissive of women's problems and...I, it's quite dismissive of...you know any, any you know, periods and things like that, periods, uterus, they're almost like dirty words, anything to do with a period, anything to do with anything like that is you know, ooh, you know bad voodoo erm...just here's some painkillers, pray for yourself you know...

137. R: ok so it's kind of seeing that the women aren't getting the support that they need, that's kind of making you angry from that

139. P12: yeah (pause)

142. R: (pause) and on the back of that, in terms of that support that you've got from healthcare professionals, can you tell me a bit about that whether it's been there, whether it's not been there, especially at times when you have perhaps have been feeling a bit more emotionally vulnerable due to the condition, and just tell me a bit about your experiences there

145. P12: well obviously there was the doctor who just...told me not to come back or he'd take my coil out, that wasn't great erm...there was another one that happened quite recently when they put me on the proestop injections, they initially told me that I wouldn't...I could just get my coil taken out, but the proestop itself was actually a contraceptive, I then went and got the injection, and on my way out the door they were like oh do you want the leash that comes with it, and I thought actually I will give it a read because I'd need to see what medications it would interact with, and I read it and it said it's not a contraceptive, you need to be on something else as well, and I was like wow ok they gave me completely the wrong information, so I then rang the hospital er and I spoke to a consultant that had prescribed me the proestop injections who
Appendix 14: Sample of Coding Process using NVivo

P12: some of them, yeas some of them

R: and I guess obviously you saw the advert on the facebook page for the support group. I me a little about that and kind of what you use that for and what kind of support you get out of it?

P12: so I don’t post in the group, I don’t think I’ve ever posted in the group. I tend to kind of read the posts as they come across my newsfeed, partially to kind of understand, cause I’ve, I’m not properly in the system yet… I’m still in limbo between being referred from gynecology to an actual endometriosis hosp…. like endometriosis centre, so I kind of use it as like real time research into how it actually is to be in that system, and also I kind of read it alone here, there are other people that are going through similar things.

R: and do you find that kind of being able to do that research and being able to realise that other people going through that similar thing, how does that make you feel, is that I mean seem like a silly question, is this quite a positive thing for you?

P12: sometimes positive, sometimes it’s a little negative, so positive because I feel like I, there are other people going through this, but negative because there are other people going through this, and because there are so many women, it’s like one in 10 women, and there’s stories and hospitals that are equipped to deal with this particular condition, and it makes it very clear that these women, you know I see posts from women you are like oh I went to A&E and I was in so much pain, and they just, they just gave me some ibuprofen and told me to kind of things like that. erm…it just, you know (pause) the medical system in general is so…. I’m quite dismissive of women’s problems and… I, it’s quite dismissive of… you know any, any periods and things like that, periods. uterus, they’re almost like dirty words, anything to do with anything like that is you know, ooo, you know bad voodoo or…some painkillers, pray for you yourself you know...

R: ok so it’s kind of seeing that the women aren’t getting the support that they need, that’s kind you angry from that
Appendix 15: Thematic Map of Thematic Analysis Results

Theme 1) A community who can relate: the value of true understanding

- **Subtheme: Real understanding**
  - Codes:
    - You’re not alone
    - They get it

- **Subtheme: Contributing to the community**
  - Codes:
    - Helping other women

- **Subtheme: Becoming fully informed**
  - Codes:
    - Getting full information
    - Others’ stories: help and harm

Theme 2) Being heard and acknowledged: attempted acts of empathy

- **Subtheme: Being present and human**
  - Codes:
    - Active listening & space to process
    - Open invitation of support
    - Unconditional care & understanding

- **Subtheme: The impact of words**
  - Codes:
    - An emotional check in
    - Judgement, comparisons & lack of empathy
    - Well meaning but mis-judged comments

- **Subtheme: Practical empathy**
  - Codes:
    - Flexibility from others
    - People try to solutionise
    - Practical support
    - Support networks educate themselves

- **Subtheme: Self-compassion**
  - Codes:
    - Engaging with hobbies & distractions
    - Slowing self down

Theme 3) A taboo condition: a long way to go

- **Subtheme: A lack of awareness**
  - Codes:
    - Others don’t know what you’re going through
    - GPs need better training

- **Subtheme: Services need to change**
  - Codes:
    - Holistic approach is needed
    - Too many hurdles for non-specific support
    - Services don’t offer support
    - Physical is the priority

- **Subtheme: Too difficult to discuss**
  - Codes:
    - Periods & emotions are taboo
    - Keep it to myself & just deal with it
    - Providing support is hard on others
    - Honesty & openness not comfortable or easy
<table>
<thead>
<tr>
<th>No</th>
<th>Item</th>
<th>Guide and description</th>
<th>Present (Y/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Aims</td>
<td>State the research question the synthesis addresses</td>
<td>Y</td>
</tr>
<tr>
<td>2</td>
<td>Synthesis methodology</td>
<td>Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)</td>
<td>Y</td>
</tr>
<tr>
<td>3</td>
<td>Approach to searching</td>
<td>Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until theoretical saturation is achieved)</td>
<td>Y</td>
</tr>
<tr>
<td>4</td>
<td>Inclusion criteria</td>
<td>Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)</td>
<td>Y</td>
</tr>
<tr>
<td>5</td>
<td>Data sources</td>
<td>Describe the information sources used (e.g. electronic databases [MEDLINE, EMBASE, CINAHL, psycINFO, Econlit], grey literature databases [digital thesis, policy reports], relevant organisational websites, expert information specialists, generic web searches [Google Scholar], hand searching reference lists) and when the searches were conducted; provide the rationale for using the data sources</td>
<td>Y</td>
</tr>
<tr>
<td>6</td>
<td>Electronic search</td>
<td>Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)</td>
<td>Y</td>
</tr>
<tr>
<td>7</td>
<td>Study screening methods</td>
<td>Describe the process of study screening and sifting (e.g. title, abstract, and full text review, number of independent reviewers).</td>
<td>Y</td>
</tr>
<tr>
<td>8</td>
<td>Study characteristics</td>
<td>Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collections, methodology, analysis, research questions)</td>
<td>Y</td>
</tr>
<tr>
<td>9</td>
<td>Study selection results</td>
<td>Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development)</td>
<td>Y</td>
</tr>
<tr>
<td>10</td>
<td>Rationale for appraisal</td>
<td>Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct, [validity and robustness].)</td>
<td>Y</td>
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<td></td>
<td><strong>appaisal items</strong></td>
<td>State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. existing tools; CASP, QARI, COREQ, Mays and Pope; reviewer developed tools; describe the domains assessed; research team, study design, data analysis and interpretations, reporting)</td>
<td>Y</td>
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<tr>
<td></td>
<td><strong>apraisal process</strong></td>
<td>Indicate whether the appraisel was conducted independently by more than one reviewer and if consensus was required</td>
<td>Y</td>
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<tr>
<td></td>
<td><strong>apraisal results</strong></td>
<td>Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment, and give the rationale</td>
<td>Y</td>
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<tr>
<td></td>
<td><strong>data extraction</strong></td>
<td>Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies (e.g. all text under the headings “results/conclusions” were extracted electronically and entered into a computer software)</td>
<td>Y</td>
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<tr>
<td></td>
<td><strong>software</strong></td>
<td>State the computer software used, if any</td>
<td>N/A</td>
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<tr>
<td></td>
<td><strong>number of reviewers</strong></td>
<td>Identify who was involved in coding and analysis</td>
<td>Y</td>
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<tr>
<td></td>
<td><strong>coding</strong></td>
<td>Describe the process for coding of data (e.g. line by line coding to search for concepts)</td>
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<tr>
<td></td>
<td><strong>study comparison</strong></td>
<td>Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts and new concepts were created when deemed necessary)</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td><strong>derivation of themes</strong></td>
<td>Explain whether the process of deriving the themes or constructs was inductive or deductive</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td><strong>quotations</strong></td>
<td>Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations or the author’s interpretation</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td><strong>synthesis output</strong></td>
<td>Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).</td>
<td>Y</td>
</tr>
</tbody>
</table>
Appendix 17: Completed COREQ Checklist for Paper 2

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

<table>
<thead>
<tr>
<th></th>
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<tr>
<td><strong>Domain 1: Research team and reflexivity</strong></td>
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<tr>
<td>Personal characteristics</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Interviewer/facilitator</td>
<td>1</td>
<td>Which author/s conducted the interview or focus group?</td>
<td>63</td>
</tr>
<tr>
<td>Credentials</td>
<td>2</td>
<td>What were the researcher’s credentials? E.g. PhD, MD</td>
<td>63</td>
</tr>
<tr>
<td>Occupation</td>
<td>3</td>
<td>What was their occupation at the time of study?</td>
<td>63</td>
</tr>
<tr>
<td>Gender</td>
<td>4</td>
<td>Was the researcher male or female?</td>
<td>63</td>
</tr>
<tr>
<td>Experience and training</td>
<td>5</td>
<td>What experience or training did the researcher have?</td>
<td>63</td>
</tr>
<tr>
<td>Relationship with participants</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Relationship established</td>
<td>6</td>
<td>Was a relationship established prior to study commencement?</td>
<td>63</td>
</tr>
<tr>
<td>Participant knowledge of the interviewer</td>
<td>7</td>
<td>What did the participants know about the researcher? E.g. personal goals, reasons for doing the research</td>
<td>63</td>
</tr>
<tr>
<td>Interviewer characteristics</td>
<td>8</td>
<td>What characteristics were reported about the interviewer/facilitator? E.g. bias, assumptions, reasons and interests in the research topic</td>
<td>63</td>
</tr>
<tr>
<td><strong>Domain 2: Study design</strong></td>
<td></td>
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<tr>
<td>Theoretical framework</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methodological orientation and theory</td>
<td>9</td>
<td>What methodological orientation was stated to underpin the study? E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</td>
<td>64</td>
</tr>
<tr>
<td><strong>Participant selection</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sampling</td>
<td>10</td>
<td>How were participants selected? E.g. purposive, convenience, consecutive, snowball</td>
<td>60</td>
</tr>
<tr>
<td>Method of approach</td>
<td>11</td>
<td>How were participants approached? E.g. face-to-face, telephone, mail, email</td>
<td>61</td>
</tr>
<tr>
<td>Sample size</td>
<td>12</td>
<td>How many participants were in the study?</td>
<td>61</td>
</tr>
<tr>
<td>Non-participation</td>
<td>13</td>
<td>How many people refused to participate or dropped out? Reasons?</td>
<td>61</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting of data collection</td>
<td>14</td>
<td>Where was the data collected? E.g. home, clinic, workplace</td>
<td>63</td>
</tr>
<tr>
<td>----------------------------</td>
<td>----</td>
<td>----------------------------------------------------------</td>
<td>----</td>
</tr>
<tr>
<td>Presence of non-participants</td>
<td>15</td>
<td>Was anyone else present besides the participants and researchers?</td>
<td>63</td>
</tr>
<tr>
<td>Description of sample</td>
<td>16</td>
<td>What are the important characteristics of the sample? E.g. demographic data, date</td>
<td>62</td>
</tr>
</tbody>
</table>

**Data collection**

<table>
<thead>
<tr>
<th>Interview guide</th>
<th>17</th>
<th>Were questions, prompts, guides provided by the authors? Was it pilot tested?</th>
<th>61-63</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repeat interviews</td>
<td>18</td>
<td>Were repeat interviews carried out? If yes, how many?</td>
<td>60</td>
</tr>
<tr>
<td>Audio/visual recording</td>
<td>19</td>
<td>Did the research use audio or visual recording to collect the data?</td>
<td>64</td>
</tr>
<tr>
<td>Field notes</td>
<td>20</td>
<td>Were field notes made during and/or after the interview or focus group?</td>
<td>64</td>
</tr>
<tr>
<td>Duration</td>
<td>21</td>
<td>What was the duration of the interviews or focus group?</td>
<td>64</td>
</tr>
<tr>
<td>Data saturation</td>
<td>22</td>
<td>Was data saturation discussed?</td>
<td>62</td>
</tr>
<tr>
<td>Transcripts returned</td>
<td>23</td>
<td>Were transcripts returned to participants for comment and/or correction?</td>
<td>64</td>
</tr>
</tbody>
</table>

**Domain 3: analysis and findings**

**Data analysis**

<table>
<thead>
<tr>
<th>Number of data coders</th>
<th>24</th>
<th>How many data coders coded the data?</th>
<th>64</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description of the coding tree</td>
<td>25</td>
<td>Did authors provide a description of the coding tree?</td>
<td>64</td>
</tr>
<tr>
<td>Derivation of themes</td>
<td>26</td>
<td>Were themes identified in advance or derived from the data?</td>
<td>64</td>
</tr>
<tr>
<td>Software</td>
<td>27</td>
<td>What software, if applicable, was used to manage the data</td>
<td>64</td>
</tr>
<tr>
<td>Participant checking</td>
<td>28</td>
<td>Did participants provide feedback on the findings?</td>
<td>64</td>
</tr>
</tbody>
</table>

**Reporting**

<table>
<thead>
<tr>
<th>Quotations presented</th>
<th>29</th>
<th>Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? E.g. participant number</th>
<th>64</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data and findings consistent</td>
<td>30</td>
<td>Was there consistency between the data presented and the findings?</td>
<td>64 onwards</td>
</tr>
<tr>
<td>Clarity of major themes</td>
<td>31</td>
<td>Were major themes clearly presented in the findings?</td>
<td>65 onwards</td>
</tr>
<tr>
<td>Clarity of minor themes?</td>
<td>32</td>
<td>Is there a description of diverse cases or discussion of minor themes?</td>
<td>65 onwards</td>
</tr>
</tbody>
</table>
Appendix 18: Completed CASP for Paper 2

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.

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Critical Appraisal Skills Programme (CASP) part of Oxford Centre for Triple Value Healthcare www.casp-uk.net
Paper for appraisal and reference: Women’s experiences of emotional and psychological support for endometriosis: a qualitative study

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

HINT: Consider
• what was the goal of the research?
• why it was thought important?
• its relevance.

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: In the final paragraph of the introduction, it clearly states that “the current study therefore aimed to qualitative explore women’s experiences of accessing and receiving psychological and emotional support...”.

2. Is a qualitative methodology appropriate?

HINT: Consider
• If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.
• Is qualitative research the right methodology for addressing the research goal?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: The final paragraph in the introduction states that the aim is to qualitatively explore women’s experiences, implying qualitative methodology is appropriate. It also mentions adding women’s narratives to the literature, which is consistent with a qualitative approach.

Is it worth continuing? Yes
3. Was the research design appropriate to address the aims of the research?

HINT: Consider

• If the researcher has justified the research design (e.g. have they discussed how they decided which method to use).

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: Design discussed, and rationale for methods justified (e.g. why using thematic analysis with a critical realist perspective).

4. Was the recruitment strategy appropriate to the aims of the research?

HINT: Consider

• If the researcher has explained how the participants were selected.
• If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study.
• If there are any discussions around recruitment (e.g. why some people chose not to take part).

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: Clear description of recruitment in method section, including why participants were recruited from two separate domains. Discussions around recruitment, and reasons for participant drop out, also included.
5. Was the data collected in a way that addressed the research issue?

HINT: Consider

- If the setting for the data collection (e.g. clinic, charity) has been justified.
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen.
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide).
- If methods were modified during the study. If so, has the researcher explained how and why (if applicable).
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data.

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: 2 settings for the data collection clearly justified; clear that semi-structured interviews were used; methods justified (e.g. TA and critical realist perspective); clear statement of number of interviews and topic guide; methods were not modified so this is N/A; form of data is clear; reaching information power discussed in place of data saturation.

6. Has the relationship between researcher and participants been adequately considered?

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location.
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design (if applicable).

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: Researcher’s own role of discussed as well as interest in the topic area and why, as well as this being explained to participants. Discussion section also acknowledges that results were discussed between multiple authors, so that they were not just influenced by the lead researcher.
Section B: What are the results?

7. Have ethical issues been taken into consideration?

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study).
- If approval has been sought from the ethics committee.

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: Ethics clearly described – mentioned approval from ethics committee as well as reference, participant information sheet, informed consent given, maintaining confidentiality by using anonymised quotes, and distress management procedures being in place – showing that researcher would have a procedure for handling effects of study. Debrief also mentioned.

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process.
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process.
- If sufficient data are presented to support the findings.
- To what extent contradictory data are taken into account.
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comment: Data analysis clearly described in methods section. Clear description of process leading to derivation of themes. Description of why the data (quotes) presented were chosen. Plenty of quotes used to illustrate the data. Contradictory findings included and demonstrated through quotes and written descriptions (e.g. some women finding online stories helpful, others not); discussion section discusses multiple perspectives informing analysis, to reduce bias.
9. Is there a clear statement of findings (e.g. clear and concise and summed up somewhere)?

HINT: Consider

• If the findings are explicit.
• If there is adequate discussion of the evidence both for and against the researcher’s arguments (for = linking to existing research, against = study limitations generally).
• If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst).
• If the findings are discussed in relation to the original research question.

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

Comments: Clear summary of findings at beginning of results section and beginning of discussion section. Findings clear and explicit. Discussion includes research that both fits with the data, but also demonstrates how this research is novel, and limitations included that help to support evidence against arguments made. Researcher has discussed credibility e.g. multiple perspectives adding to analysis. Original research question referenced in discussion.

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

• If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research- based literature).
• If they identify new areas where research is necessary.
• If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.

Comments: Discussion includes how the research is novel, and how it relates to existing knowledge. New areas of research discussed, and how the research can be used for policy and practice also discussed.
11. Are the study’s theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?

<table>
<thead>
<tr>
<th>Yes</th>
<th>X</th>
<th>Somewhat</th>
<th>No</th>
<th>Can’t Tell</th>
</tr>
</thead>
</table>

HINT: Consider

- Is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described?
- Is there evidence of problematic assumptions about the chosen method of data analysis? E.g. assuming techniques or concepts from another method (e.g. grounded theory) apply to chosen method (e.g. thematic analysis) without discussion or justification?
- Is there evidence of conceptual clashes / confusion in the paper? E.g. claiming a constructionist approach but then treating participants’ accounts as a transparent reporting of their experience and behaviour?

Comments: Method and methodology described and justified, and research is consistent with a critical realist perspective. No evidence of conceptual clashes or confusion.