

Doctorate in
Clinical Psychology

Lancaster
University



Submitted in Partial Fulfilment of the Lancaster University Doctorate in Clinical Psychology

July 2021

Doctoral Thesis

The Experience of Psychological Care for Women with Endometriosis

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Statement of word count

	Main Text	Appendices	Total
Thesis Abstract	300	-	300
Section 1: Literature Review	7,982	8,056	16,038
Section 2: Research Paper	7,998	7,788	15,786
Section 3: Critical Appraisal	3,979	140	4,119
Section 4: Ethics Section	4,398	1,930	6,328
Total	24,657	17,914	42,571

Thesis Abstract

This thesis explores the experiences of women with endometriosis. A systematic literature review was conducted examining women's experience of their healthcare encounters. On average in the United Kingdom, it takes 8 years to diagnose, and involves multiple healthcare encounters. Improved policy and awareness have led to an increase in research in endometriosis. A meta-ethnographic approach was adopted to analyse 23 papers. Two themes were identified; 1) Women are Dismissed (with the subtheme's 'women as hysterical', 'indifference to suffering', and 'a battle to be heard'). (2) Who is the expert? (With the subthemes 'lack of knowledge' and 'expert patient'). The findings of this review highlight the troubled relationships between women with endometriosis and their Healthcare professional (HCPs). It recommends psychologists provide training for HCPs.

The empirical paper in section two of this thesis explored the experiences of women who have accessed psychological care for support with their endometriosis. Data was collected via semi structured interviews with five women and was analysed using interpretative phenomenological analysis. Four themes were identified: (1) Therapeutic alliance, (2) Permission to speak; this was facilitated by the therapist's ability to provide an adequate therapeutic frame, when this was not adequate, the women felt unable to speak about stigma, (3) Therapy can be empowering, (4) Managing endometriosis means managing mental health. Future research should consider the efficacy of psychological interventions, as well as individualised, culturally specific support.

Section three of this thesis details a critical appraisal of the research project, making specific note my interest in the topic and details some of the steps taken to engage in reflexivity. This section also outlines some challenges to conducting research during a global

pandemic and the steps taken to address these. Finally, this section concludes with consideration for the role of psychologists within the healthcare system in supporting women with endometriosis.

Declaration

This thesis represents research activity completed between January 2020 and July 2021 undertaken for the Doctorate in Clinical Psychology at Lancaster University. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of an academic qualification elsewhere.

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Acknowledgements

I would firstly like to thank the women who took part in this study. I was truly inspired by your courage and bravery in the face of real adversity. It is my sincere hope that this research speaks to your experience and that it will be helpful for others going forward. I would also like to thank Endometriosis UK for their support with recruitment for this project.

I would like to thank my research supervisors Dr Craig Murray and Dr Claire Hardy for your guidance throughout this project; particularly as we all navigated our way through the pandemic. I would also like to thank Dr Wendy Macdonald for your ongoing support and empathy throughout this journey.

Thank you to Maria Reilly for your patience and guidance throughout these last three years, I feel so much more confident in my writing because of our sessions.

A special thank you to my friends Michelle, Emma, and Stephanie; without your input, guidance, and encouragement I would never have made it this far. You are all incredible women, and you inspire me every day.

Thank you to my family who have supported me on the long road to this point. And mostly I would like to thank Padraic and Jack, your love and support got me through every step. I am so lucky to have you in my corner, here's to the future!

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Section 1 -Literature Review

Women with Endometriosis and their experience of the healthcare encounter: A meta-synthesis

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Word Count: 7,982

(excluding references, tables, figures and appendices)

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Abstract

Objective: Endometriosis is a painful gynaecological condition that is present in 1 in 10 women. On average in the United Kingdom, it takes 8 years to diagnose, and involves multiple healthcare encounters. Improved policy and awareness have led to an increase in research in endometriosis. The aim of this review is to explore women's experience of their healthcare encounters for their endometriosis.

Design: A meta-ethnography approach was used to review and synthesise the qualitative literature.

Main Outcome Measures: This consisted of a systematic literature search of five databases (Medline, CINAHL, EMBASE, PsychInfo & SCOPUS). Inclusion and exclusion criteria were applied, and the Critical Appraisal Skills Programme was used to evaluate the included studies, scores ranged from 17-24 of a possible 24.

Results: 23 studies were included in this meta-synthesis. Two themes were identified, each with subthemes. (1) Women are Dismissed (with the subtheme's 'women as hysterical', 'indifference to suffering', and 'a battle to be heard'). (2) Who is the expert? (with the subthemes 'lack of knowledge' and 'expert patient').

Conclusion: Healthcare encounters between women and their HCPs are often experienced as tense and frustrating, resulting in the women feeling anxious and disempowered. Future research should explore the impact of the physical investigations, as well as gaining the perspectives of HCPs.

Keywords: *diagnostic delay; doctor-patient communication; endometriosis; healthcare encounter; meta-ethnography; review; psychosocial implications; pain communication.*

Introduction

Endometriosis is a painful gynaecological condition which is estimated to affect 1 in 10 women in the United Kingdom (EndometriosisUK, 2019). It occurs when endometrial tissue similar to that found in the womb is found in other parts of the body, typically in the pelvic area. The most reported symptoms include painful or irregular periods, including heavy bleeding, bleeding between periods, pain during or after sex, and pain when using the toilet (National Health Service, 2020). Other symptoms reported include chronic pelvic pain, back pain, urinary tract infection, fatigue and difficulty with conceiving (Ballard, Seaman, De Vries, & Wright, 2008). There is no known cure for endometriosis and the focus of treatments are concerned with symptom reduction (Peiris, Chaljub, & Medlock, 2018). There are numerous psychosocial implications arising from the symptoms of endometriosis.

A previous review by Culley et al. (2013) found that endometriosis has far reaching psychosocial impacts on women's lives, including: difficulties in work, relationships, fertility and mental health. In terms of employment, research shows that the women were less likely to be able to work in their preferred field and were more likely to require time off work due to their symptoms (Soliman, Coyne, et al., 2017; Sperschneider et al., 2019). A systematic review by Barbara et al. (2017) found that two thirds of women with endometriosis experienced pain during or after sex; this had an impact on their psychological wellbeing, as well as having an impact on their relationship. Some women with endometriosis can struggle with fertility difficulties. Although the link between the two is not clear, NICE guidelines recommend a specific pathway for women where fertility is a priority (NICE, 2017). Coping with infertility can have a negative impact on wellbeing; this is particularly the case where having children is tied to identity and valued within society (Facchin, Buggio, Dridi, & Vercellini, 2019; Riazi et al., 2014). These experiences can have negative consequences for women's mental health.

Previous studies have shown that women with endometriosis are more likely to experience depression and anxiety (Chen et al., 2016; Laganà et al., 2015; Roomaney & Kagee, 2015). Roomaney,

Kagee, and Heylen (2020) found that 43.1% of women surveyed experienced moderate to severe depression; noting that negative feelings about healthcare professionals was predictive of depressive symptoms. Despite recognising the psychosocial impact of endometriosis, research on psychological interventions is minimal. Evans, Fernandez, Olive, Payne, and Mikocka-Walus (2019) conducted a systematic review and found a small number of papers (n= 12), with a variety of interventions, including yoga, mindfulness, relaxation, and cognitive behavioural therapy.

Adding to the distress experienced by women is a delay in getting a diagnosis. Within the United Kingdom there is currently a delay of 8 years from symptom onset to diagnosis (Ghai, Jan, Shakir, Haines, & Kent, 2020). There has been little improvement in reducing this; in 2006 Ballard et al reported a delay of 8.5 years. Similar delays have been observed across the world: in Australia the average is estimated at 6.4 years (O'Hara, Rowe, & Fisher, 2020); in Canada it is 5.4 years (Singh et al., 2020); in the United States of America it is 4.4 years (Soliman, Fuldeore, & Snabes, 2017), and in Germany and Austria it is 10.4 years (Hudelist et al., 2012). A recent All Parliamentary Party Group in the United Kingdom commissioned a report on endometriosis; they found that prior to receiving an accurate diagnosis 58% of the women surveyed (n = 10,783), visited their general practitioner more than 10 times with their endometriosis symptoms; 21% visited doctors in hospital and 53% attended accident and emergency departments (Amess, Doyle-Price, Hardy, Bardell, & Furniss, 2020). These findings highlight how women must access healthcare repeatedly before getting an accurate diagnosis; this can present challenges to the healthcare professionals.

A small number of recent studies have explored the viewpoint of healthcare professionals (HCPs) in these encounters. A survey of gynaecologists found that 45% believed chronic pain was managed poorly (Leow, Szubert, & Horne, 2018). Some HCPs found interactions with women who have endometriosis challenging; in part this is due to a lack of knowledge making them question their own competence. This was true of a range of HCPs, including general practitioners (GPs), gynaecologists, and nurses (Bach, Risoer, Forman, & Seibaek, 2016; Grundström, Kjølhed, Berterö, &

Alehagen, 2016; Van Der Zanden, Arens, Braat, Nelen, & Nap, 2018; Van Der Zanden et al., 2020). HCPs also described difficulties in these encounters arising from interpersonal struggles; whereby the HCP found women challenging, stating that they required a high level of support (Bach et al., 2016; Grundström et al., 2016). In a study by Young, Fisher, and Kirkman (2017), HCPs linked endometriosis to poor mental health, where they questioned their ability to address the psychosocial aspects of the illness. Further research with HCPs to explore these challenges and the potential impact on the healthcare encounter would be beneficial. While the number of papers outlining the perspective of HCPs is limited, research exploring the viewpoint of women with endometriosis has grown substantially in recent years. Given the nature of the difficulties described by HCPs, it is important to consider the perspectives of women with endometriosis, and how they experience these encounters.

Rationale and context for the meta-ethnography

Over the last four years there has been an increased awareness of the need for better care for women with endometriosis at a policy level (Amess et al., 2020; Horne, Saunders, Abokhrais, & Hogg, 2017). At the time of writing, the government in the United Kingdom is calling for input from the public to develop the first Women's Health Strategy; noting that conditions which are specific to women are not well researched or understood (Department of Health & Social Care, 2021, p. 1). Within these documents endometriosis is mentioned as an area that requires more investment and education. In Australia, following recommendations from the National Action Plan for Endometriosis in 2018, the government have announced the development of new guidelines surrounding the clinical management of endometriosis (Department of Health, 2018; Hunt, 2021). This highlights the importance of research which accurately summarises the current literature regarding women's experiences of their healthcare encounters for their endometriosis.

A mixed methods systematic review by Dancet et al. (2014) explored women's care for endometriosis through a structured framework of patient centredness. They mapped the data from the 12 papers identified onto predetermined domains of patient centredness: some of these included

access to care, coordination and integration of care, involvement of significant others, patient values and information. The review took a broad approach to women's overall experience of accessing services and their transition through departments; as a result, it only briefly explored the experiences of women's encounters with HCPs. They found that women valued healthcare staff who showed empathy, but healthcare services did not always meet these needs. The aim of this review is to explore in depth the experience of healthcare encounters for women with endometriosis and develop an understanding for why their needs may not be addressed.

In recent years there has been an increase in the amount of qualitative research regarding the experiences of women with endometriosis; many of these papers have specifically explored healthcare encounters. Therefore, a meta-synthesis would be appropriate at this time. A meta-synthesis is a method to provide an integrated and cumulative examination of qualitative evidence. There are various methods for synthesising qualitative research, including meta-ethnography, thematic synthesis, meta-narrative, grounded theory, ecological triangulation and framework synthesis (Barnett-Page & Thomas, 2009; Toye et al., 2014). Having a greater understanding of women's healthcare encounters can inform the development of services; specifically, the intention is that the findings of this review can help guide training for HCPs. It is hoped that having a workforce with a greater understanding of women's needs in these encounters, may contribute to reducing the delay in diagnosis.

Materials and Methods

Approach

This review aims to answer the question, "what are the experiences of healthcare encounters for women with endometriosis." In order to provide new knowledge, an interpretive approach was required. Meta-ethnography was chosen, as it is ideally placed to provide an interpretive analysis, as opposed to a purely aggregative approach (France et al., 2019). The meta-ethnography analysis allows for considering the context of each study and synthesizing the interpretations of the authors (Allen,

2017). Reporting in this paper followed guidance by France et al. (2019) for detailing meta-ethnography analyses.

Search Strategy

A subject librarian from Lancaster University Health Sciences department was consulted to review the search strategy. The SPIDER tool was utilised to identify the appropriate search terms (Cooke, Smith, & Booth, 2012). This stands for Sample, Phenomenon of Interest, Design, Evaluation, Research Type; see appendix 1-A for detailed description of the search terms for each area. The search consisted of subject headings specific to each database, and free search terms. Searching title or abstract, five databases were searched on the 27th of March 2021 (PsychInfo, Medline, CINAHL, EMBASE, and Scopus). These databases were chosen as they cover research in the fields of medicine, nursing, and allied health professionals.

The criteria for inclusion in the review was: (a) studies must be published in English, (b) published in a peer review journal, (c) primary research only, (d) qualitative research including direct reports of experience (e.g. interview/ focus group/ blogs/ diary), (e) the aim of the studies is to understand the experiences of individuals with endometriosis, including the experience of healthcare encounters, (f) themes are evidenced by participant quotes, (g) individuals with endometriosis experiences or perceptions can be attained and are separate from the perspectives of others, (h) all healthcare settings (e.g. primary, secondary, or tertiary care).

A total of 1,924 studies were retrieved from the search and imported into Endnote, with 1,527 remaining after duplicates were removed. Titles and abstracts were reviewed against the eligibility criteria, which left 31 papers remaining. The full text was read, and a further eight papers were excluded: two were not specific to the healthcare encounter (Rea et al., 2020, Riazi et al., 2014); three due to the inclusion of other papers by these authors that report on the same findings with no new themes identified (Berterö, Alehagen, & Grundström, 2019; Cole, Grogan, & Turley, 2020; Seear, 2009c); and three due to limited or no participant quotes evidencing themes (Cox, Henderson,

Andersen, Cagliarini, & Ski, 2003; Denny, 2004; Roomaney & Kagee, 2018). Outlined below is the diagrammatic representation of the search, as per Prisma (Moher, Liberati, Tetzlaff, Altman, & Group, 2009).

[INSERT FIGURE 1]

In total 23 papers were included in this study; Table 1 outlines the characteristics of each study. The papers reported findings from Australia (n=8), Brazil (n=1), Europe (n=1), Italy (n=1), Puerto Rico (n=1), Sweden (n=3), United Kingdom (n=7) and United States (n=1), and one that was noted as international (n=1). Sample size ranged from 9 to 74 women with endometriosis. Data was collected in numerous ways, including interviews, focus groups and from written online accounts.

[INSERT TABLE 1]

There were two stated instances of papers where the same sample had been used (Seear, 2009a; Seear, 2009b; Young et al., 2016, & Young et al., 2020). In both instances a new research question was posed, and new themes were reported. While it was not explicitly stated, it appears that some of the same sample was used in both (Denny, 2009; Denny & Mann, 2008). The data was collected at two different time points, and new themes were identified.

Between the development of the search strategy and carrying out the final search, a review was published with a similar research question (Pettersson & Berterö, 2020). Supervisors were consulted and it was decided that due to the paper being published within 6 months of the completion of this project, this review would go ahead. Despite being published in 2020, it was noted that the full search by Pettersson & Berterö was conducted in August 2017, with smaller, more focused searches in 2018 and 2019. It was felt that there were potentially more papers released between their last search and the present. Their study included 14 papers, 11 of which met the inclusion criteria for this study, with a further 12 identified. It was also observed that the authors took a different

methodological approach to their synthesis, namely a thematic approach. The lead researcher did not read the review until after the results for this meta-ethnography were finalised.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP) is a tool for appraising the quality of qualitative studies. CASP is the most commonly cited measure used in previous reviews in the area of chronic pelvic pain (Evans et al., 2019; Toye et al., 2013; Toye et al., 2014). It comprises of 10 questions; the purpose of the first two questions are concerned with screening to identify appropriate research, while the remaining questions cover design, recruitment, ethics, analysis and the implications of the research. The decision was made to use a scoring system for the CASP, as outlined by Duggleby et al. (2010). A similar scoring approach was used by Toye et al. (2014). A score of 1 (weak) was attributed to studies that had little or no description related to the question; a score of 2 (moderate) for studies that partially described their methods; and a score of 3 (strong) for studies that fully explained the issues. The CASP was conducted on all papers in this review (see Table 2). Two papers were reviewed by a psychology colleague, ratings were in agreement and a final score awarded. The scores ranged from 17 to 24 out of a possible 24.

[INSERT TABLE 2]

There are ongoing debates about the use of quality appraisal for qualitative research; some of these include the use of checklists, observations of the difference between quantitative and qualitative research, and questions about what determines good quality research (Garside, 2014; Sattar, Lawton, Panagioti, & Johnson, 2021; Toye et al., 2014; Williams, Boylan, & Nunan, 2020). One criticism of using a quality appraisal checklist is that a low score may be more indicative of the constraints in the reporting guidelines of the journal, as opposed to poor quality research (Long, French, & Brooks, 2020). For this reason, no studies were excluded from this review based on their CASP score. The aim of using quality appraisal in this study was to examine the quality of the papers

in order to identify whether the themes in the synthesis are reliant on weaker scoring papers. This was not the case, as each theme was evidenced by higher scoring papers.

Data Synthesis

This paper followed seven steps for conducting a meta-ethnography, as outlined by Noblit and Hare (1988); this has been further detailed by Sattar et al. (2021). Initial phases related to identifying a research question and deciding what is relevant. This was followed by a line by line reading of the papers; the data was extracted consistent with recommendations by Sattar et al. (2021), see appendix 1-B. The following phases involved determining how the studies were related; studies and notations were reviewed for similarities and discrepancies, with descriptive categories identified (see Appendix C). A reciprocal translation was conducted, namely notations in each category were grouped to form a narrative. From this third order constructs were identified. A line of argument synthesis was decided, as the papers covered the full range of experiences across the diagnostic pathway. As there were no studies which contradicted others entirely, a refutational synthesis was not required. Detailed actions taken for this paper are outlined in Table 3.

[INSERT TABLE 3]

Reflexivity

The researcher is a trainee clinical psychologist who has family and friends with endometriosis, living in United Kingdom, Ireland and Canada, all of whom have had variable interactions with healthcare systems while getting their diagnoses. A research diary was maintained throughout the process to monitor the potential for bias. This served as a space for the researcher to reflect on their own responses to the material; as well as a prompt to ensure the themes were grounded in the data. Themes and analysis were discussed with supervisors.

Results

Studies examined the experiences of women who encountered various healthcare professionals, including GPs, gynaecologists, psychologists, physiotherapists, nurses, and occupational therapists. Where this is identified in the quotes, it will be noted which professionals the women are referencing; otherwise, for consistency, they will be referred to as healthcare professionals (HCPs) for the remainder of this paper.

Two themes were identified 1) Women are Dismissed and 2) Who is The Expert? Each theme has sub-themes.

[INSERT TABLE 4]

A table outlining which studies contributed to each theme is also outlined see Table 5.

[INSERT TABLE 5]

Theme One: Women are Dismissed

Throughout the papers a recurring feature of women's experiences was of a significant delay in the diagnosis of their endometriosis. This meant repeated presentations to services before the correct cause of their difficulties could be determined. Women in 20 studies described experiences of feeling dismissed by their HCPs. Three subthemes were identified to elucidate this dismissal: women as hysterical; indifference to suffering; and a battle to be heard.

Women as hysterical

In 14 papers women described being met with an attitude of disbelief, noting that HCPs did not acknowledge their symptoms or distress. Instead, the women were left with the feeling that their healthcare professionals viewed them as exaggerating or imagining their symptoms. For some this was explicit in the language used by HCPs during their encounters. "One of the GPs actually told me that period pains didn't exist and it was just women being stupid, so I didn't actually get any painkillers." (Denny & Mann, 2008, p. 114).

The women describe having their symptoms regularly dismissed, with the insinuation that their suffering was psychological, and therefore not real, “You are going to have painful periods because psychologically you believe they are going to be painful. You just need to relax.” (Sbaffi & King, 2020, p. 381);

In other instances, the HCPs acknowledged the pain was real, but they attributed the cause to psychological factors. “I would re-present, and I think they started to think that it was psychosomatic. So I got this whole kind of patronizing, non-believing attitude” (Markovic, Manderson, & Warren, 2008, p. 359).

Not only did the women report that this dismissal accounted for further delays in diagnosis, but it also contributed to a sense of disappointment and frustration (Facchin, Saita, Barbara, Dridi, & Vercellini, 2018) This anger occurred as the women perceived their HCPs as having the power in these encounters; the HCPs had the power to decide treatments as well as influence how women were viewed. Women feared being labelled by professionals, this is evident in the use of language such as “hypochondriac” (Grundstrom et al., 2020), a “mad woman” (Young, Fisher, & Kirkman, 2020) and regional equivalents “changa” (Matías-González, Sánchez-Galarza, Flores-Caldera, & Rivera-Segarra, 2020) or “sook” (Moradi, Parker, Sneddon, Lopez, & Ellwood, 2014), to represent them as irrational. Describing women as irrational meant that their experiences were ignored, and their interactions viewed as problematic. “I went to the doctor at least twice a month with these symptoms and pretty soon they told me that I just had an anxiety disorder.” (Krebs & Schoenbauer, 2019, p. 5) In some cases, this led to women avoiding healthcare encounters, “It happened with a specialist, who after every operation told me that I was a “changa”. I have not been to a gynaecologist for more than a year” (Matías-González et al., 2020, p. 70)

This avoidance extended beyond presenting with endometriosis symptoms, with some women reporting a fear of being labelled as requiring mental help, even when seeking support for other health complaints (Grundström et al., 2020). Frequent dismissals led to a feeling of mistrust in

the medical system, and in some cases the women lost trust in themselves. When they received their diagnosis of endometriosis, it re-confirmed for them that there was something wrong, and more specifically it meant they were not “crazy” (Zale, Lambert, LaNoue, & Leader, 2020).

Battle to be heard.

Following on from the previous subtheme of endometriosis pain being viewed as psychological, is the subtheme of a battle to be heard. When women encountered HCPs, who did not attribute their symptoms to a psychological difficulty, it did not guarantee that they were heard or believed. Women still experienced having their symptoms dismissed. In some cases, this was due to a misdiagnosis where they were attributed to another health condition. In other cases, the women simply struggled to be heard by professionals, 12 papers contributed to this theme.

Women spoke about receiving misdiagnoses from HCPs, stemming from their symptoms not being heard. “The gynaecologist tells me that these are gases, that I have nothing... and I’m like “doctor, they are not gases, the pain I have is too strong, I have something.” (Matías-González et al., 2020, p. 70) Others experienced dismissive ‘unhelpful advice’ from HCPs, “I was given advice like ‘start exercising or something’. It made me feel as if I was being ridiculed.” (Grundström et al., 2018, p208).

Several studies explored the anticipation before attending appointments, and the subsequent feelings of disappointment that arose when HCPs hadn’t listened to the women (Grogan, Turley, & Cole, 2018; Moradi et al., 2014; São Bento & Moreira, 2017; Zale et al., 2020).

“I had a lot of questions and thought that because he is a specialist having to deal with hundreds and hundreds of people that he can give me the answers to my questions, but he did not have time to talk.” (Moradi et al., 2014, p. 6).

Trying to find the space and time to talk, and have their symptoms taken seriously was described by several studies as a ‘battle’ (Bullo 2018, Grogan et al., 2018, Young et al., 2020). “The

lack of understanding, lack of sympathy, lack of getting your head around it, lack of being believed. I feel like I've fought so many battles and I'm weary as a result of it." (Bullo, 2018, p. 577).

The women valued HCPs who took "... the time to listen to the history, experience, symptoms, my story and me." (Fernley, 2021, p. 47). By providing this space the HCPs communicated to the women that their experiences were valid, and the HCPs could contain their distress, "He started by saying: "Now I've read through your medical journal (!). I understand you've had a tough time. How can I help you?" NO doctor has ever said that to me." (Grundström et al., 2020, p.24)

Indifference leads to suffering.

There were 13 papers which explored the concept of how women were met with indifference to their suffering in their healthcare encounters. The apathy was multifaceted; primarily, it referred to the women's experience of speaking about the physical pain resulting from their endometriosis, and how this was normalised (n=9). However, a smaller set of papers referred to the indifference of HCPs to the distress arising from the healthcare encounters themselves; with four papers explored the pain arising from repeated physical investigations, and five papers discussed suffering arising from the insensitive delivery of health information (see Table 6).

One of the key symptoms related to endometriosis is painful periods. In nine studies women spoke about having this pain normalised by the HCPs they encountered.

"When I continued to be ill, when I had my period, my mother took me to the family doctor and he said, this is just, this is what a woman has to put up with –I can still remember the words – and this is your child's lot in life, and I thought, this is pretty poor, but [I] took that on board at that age." (Markovic et al., 2008, p. 356).

The indifference of the HCPs was based on the inaccurate belief that it is a 'woman's lot to suffer' (Markovic et al., 2008; São Bento & Moreira, 2017). The impact of this message is that the women questioned whether pain is to be expected, and if so, how much.

“It was like, well everyone complains of painful periods and I was like well I can’t go to the toilet without it hurting. You know I can’t have sex without it hurting, this can’t be normal. You’re telling me it’s normal?”(Denny & Mann, 2008, p. 114).

Not only did the women question what is normal, they were also left questioning their own resilience and coping, “It took us years to find someone who actually discussed endo, as many put it [the pain] down to me being “weak” and “letting the pain get to me.” (Rowe, Hammarberg, Dwyer, Camilleri, & Fisher, 2019, p. 4).

Four papers explored pain that arises from the healthcare encounter itself, making specific mention of the physical investigations. The delay in diagnosing endometriosis means that women have multiple healthcare encounters before confirmation of their diagnosis. Women in the studies felt they had to tolerate uncomfortable and sometimes painful investigations so that they could have their diagnosis confirmed (Grundström et al., 2020; Grundström et al., 2018; Hållstam et al., 2018; São Bento & Moreira, 2017). These encounters, while ordinary for HCPs, may be experienced as distressing for the women.

“just lying in the chair, to ... it’s pure trauma. For me it’s just, like, an assault in this chair where they’ve, sort of, almost pushed me down and, like, just now, ‘you ... you’re a woman, now we’re going to push that up you, you’ll manage it just relax now...”(Hållstam, Stålnacke, Svensén, & Löfgren, 2018, p. 100).

Five papers discussed the delivery of a diagnosis of endometriosis. In some cases, consideration was not given to the potential distress and pain that this can cause, “I contemplated suicide because I’ve always wanted a family... They need to be very careful with how they talk to women...They don’t realise the impact that it does have and it’s a lasting impact...You don’t just leave it behind.” (Young, Fisher, & Kirkman, 2016, p. 559). In some cases, women were given their diagnosis while recovering from surgery and with no plans for follow up. One study noted that the language used by HCPs when describing endometriosis can be traumatising, “rotten, spoiled from within ... it

was very ugly(P8); it's all spread out on the inside (P9), the damage is done (P11) and horrible on the inside (P17)"(São Bento & Moreira, 2017, p. 3029).

After these encounters women were left scared, lonely, confused, and apprehensive about the future (Facchin et al., 2018; Grogan et al., 2018; Rowe et al., 2019; Young et al., 2016).

Theme Two: Who is the expert?

The second theme centres around the idea of expertise; two subthemes were identified. A lack of knowledge on the part of the HCPs prompted women to question who the expert is.

Lack of knowledge

14 papers noted that women experienced a recurrent lack of knowledge on the part of the HCPs they encountered. This occurred at all stages of the diagnostic pathway. The studies discussed feelings of anxiety related to accessing services and not understanding the cause of their difficulties. Instead, they felt that only their symptoms were treated (Rowe et al., 2019; Sbaffi & King, 2020, Young et al., 2020). When they received their diagnosis, there was anger that endometriosis had never been mentioned as a potential cause, "No, not a clue what it was. Never heard the word [endometriosis] from medical professionals - they treated symptoms." (Sbaffi & King, 2020, p. 381).

When the participants received their diagnosis, they noted a lack of knowledge from HCPs in terms of treatments. The studies explored frustration with receiving inaccurate medical information, including 'myths' about cures for endometriosis. Women were encouraged to have children as a solution, regardless of their circumstances (Fernley 2021, Grundström et al., 2020: Markovic et al., 2008). Others were told that their endometriosis could not explain their level of pain, "He obviously had no idea how this disease can affect you at all. He told me, "You've only got spots of [endometriosis], lots of women have that and they get on with their life." (Denny, 2009, p. 991)

The consequences of a lack of knowledge, misdiagnoses and poor follow up support meant the women lost trust in their HCPs. Some women felt abandoned by their HCPs, "And then they just

said ‘There is no plan’.” (Grundström et al., 2018, p. 208), “They don’t offer you much except surgery and Mirena...” (Young et al., 2020, p.27) Others were angry as they had previously trusted their HCPs “...I assumed my GP was a well-educated man.”(Sbaffi & King, 2020, p. 382). The consequences ensuing from the delay in diagnosis was another source of anger and disappointment.

“I was not diagnosed for so long and it has affected my life. I’m not able to have children right now because of my endometriosis and I don’t know if I’m going to be able to, and I blame the doctors, I do” (Zale et al., 2020, p. 73).

When encountering this lack of knowledge, women noted that the response of the HCP determined whether the encounter was positive or negative. Three papers spoke about how some HCPs recognised this lack and actively learnt about endometriosis, in order to provide better care; this made the women feel acknowledged and contained (Denny & Mann, 2008; Facchin et al., 2018; Sbaffi & King, 2020). When HCPs took the time to explain this to patients, they felt empowered, “...but I can see the whole, I’ve got some kind of what I call a helicopter view, before, I was bang in the middle, I just ran about in total blind chaos ...”(Hållstam et al., 2018, p. 101).

Expert patients

The lack of knowledge of endometriosis prompted the women to become expert patients so they could advocate for appropriate care; 14 papers discussed this theme. For some of the women in the studies becoming an expert patient was empowering; for others, it was done to protect themselves. Women spoke of a need to guard against medical interventions that their own knowledge told them was incorrect. This was something that occurred at all levels of the medical system, “I have had doctors who are gyne registrars try injecting me with things that I know I shouldn’t be injected with, or that is the wrong medication from just my own research or knowing my own medical procedure.” (Grogan et al., 2018, p. 1370)

When women were confronted with HCPs that were not experienced in their condition, they were forced to become the educator, “With two of my doctors, I had to explain to them what endometriosis is and how to treat it. So you can’t exactly go to them and ask for help with my treatment”. (Moradi et al., 2014, p. 6)

While this may have shifted the traditional power balance, the women’s worries were not contained. They experienced this as a cue that they needed to gain expertise, “you have to be your own doctor.” (Young et al., 2020). Some questioned HCP’s ability to ever come to the right diagnosis, confirming that the shift towards the position of ‘expert patient’ is necessary, “No doctor ever said the word endometriosis to me. Ever. And I guess if I hadn’t come across it, I’d probably continue to be living in extraordinary pain for a long time.”(Zale et al., 2020, p. 73).

For some women this prompted anger at HCPs and medicine in general for not being more knowledgeable (Seear, 2009a). This was particularly the case where women had experienced multiple misdiagnoses and numerous medical investigations before identifying endometriosis (Bullo, 2018; Denny & Mann, 2008; Facchin et al., 2018; Fernley, 2021). Others recognised that not all HCPs can be expert in endometriosis; in these instances, it is important for them to be willing to refer to HCPs who are more experienced (Rowe et al., 2019; Young et al., 2020).

As well as recognising the need for appropriate medical expertise, several studies explored the idea of the women as having their own expertise, which is not always accounted for in their healthcare encounters (Denny & Mann, 2008; Fernley, 2021; Seear, 2009b; Young et al., 2020). Some women felt that HCPs experienced their knowledge as a barrier, “He did not like that I was very well informed, he told me my needs were too great for what he could do for me.”(Sbaffi & King, 2020, p. 381).

These encounters were easier to navigate when the women were perceived as using their expert patient status to ‘come alongside’ the HCPs. Women were encouraged by their HCP to become more involved in the management of their care; here space was made for conversations with all

parties. A plea for collaborative working was identified by a participant in Young et al. (2020), “If . . . those messages can get through to GPs and surgeons, so that women are treated as partners in their health, instead of patients that have things done to them, that would be a good thing.” (p. 37)

A battle for power can ensue when HCPs do not treat women as partners and when they do not acknowledge their own lack; in this case the women must “fight for proper care.” (Grundström et al. 2020, p. 23) Despite this being a cause of anxiety, it was empowering for some, as it meant that they had the ability to change HCPs (Fernley, 2021; Krebs & Schoenbauer, 2019) or access other treatments (Ballard, Lowton, & Wright, 2006; Rowe et al., 2019).

Discussion

The aim of this review was to gain an understanding of healthcare encounters for women with endometriosis. The results indicate that the journey through healthcare is fraught with dismissal and questions about expertise. Some positive interactions were discussed; the women valued HCPs who took the time to learn about their condition and listen to them. A line of argument was constructed to explore how the themes presented in this paper related to each other. This elucidated a long healthcare journey, that is fraught with interpersonal tensions. The healthcare journey is not necessarily linear; instead, these experiences could occur at any stage in the diagnostic pathway. The steps of the journey are demonstrated in Figure 2, alongside the identified emotions and implications.

INSERT FIGURE 2

When presenting to healthcare for support with their symptoms, women experienced anticipation in advance of the appointment, only to be confronted with dismissal. This could be in the form of having their physical symptoms treated as psychological. Where the pain could not be regarded as such, it was normalised and minimised. Throughout the process women described a battle to be heard by their HCPs and feared being labelled as difficult. Some women stopped accessing services at this point. Due to feelings of desperation and increasing levels of pain, others continued to

seek help but were frequently presented with HCPs who lacked knowledge of endometriosis. This created anxiety and frustration, which prompted the women to become 'expert patients' in response.

This review has extended beyond the review by Pettersson and Berterö (2020). Due to the recent increase of research in endometriosis, an additional 12 papers were identified. Both reviews found similar themes in terms of women's pain being normalised, encountering medical myths, and HCP's lack of knowledge. This paper, however, extends the conceptualisation of 'pain being normalised' to include the physical and emotional distress resulting from medical investigations, as well as from poor communication. The consequences arising from encountering a lack of knowledge in HCPs is also extended upon in this paper; namely, women need to become expert patients.

While the subthemes in this meta-ethnography are presented separately, they are in fact interlinked. This is particularly the case for the three subthemes of Women are Dismissed. The women in the studies described being treated as 'unreliable narrators' of their illness. This can be traced to outdated understandings of women's health, such as hysteria, when women's pain was conceptualised as resulting from a 'wandering womb' and later as a mental disorder (C. E. Jones, 2015). Links between endometriosis and hysteria are being made more frequently in recent studies (Guidone, 2020; Nezhat, Nezhat, & Nezhat, 2012; Yovich, 2020). Jones (2015) argues that understandings of endometriosis have been heavily influenced by conceptions of hysteria and its treatments. Historical remedies for hysteria included pregnancy, blood purifying, beatings, marriage, increased sex, abstinence from sex, mixtures for purging, psychoanalysis, as well as electric shock (Meek, 2013; Risse, 1988; Tasca, Rapetti, Carta, & Fadda, 2012). While most of these remedies are no longer used, some myths remain, as women in this review were encouraged to have a child as a cure for their endometriosis.

The stigma surrounding hysteria is still relevant today, as women in these studies were fearful of being labelled hypochondriac. Authors in several studies made direct reference to the power imbalance in the relationship between the women and HCPs (Young et al., 2020; Bullo 2018;

Grundström 2020). This fear of labelling and not being believed is not entirely subjective, as research conducted with HCPs has identified that some do believe in myths surrounding endometriosis being connected to psychiatric illness (Grundström et al., 2016). A study by Young, Fisher, and Kirkman (2018), exploring the perceptions of GPs and gynaecologists, found that several questioned whether their patients' illness was psychosomatic, "Do mad people get endo or does endo make you mad? It's probably a bit of both." (p. 13). Research by Bach et al. (2016) found that women who have repeat admissions and ongoing pain were experienced as 'difficult' by their nursing team.

The power imbalance played out in the theme of expertise also. Participants in the studies gained knowledge and became expert patients, as a defence against the anxiety that arose from HCPs lack of knowledge. Whelan (2007) notes that without the lack of knowledge from HCPs', women with endometriosis would not have gained this expertise. Difficulties arise when patient knowledge is not respected. Previous research found that knowledge alone did not equate to power, in terms of shared decision making; patients still perceived a lack of power to influence the medical decisions (Francis, Carryer, & Wilkinson, 2019; Joseph-Williams, Elwyn, & Edwards, 2014). Thorne, Ternulf Nyhlin, and Paterson (2000) found that HCPs retained the role of expert, even in encounters where they did not have the necessary knowledge of chronic illness. Previous studies exploring the perspectives of HCPs confirmed the experiences the women identified, in terms of a lack of knowledge (Leow et al., 2018; Van Der Zanden et al., 2018; Van Der Zanden & Nap, 2016; Van Der Zanden et al., 2020). A recent study by Dixon, McNiven, Talbot, and Hinton (2021), investigating GPs' perspectives on healthcare encounters, shows that the delay in diagnosis is more complex than simply lacking knowledge. Participants in the study spoke about a hesitation to discuss endometriosis as a possibility until they were sure this was the correct diagnosis. This highlights the difference in expertise between patient and HCP, whereby patients are focused on day-to-day coping with illness and the HCP is focused on biomedical diagnostic procedures (Hartzler & Pratt, 2011).

The findings in this review also aid with understanding the ongoing delay in diagnosing endometriosis. Previous studies have explored stigma surrounding menstruation, and how this creates a delay on the part of the patient in accessing services (Ballard et al. 2006; Gupta et al., 2018; Hudelist et al., 2012; Seear 2009c). This stigma occurs within all aspects of women's life, with friends, family and at work. This context is important to understand for the HCPs, as when women present to services to discuss their painful periods, in many cases they have already had to overcome stigma surrounding their menstruation (Seear, 2014). The women experienced normalisation of their pain within their encounters with HCPs, confirming their prior experiences with stigma. The anticipation before their appointment and the subsequent disappointment was discussed within the studies in this review. Research exploring the perceptions of GPs and gynaecologists by Fernandes, Skotnes, Major, and Falcão (2020) found that they believed it to be important for HCPs to be aware of the stigma surrounding diseases such as endometriosis.

Pain is normalised is a common theme within endometriosis literature, but in this review several papers expanded on this concept of pain, understanding it to mean that it is a woman's lot to suffer. The implication for expecting suffering is that in some instances, as described in the papers, there is not enough effort made to ensure that women do not suffer more than is necessary. It is important to note that pain relating to the physical investigation was only found in a small subset of papers (n=4); two of the papers were by the same authors (Grundström et al., 2020; Grundström et al., 2018,)), and three were conducted in Sweden, with the earliest being reported in 2017. This may be due to the research interests of the team, allowing for a heightened awareness of the pain, as Grundström, Wallin, and Bertero (2011) had previously explored the experiences of women undergoing gynaecological examinations. While this has not been researched specifically in women with endometriosis, other studies have looked at the link between women's experiences of undergoing gynaecological examinations and psychological distress. Factors influencing the level of distress are the gender and relationship with the HCP, the number of people present, the perceived necessity of the investigation, and fears about pain during the investigation (Grundström et al., 2011;

Sharp et al., 2013; Yanikkerem, Ozdemir, Bingol, Tatar, & Karadeniz, 2009). Women stated that they felt less distress when they trusted their HCP and when only one other person was present. Several factors related to these findings are relevant to endometriosis. The interpretations of the authors included in this review describe women having difficult relationships with HCPs, as well as feeling that these exams are painful, but necessary to get support.

The second element related to the indifference to women's pain is connected to the delivery of a diagnosis of endometriosis. A diagnosis can be life changing for women; for some women it can be validating, once they have time to adjust to it (Grundström et al., 2018; Roomaney & Kagee, 2018). For some of the women in this review, the news was not delivered in a sensitive manner. Girgis and Sanson-Fisher (1998) outlined essential steps for breaking bad news to patients; this includes ensuring the news is delivered sensitively in a quiet place, while allowing sufficient time for the conversation. These considerations have been missing from the delivery of an endometriosis diagnosis, with women in the studies feeling adrift both when receiving their diagnosis and after (Facchin et al., 2018; Grogan et al., 2018; Rowe et al., 2019; Young et al., 2016). Brown et al. (2009) found that doctors' ability to deliver bad news appropriately was impacted by fatigue and burn out. Delivering bad news was more stressful for physicians where they felt medically unable to make a difference (Ptacek & McIntosh, 2009).

Limitations

The studies included in this review are primarily from western countries. Although there is a variation in the levels of affordable access to healthcare in the countries included, all have established health systems. Therefore, this review does not account for the perspective of women's healthcare encounters in less established systems.

Another potential limitation of the findings is in relation to a selection bias. Many of the studies recruited participants from hospitals, support groups, and from online blogs. This may represent a sample of women who are struggling with their endometriosis, or have in the past,

particularly those who have chronic pain. Facchin et al. (2017) found that women who experienced chronic pelvic pain as a symptom of their endometriosis were more likely to be distressed. Therefore, this may not be representative of all individuals with endometriosis (De Graaff et al., 2015).

Throughout this paper the term HCP has been used to refer to a variety of healthcare professionals; this is a broad term and may be considered another limitation of the review. Focusing specifically on one professional group may have provided a clearer picture of the healthcare journey and identified where women experienced the most problematic or supportive encounters. While a more specific focus may have yielded clear results, it may also have been difficult, as several of the papers and participants did not specify the healthcare professionals they were speaking about. In particular this was the case when studies and participants referenced a doctor; it was not always clear whether this was a GP, gynaecologist or emergency room doctor.

Clinical Implications & Future Research

This meta-ethnography highlights that there has been little change in women's experience of their healthcare encounters over time. Studies from 2006 reported similar findings of dismissal and frustration as studies from 2021; included was a lack of knowledge and outdated myths regarding pregnancy as a cure for endometriosis. By taking a meta-ethnographic approach, this review frames these themes within a conceptual model of women's healthcare encounters. This model offers a visual representation of the behaviours leading to difficult healthcare encounters, while also outlining the emotional consequences. Exploring the healthcare encounters in this way, can highlight potential areas for intervention, including a role for psychology. Wahass (2005) notes that the function of a psychologist in health settings is multifaceted, including: individual assessment, formulation, intervention, teaching, supervision, consultation, and research. This review highlights the need for training for HCPs on topics such as stigma, the mind-body connection, historical narratives surrounding mental health in women, a psychological understanding of pain and associated management strategies, as well as the psychosocial impacts of endometriosis. These are all subjects

that psychologists would be well placed to teach other HCPs (British Psychological Society, 2007). The Journey Through Healthcare diagram (Figure 2) could be used as a tool within these training sessions.

It is beyond the scope of this research to explore the question of pain resulting from repeated physical investigations. The psychological cost of these investigations has not been fully explored in the literature to date. Given that the studies included in this review identified this as a traumatising experience, but one that the women felt was necessary for them to access support, there is an imperative to explore the impact of these examinations. While further research would be beneficial, there may also be a role for psychologists clinically to provide support to women in preparation for, and after these investigations.

This review focused on the perspectives of women with endometriosis. A future review focusing on the experiences of HCPs would be beneficial in assessing how best to support healthcare encounters.

Notes

Throughout this paper the term 'woman' was used to describe patients with endometriosis; this is for consistency and clarity purposes only. The author recognises that not all individuals with endometriosis identify as women.

Acknowledgments

None.

Declaration of interest statement

None.

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Table 1 – Table of Papers included in review

Authors	Year	Country of analysis	Journal	Study aim/research question	Research design	Analysis	Sample
Ballard et al	2006	United Kingdom	Fertility and Sterility	To examine the reasons for the delay in diagnosing endometriosis.	Qualitative - semi-structured interviews	Thematic Analysis	32 women with endometriosis
Bullo	2018	United Kingdom	Discourse & Communication	To explore dis/empowerment caused by discourses in the healthcare and social environment of women with endometriosis.	Qualitative - Interviews	Discourse Analysis	21 women with endometriosis
Denny	2009	United Kingdom	Qualitative Health Research	To explore women's experience of living with endometriosis.	Qualitative - Interviews	Narrative Analysis	27 women with endometriosis
Denny & Mann	2008	United Kingdom	European Journal of Obstetrics & Gynecology and Reproductive Biology	Aim to explore the experience of women with endometriosis in the primary care setting.	Qualitative - Interviews	Thematic Analysis/story telling	30 women with endometriosis
Facchin et al	2018	Italy	Journal of Health Psychology	To provide a broader understanding of how endometriosis affects women's psychological health.	Qualitative - Interviews	Grounded Theory	74 women with endometriosis
Fernley	2021	Australia	Journal of Endometriosis and Pelvic Pain Disorders	To witness and synthesise the collective experience of 49 women's online written accounts about their endometriosis diagnosis journey.	Qualitative - Online Written Accounts	Thematic Analysis	49 Written accounts by women with endometriosis
Grogan et al	2018	United Kingdom	Psychology & Health	To understand women's experiences of coping with endometriosis, and impact on their lives.	Qualitative - Interviews	Thematic Analysis	34 women with endometriosis

Grundström et al	2020	Sweden	Australian Journal of Advanced Nursing	The aim of this study was to identify and describe endometriosis healthcare experiences based on affected individuals' blog posts	Qualitative - Online Written Accounts	Thematic Analysis	16 Blog posts by women with endometriosis
Grundström et al	2018	Sweden	Journal of Clinical Nursing	To identify and describe the experience of healthcare encounters among women with endometriosis.	Qualitative - Interviews	Interpretative phenomenological analysis	9 women with endometriosis
Hållstam et al	2018	Sweden	Sexual & Reproductive Healthcare	To explore women's experience of severe painful endometriosis and its treatment.	Qualitative - Interviews	Grounded Theory	13 women with endometriosis
Jones et al	2004	United Kingdom	Journal of Psychosomatic Obstetrics & Gynecology	Objective is to explore and describe the impact of endometriosis upon quality of life.	Qualitative – Interviews	Grounded Theory	24 women with endometriosis
Kerbs et al	2019	Worldwide	Health Communication	What competing discourses animate women's experience of endo diagnoses, and in what ways does the interplay of competing discourses construct women's experience of endo diagnoses?	Qualitative- Online Written Accounts	Thematic Analysis & computational analysis	40 written accounts by women with endometriosis
Markovic et al	2008	Australia	health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine	To understand the relationship between the patient's socio-demographic background and health-related phenomena, by identifying distinctive differences among women's narratives.	Qualitative - Interviews	Grounded Theory	30 women with endometriosis
Matías-González et al	2021	Puerto Rico	Journal of Psychosomatic Obstetrics & Gynecology	Thus, the purpose of this study was to explore and document experiences of stigmatization among women living with endometriosis	Qualitative- Interviews	Thematic Analysis	50 women with endometriosis

Moradi et al	2014	Australia	BMC Women's Health	Explore women's experiences of the impact of endometriosis and whether there are differences across three age groups.	Qualitative - focus groups	Thematic Analysis	35 women with endometriosis
Rowe et al	2019	Australia	Journal of Psychosomatic Obstetrics & Gynecology	Aim was to compare women's and health professionals' perceptions of quality of endometriosis health care and opportunities for improvements.	Qualitative- Group Discussion & Interview	Framework Analysis	46 women with endometriosis
São Bento et al	2017	Brazil	Ciencia & saude coletiva	To discuss the meaning of the illness experience of women with endometriosis in the interface with institutional violence.	Qualitative - Interviews	Narratives of Life	20 women with endometriosis
Sbaffi et al	2020	Europe	Journal of Consumer Health on the Internet	To evaluate the role of the Internet in the diagnosis, treatment options and support of people living with endometriosis	Mixed Methods- Qualitative - Interviews	Thematic Analysis	12 women with endometriosis
Seear (a)	2009	Australia	Health, Risk & Society	To examine medical non-compliance in women with endometriosis	Qualitative - semi-structured interviews		20 women with endometriosis
Seear (b)	2009	Australia	Health Sociology Review	To explore self-management, self-care and patient expertise in women with endometriosis.	Qualitative - semi-structured interviews	Interactive Model Data Analysis	20 women with endometriosis. (same sample as Seear 2009a)
Young et al	2020	Australia	Feminism & Psychology	To understand how women navigate knowledge and power within the medical encounter.	Qualitative- Interviews	Thematic Analysis	20 women with endometriosis (re-analysis Young 2016)
Young et al	2016	Australia	Human reproduction	To explore the experience of healthcare women have received for endometriosis and fertility.	Qualitative - Interviews	Thematic Analysis	20 women with endometriosis

Zale et al	2020	United States	Journal of Endometriosis and Pelvic Pain Disorders	Two primary aims; first, to assess the perceptions and awareness of endometriosis among healthcare providers, and second to assess the endometriosis patient experience.	Mixed Methods - Survey & Interviews	Thematic Analysis	12 women with endometriosis
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Table 2- CASP scores

Study	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Total
Ballard et al (2006)	2	3	3	2	2	3	3	2	20
Bullo (2018)	3	3	3	1	2	3	3	2	20
Denny (2009)	3	3	3	3	3	3	3	1	22
Denny et al (2008)	3	3	3	1	2	3	3	2	20
Facchin et al (2018)	3	3	3	1	3	2	3	3	21
Fernley (2021)	3	3	3	1	3	2	2	2	19
Grogan et al (2018)	3	3	3	3	3	3	3	3	24
Grundstrom et al (2018)	3	3	3	3	3	3	3	3	24
Grundstrom et al (2020)	3	3	3	2	3	3	3	3	23
Hallstam et al (2018)	2	3	3	3	3	3	3	2	22

Jones et al (2004)	3	3	3	1	2	3	3	2	20
Kerbs et al (2019)	3	3	3	1	1	3	2	2	18
Markovic et al (2008)	3	3	3	1	1	2	3	2	18
Matías-González et al (2021)	3	3	3	1	3	3	3	3	22
Moradi et al (2014)	3	3	3	2	3	3	3	3	23
Rowe et al	2	2	3	2	3	2	2	2	18
São Bento et al	2	3	2	2	2	2	2	2	17
Sbaffi et al	2	2	3	1	3	2	3	3	19
Seear (2009a)	3	2	2	1	3	3	3	3	20
Seear (2009b)	3	3	3	1	3	3	3	3	22
Young et al (2016)	2	3	3	1	3	2	2	3	19
Young et al (2020)	3	3	3	2	3	3	3	3	23
Zale et al	3	3	3	1	3	3	3	3	22

Table 3 – Detailed steps of meta- ethnography

Phases of Meta-ethnography	Outlining process as applied to this paper
1. Getting started	Searches were conducted to identify previous reviews. None specifically to women’s healthcare encounters were identified at that time. The question was identified as “what are the experiences of women with endometriosis in relation to their healthcare encounters.”
2. Deciding what is relevant to the initial question	Due to the aim of extending understanding of these experiences, included studies were required to have participant quotes to evidence themes. Inclusion and exclusion criteria were established. These criteria were applied to papers retrieved in the literature search.
3. Reading the studies	23 papers were identified. Data was extracted using a word document with a layout proposed by Sattar et al (2021) (see appendix 1-B). Initial notations were made alongside second order data. This process was conducted for all papers. A table in excel was also created; this recorded detail of the studies including location, methodology, participants.
4. Determining how the studies are related	Notations from each paper were labelled with the study name and printed. These were cut up and spread out. Notations with similar content were grouped into new categories and given a descriptive label.
5. Translating studies into one another	Starting with the categories, the notations from each paper were read and considered alongside the excel table with study characteristics. A translation table was created for each category (see appendix 1-C). This was completed until notations from all 23 papers were included.

6. Synthesising Translations	<p>The aim of synthesising the translations is to go beyond the parts, or the individual studies. A reciprocal translation was conducted, whereby studies were reviewed to identify similar notations and how these related to each other. Third order constructs were developed, capturing these similarities, and added to the translation table. Initially the subthemes women as hysterical, battle to be heard and indifference to suffering, were separate, but once considered as a whole, these exposed the overarching theme of Women are Dismissed. The same process occurred for the theme Who is The Expert.</p> <p>After this a line of argument synthesis was identified, exploring how the themes Women are Dismissed and Who is the Expert were related to each other, and how they could elucidate the experience of healthcare encounters further. This is represented in the figure 2.</p>
7. Expressing the synthesis	<p>The synthesis outlined similar experiences of women in their healthcare encounters, these were expressed via the reciprocal translations. The journey throughout the healthcare encounters, albeit not a linear journey, is fraught with challenges and setbacks, this was expressed in prose and via a diagram.</p>

Table 4 - Table of Themes

Theme	Subtheme
Women are Dismissed	Women as hysterical Indifference to suffering Battle to be heard
Who is the expert	Lack of Knowledge Expert patient

Table 5- Contribution of studies to themes

Study	Women are Dismissed			Who is the Expert	
	Women as hysterical	Indifference to suffering	Battle to be heard	Lack of knowledge	Expert patient
Ballard et al (2006)		X		X	X
Bullo (2018)	X		X		X
Denny (2009)		X		X	
Denny & Mann (2008)	X	X	X	X	X
Facchin et al (2018)	X	X			X
Fernley (2021)			X	X	X
Grogan et al (2018)	X	X	X		X
Grundström at al (2018)	X	X	X	X	
Grundström at al (2020)	X	X	X	X	X
Hallstam et al (2018)		X		X	
Jones et al (2004)	X			X	
Kerbs et al (2019)	X				X
Markovic et al (2008)	X	X		X	
Matías-González et al (2021)	X		X		
Moradi et al (2014)	X	X	X		
Rowe et al (2019)		X		X	X
São Bento et al (2017)		X	X	X	
Sbaffi et al (2020)	X				X
Seear (2009a)				X	
Seear (2009b)					X
Young et al (2016)		X	X		X
Young et al (2020)	X		X	X	X
Zale et al (2020)	X		X	X	X
TOTAL	14	13	12	14	14

Table 6- Breakdown of papers contributing to Indifference to Suffering.

Study	Indifference to suffering		
	Pain is normalised	Distress medical procedure	Distress from delivery of healthcare
Ballard et al (2006)	X		
Bullo (2018)			
Denny (2009)	X		
Denny & Mann (2008)	X		
Facchin et al (2018)	X		X
Fernley (2021)			
Grogan et al (2018)			X
Grundström et al (2018)	X	X	
Grundström et al (2020)		X	
Hallstam et al (2018)		X	
Jones et al (2004)			
Kerbs et al (2019)			
Markovic et al (2008)	X		
Matías-González et al (2021)			
Moradi et al (2014)	X		
Rowe et al (2019)	X		X
São Bento et al (2017)	X	X	X
Sbaffi et al (2020)			
Seear (2009a)			
Seear (2009b)			
Young et al (2016)			X
Young et al (2020)			
Zale et al (2020)			

Figure 1 – PRISMA diagram

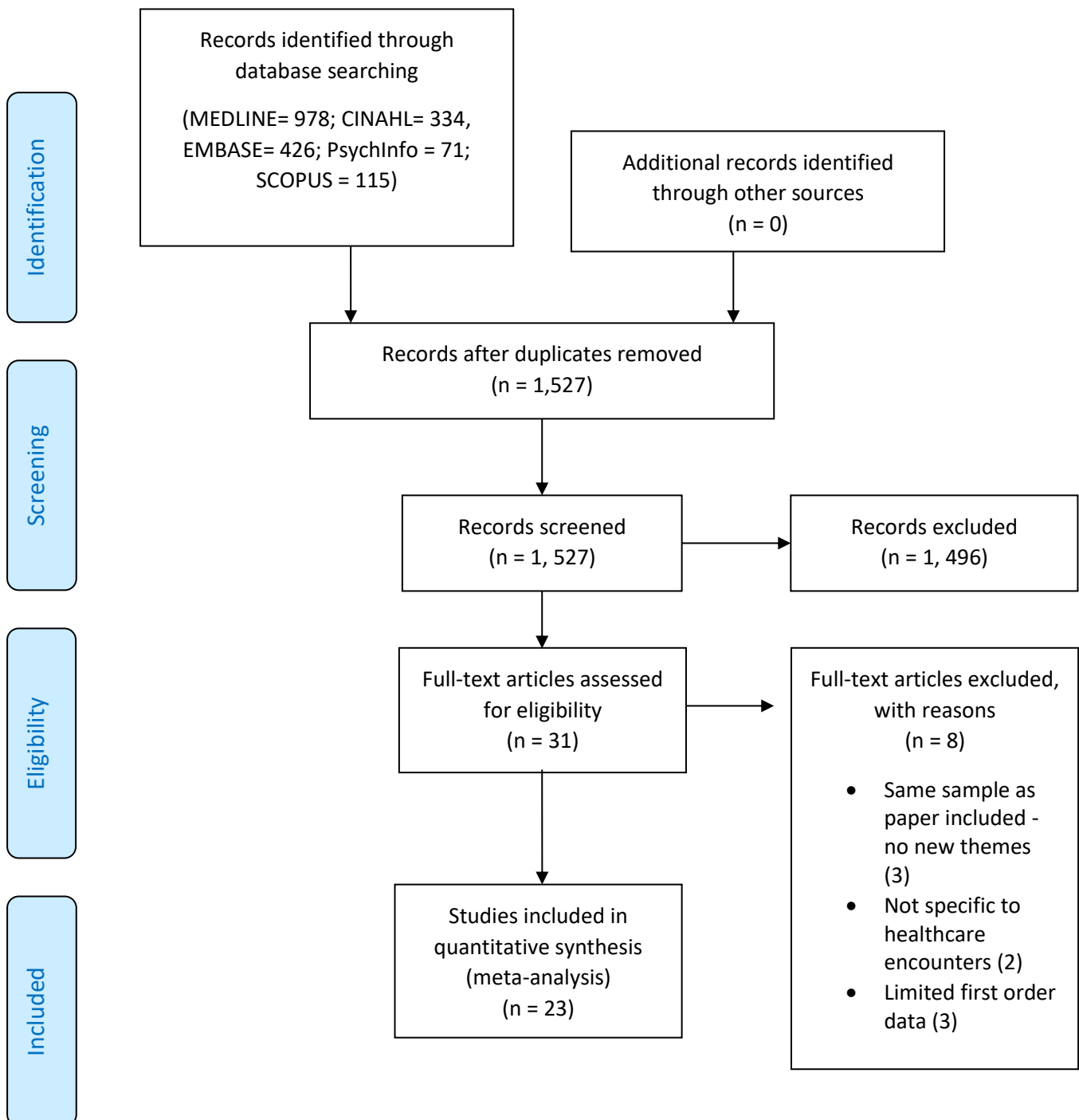
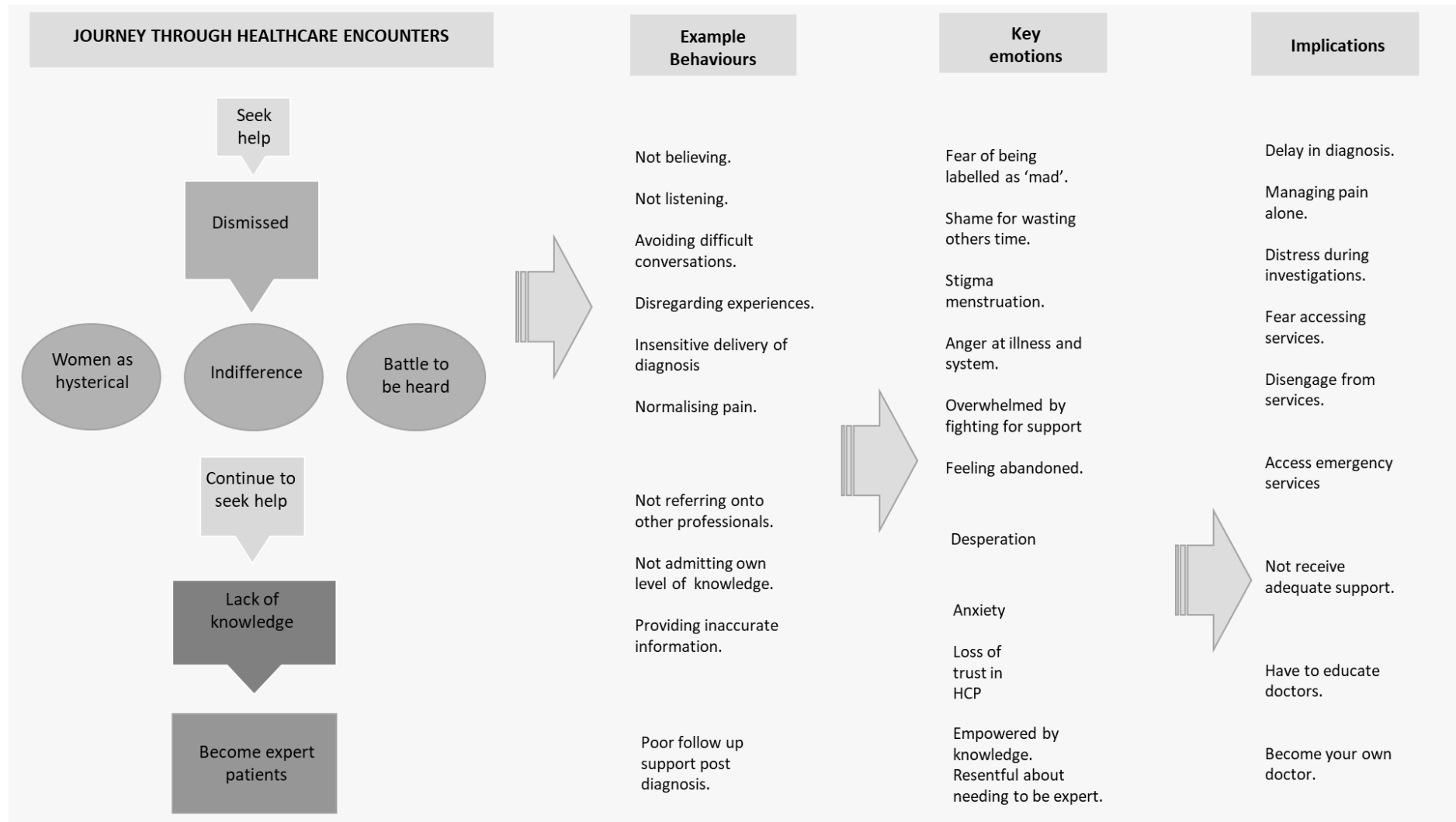


Figure 2- Diagram Healthcare Encounter



Appendix 1 – A: Search Terms in SPIDER Framework

Medline

Sample	(MH "Endometriosis") OR TI endometriosis OR AB Endometriosis
Phenomenon of Interest	(MH "Delivery of Health Care+") OR (MH "Patient Satisfaction+") OR AB (Psycholog* OR Physician* OR Physio* OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR gynaecolog* OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker) OR TI (psychology* OR Physician* OR gynaecolog* OR Physio* OR healthcare interaction OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker)
Design	(MH "Qualitative Research+")
Evaluation	OR AB ("qualitative" OR "interview" OR "qualitative interview*" OR "perception*" OR "satisf*" OR "value*" OR
Research Type	"perceive*" OR "perspective*" OR "view*" OR "experience" OR "belie*" OR "feel*" OR "know*" OR "understand*" OR “qualitative analysis” OR “qualitative research) OR TI ("qualitative" OR "interview" OR "qualitative interview*" OR "perception*" OR "satisf*" OR "value*" OR "perceive*" OR "perspective*" OR "view*" OR "experience" OR "belie*" OR "feel*" OR "know*" OR "understand*" OR “qualitative analysis” OR “qualitative research)

PsychInfo

Sample	(MH "Endometriosis") OR TI endometriosis OR AB Endometriosis
Phenomenon of Interest	(DE "Quality of Services") OR DE "Client Satisfaction") OR TI (psycholog* OR Physician* OR Physio* OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR gynaecolog* OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker) OR AB (psycholog* OR Physician* OR Physio* OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR gynaecolog* OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker)
Design Evaluation Research Type	(DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-Structured Interview" OR DE "Thematic Analysis") OR TI ("qualitative" OR "interview" OR "qualitative interview*" OR "perception*" OR "satisf*" OR "value*" OR "perceive*" OR "perspective*" OR "view*" OR "experience" OR "belie*" OR "feel*" OR "know*" OR "understand*" OR "qualitative analysis" OR "qualitative research") OR AB ("qualitative" OR "interview" OR "qualitative interview*" OR "perception*" OR "satisf*" OR "value*" OR "perceive*" OR "perspective*" OR "view*" OR "experience" OR "belie*" OR "feel*" OR "know*" OR "understand*" OR "qualitative analysis" OR "qualitative research"

CINAHL

Sample	(MH "Endometriosis") OR TI endometriosis OR AB Endometriosis
Phenomenon of Interest	(MH "Delivery of Health Care+") OR (MH "Patient Satisfaction+") AB (Physician* OR Physio* OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR gynaecolog* OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker) OR TI (Physician* OR gynaecolog* OR Physio* OR healthcare interaction OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker)
Design Evaluation Research Type	MH "Qualitative Studies+") OR AB ("narrative" OR "discourse" OR "diary" OR "focus group" OR "Blog" OR "interview" OR "qualitative interview*" OR "perception*" OR "satisf*" OR "value*" OR "perceive*" OR "perspective*" OR "view*" OR "experience" OR "belie*" OR "feel*" OR "know*" OR "understand*" OR "qualitative analysis" OR "vignette*" OR "writ*") OR TI ("narrative" OR "discourse" OR "diary" OR "focus group" OR "Blog" OR "interview" OR "qualitative interview*" OR "perception*" OR "satisf*" OR "value*" OR "perceive*" OR "perspective*" OR "view*" OR "experience" OR "belie*" OR "feel*" OR "know*" OR "understand*" OR "qualitative analysis" OR "vignette*" OR "writ*")

EMBASE

Sample	(MH "Endometriosis") OR TI endometriosis OR AB Endometriosis
Phenomenon of Interest	Exp Patient Satisfaction AB (Psycholog* OR Physician* OR Physio* OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR gynaecolog* OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker) OR TI (psychology* OR Physician* OR gynaecolog* OR Physio* OR healthcare interaction OR Occupational therap* OR Healthcare encounters OR Healthcare professional OR general practitione*" OR GP OR "family doctor*" OR nurs* OR health personnel OR worker)
Design	Exp Qualitative Research
Evaluation	AB (qualitative OR interview OR qualitative interview* OR perception* OR satisf* OR value* OR perceive* OR perspective* OR view* OR experience* OR belie* OR feel* OR know* OR understand* OR qualitative analysis OR qualitative research) OR TI (qualitative OR interview OR qualitative interview* OR perception* OR satisf* OR value* OR perceive* OR perspective* OR view* OR experience* OR belie* OR feel* OR know* OR understand* OR qualitative analysis OR qualitative research)
Research Type	

SCOPUS

Sample	Endometriosis
Design	Qualitative Research

Appendix 1- B: Table of partial data extraction

Study Title: The double-edged experience of healthcare encounters among women with endometriosis: A qualitative study

Author: Grundstrom et al (2018)

Objective: To identify and describe the experience of healthcare encounters among women with endometriosis.

Themes:

- Myths- psychological not physical
- Trauma physical exam- repeated
- Dismissed – when answer not obvious
- Lack of competence=lack of trust
- Being heard increases trust/comfort
- Felt acknowledged: Treated as an individual
- Dismissed- Normalised pain
- More than endo

Themes	Primary Author Interpretations	Participant Quotes
Myths- psychological not physical	<p>RESULTS 4.1 Being treated with ignorance</p> <p>Looking back at their experience of healthcare encounters, the women described a long struggle characterised by ignorance, that is, exposure, disbelief and lack of knowledge. The women had to struggle with exposing the most private parts of their lives to many HCPs: baring their health, their souls and their bodies. They felt mentally exposed when having to confide their symptoms to the HCPs, describing how pain and bleeding limited and controlled their daily lives. Most women feared having a serious disease or a malformation that the HCPs were unable to detect. They felt as if they were alone in the world with these symptoms. In this vulnerable situation, it was distressful to be disbelieved by HCPs whose duty was to help them. The women often encountered the attitude that they exaggerated or imagined their symptoms or had low pain thresholds. The insinuation that psychological factors or</p>	<p><i>You have to in some way convince them that it is like this and that (//) They think that you exaggerate, and you need to try hard so that they believe you, because they don't. You experience that immediately, that they don't believe you. (Woman 9, diagnosed six years ago)</i></p>

	former abuse enhanced the symptoms was insulting to some of the women:	
Trauma physical exam-repeated	Having to undergo repeated gynaecological examinations, which are often painful to women with endometriosis, made them feel exposed in a physical way. As a gynaecological examination was part of the routine investigation, they had no other choice than to subject themselves to it:	<i>To be exposed, that is something you don't want to risk, so every time it is like a mental procedure, the sense of exposure. Well, it's almost like an abuse, it is something you don't want to do but you must. (Woman 5, diagnosed 20 years ago)</i>
Dismissed – when answer not obvious	In the prediagnosis encounters, HCPs were focused on finding an “easy explanation,” for example, infections, miscarriage or irritable bowel syndrome. When the symptoms did not disappear, the HCPs resorted to normalising and trivialising the problems. Women were told that menstrual pain was normal for every woman to endure. The women felt invisible as HCPs did not seem interested in understanding them when they gave their accounts of having to live alone, not being able to have relationships because of pain during intercourse or fear of infertility. Some women perceived the HCPs as 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 to the women:	<i>I was given advice like ‘start exercising or something’. It made me feel as if I was being ridiculed. (Woman 7, diagnosed five years ago)</i>
Lack of competence=lack of trust	The women felt that they were dependent on the HCPs’ competence as these controlled such an important part of their lives. Sometimes the women experienced that the HCPs lacked basic knowledge about endometriosis. 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?” The insecurity left them disillusioned, on the edge of despair, drifting without a goal, not knowing where they were heading:	<i>I asked: ‘What is the goal, where are we heading and what is the next step if this doesn't help?’ I never got an answer. And then they just said ‘There is no plan’. I thought it was really strange. There should be a plan, shouldn't there? There should be something because there is hopelessness when you are having this pain. . .It is the worst when you are in this situation, and there is no plan. (Woman 8, diagnosed five years ago)</i>
	Being treated with ignorance made some women feel apathetic, and a sense of hopelessness grew. Others were prompted into continuing the search for an HCP who would believe them and confirm them.	

Being heard increases trust/comfort	4.2 Being acknowledged In contrast to the feelings of being treated with ignorance, the women also spoke of encounters where they had been acknowledged, that is, they felt confirmed and visible. The common factor in these experiences was a feeling of being listened to and being believed by competent HCPs. During constructive encounters, women could say exactly how they felt, without being judged. When they felt confirmed, they no longer had to try to convince the HCPs of their symptoms. They felt less exposed, both when telling HCPs personal things and when it came to the physical exposure during examinations:	<i>She always comforts you and explains things, and that is so comforting, that you may complain more and she understands you anyway. (Woman 2, diagnosed 14 years ago)</i>
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Data extraction table based on Sattar et al. (2021)

Appendix 1- C : Translation Table for Sub-theme women as hysterical

Sub-Theme Title	Study	Original Author Theme Titles	Key Author Interpretations (second order)	Participant Quotes (first order)	Author interpretations (third order)
Women as Hysterical	Denny & Mann (2008)		Women felt that their pain (the intensity of which they would describe, for example, as 'gnawing' 'like a knife going into each ovary' or 'a wall of pain') was trivialised and dismissed as 'just period pain' or psychological in origin.	<i>"One of the GPs actually told me that period pains didn't exist and it was just women being stupid, so I didn't actually get any painkillers."</i>	
	Jones et al (2004)	Medical Professionals	The attitudes of some members of the medical profession particularly affected HRQoL. Many women felt they were wasting doctors' time because they believed that their doctors thought the problems were all in their mind.	<i>When I came for some appointments or whatever the consultant was like "you must be crazy, I don't think you've got any pain. Maybe it's just some kind of phantom pain or maybe it's just your imagination or something"</i>	Denial of symptoms- women exaggerate
	Bullo (2018)	Disempowerment caused by disbelief, pain normalisation and misdiagnosis	Of interest to this particular work is the linguistic mechanisms through which the experience of disempowerment.	<i>"the GPs ... who do give you these sort of like a pat on the head and off you go dear. You've just been anxious, off you go"</i>	
	Sbaffi & King (2020)	Knowledge of endometriosis, diagnosis and healthcare support	visited many GPs, and went from being told that...to being dismissed entirely. She felt that, while her doctors were good, they have little	<i>"You are going to have painful periods because psychologically you believe they are going to be painful. You just need to relax"</i>	

Grundström et al (2018)	Being treated with ignorance	consideration for what she was actually going through. The insinuation that psychological factors or former abuse enhanced the symptoms was insulting to some of the women.	<i>You have to in some way convince them that it is like this and that. They think that you exaggerate, and you need to try hard so that they believe you, because they don't.</i>	
Grogan et al (2018)	Battle for accurate diagnosis	Many were frustrated by lack of support from health professionals who made them feel that they were	<i>'overreacting' making a 'fuss over nothing'</i>	
Markovic (2008)	Contest	Endometriosis is one of the many conditions in which health professionals often discredit patients' experiences and label them as psychosomatic.	<i>"I would re-present, and I think they started to think that it was psychosomatic. So I got this whole kind of patronizing, non-believing attitude"</i>	
Kerbs et al (2019)	Women as neurotic	Narratives revealed that women with endo were often referred to a mental health clinician, rather than provided physical treatment.	<i>"I went to the doctor at least twice a month with these symptoms and pretty soon they told me that I just had an anxiety disorder"</i>	Symptoms are psychological
Grundström et al (2020)	The Response Plays A Significant Role	Some HCPs had even called them drug addicts, which they found offensive and degrading.	<i>"I know all too well what it is like to be distrusted by the system, to be called a hypochondriac, an addict, to hear that I am too young to be sick."</i>	Stigma- fear of being labelled 'mad'.
Matías-González et al (2020)	Health Professionals Interactions	Another participant echoed this experience and further linked it with her avoidance of seeking healthcare.	<i>"It happened with a specialist, who after every operation told me that I was a "changa". I have not been to a gynaecologist for more than a year"</i>	Power dynamics

Young et al (2020)	Women's perceptions of doctors' knowledge and power	Regardless of their perceived expertise, doctors (typically gynaecologists) were recognised by women as an "authority"	<i>Helen said that "you've got be careful" because doctors can label you "a hypochondriac" and thus a "mad woman."</i>
Moradi et al (2014)	Delayed Diagnosis	Their doctors misdiagnosed or mistreated them because they normalized symptoms and did not believe them.	<i>"...everyone pretty much thought I was just being a sook [sic] until I was diagnosed"</i>
Grundström et al (2020)	The Response Plays A Significant Role	For Maria, the lack of trust and belief in HCPs had led to a phobia of hospitals.	<i>"Even when I go in with sinusitis, I think they will say I am making it up and should seek mental help."</i>
Zale et al (2019)	Psychological Impact	Each participant interviewed spoke about the psychological aspect of this physical disease.	<i>"And it confirmed that I wasn't crazy and there was really something wrong with me."</i>
Facchin et al (2018)	Pathway to Diagnosis	Some women felt treated like they were insane.	<i>"They thought I was crazy [...] and I felt so disheartened,"</i>

Question own
competence

Appendix 1- D: Journal Submission Guidelines

Psychology & Health

Aims and scope

Psychology & Health promotes the study and application of psychological approaches to health and illness. The contents include work on psychological aspects of physical illness, treatment processes and recovery; psychosocial factors in the aetiology of physical illnesses; health attitudes and behaviour, including prevention; the individual-health care system interface particularly communication and psychologically-based interventions. The journal publishes original research, and accepts not only papers describing rigorous empirical work, including meta-analyses, but also those outlining new psychological approaches and interventions in health-related fields.

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As a result of the significant disruption that is being caused by the COVID-19 pandemic we understand that many authors and peer reviewers will be making adjustments to their professional and personal lives. As a result they may have difficulty in meeting the timelines associated with our peer review process. Please let the journal editorial office know if you need additional time. Our systems will continue to remind you of the original timelines but we intend to be flexible.

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The manuscript title, abstract and keywords, in English and in the authors' language
A biographical note (100 words) of each author in English

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Please note that this journal only publishes manuscripts in English.

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Section 2 - Empirical Paper

The Experience of Psychological Care for Women with Endometriosis

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Word Count: 7, 998

(excluding references, tables, figures and appendices)

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Abstract

Endometriosis is a painful gynaecological condition that impacts 1 in 10 women. There are many psychosocial implications, with recent calls for psychologists to be a part of women's treatment. The aim of this study is to explore women's experience of accessing psychological care for support with their endometriosis. A qualitative design was employed. Semi structured interviews were conducted and recorded. These were transcribed and analysed using interpretative phenomenological analysis. Five women with endometriosis were recruited. Four superordinate themes were identified: (1) Therapeutic alliance; psychological support as beneficial when there was a strong therapeutic alliance. (2) Permission to speak; this was facilitated by the therapist's ability to provide an adequate therapeutic frame, when this was not adequate, the women felt unable to speak about stigma. (3) Therapy can be empowering; psychoeducation was normalising and provided perspective. (4) Managing endometriosis means managing mental health; endometriosis is a chronic condition that requires ongoing support. This study highlights the role for psychologists to support both women and their healthcare teams. Future research should consider the efficacy of psychological interventions, as well as individualised, culturally specific support.

Keywords: *endometriosis; healthcare encounter; psychological therapy; psychosocial implications; pain communication; psychoeducation; therapeutic alliance*

Endometriosis is a chronic gynaecological condition whereby cells typically found in the womb are present in other areas of the body (Giudice, 2010). These cells respond to hormonal changes during menstruation by swelling and bleeding, causing the surrounding area to become inflamed. Endometriosis is estimated to affect 10% of women worldwide, equating to approximately 190 million women (Zondervan, Becker, & Missmer, 2020). Symptoms of endometriosis can include: pain during or after sex (dyspareunia), heavy or painful periods (dysmenorrhea), fatigue, infertility, or painful bowel movements (EndometriosisUK, 2019). Ballard, Seaman, De Vries, and Wright (2008) assert that while this particular combination of symptoms may be present in women without endometriosis, it is not typical. Despite this, both women and their doctors report a struggle with getting an accurate diagnosis (Fauconnier et al., 2013; Grundström, Kjølhede, Berterö, & Alehagen, 2016; Seear, 2009a).

Misdiagnosis is common for women with endometriosis, including irritable bowel syndrome, pelvic inflammatory disease, sexually transmitted infections, painful menstruation, cancer or psychiatric diagnoses (Bullo, 2019; Hudelist et al., 2012; Moradi, Parker, Sneddon, Lopez, & Ellwood, 2014; Roomaney & Kagee, 2018). In a recent survey conducted by an All Parliamentary Party Group (APPG) in the United Kingdom, 58% of women reported attending their General Practitioner (GP) more than 10 times with their endometriosis symptoms (Amess, Doyle-Price, Hardy, Bardell, & Furniss, 2020). As a result, women have described feeling frustrated, noting that healthcare professionals (HCP) were dismissive of their symptoms (Chauvet et al., 2018; Endometriosis Task Group, 2018; Grogan, Turley, & Cole, 2018). A recent study indicates that there has been little advancement in reducing the delay in diagnosis. For example, in the United Kingdom: currently it is estimated

at 8 years (Ghai, Jan, Shakir, Haines, & Kent, 2020), compared with 8.5 years in 2006 (Ballard, Lowton, & Wright). Delay in diagnosis is evident outside of the UK also, ranging from 4.4 years in United States to 10.4 years in Germany and Austria (Hudelist et al., 2012; Soliman, Fuldeore, & Snabes, 2017; Staal, van der Zanden, & Nap, 2016). Even when an accurate diagnosis is achieved, women with endometriosis struggle with numerous psycho-social implications of the illness, as outlined below (Culley et al., 2013; Young, Fisher, & Kirkman, 2015).

The Psycho-Social Implications of Endometriosis

Endometriosis symptoms such as dyspareunia, pelvic pain and fatigue can have a profound impact on intimate relationships and sexual functioning (Barbara et al., 2017; Della Corte et al., 2020). Both women and their partners report feeling dissatisfied with their sexual relationship; the pain experienced during sex impacts on their wellbeing and makes them avoidant of sex (Culley et al., 2017; Denny & Mann, 2008). Further research is required to explore the experiences of partners in same-sex relationships (Robinson, Galloway, Bewley, & Meads, 2017).

There is evidence that up to 50% of women with infertility have endometriosis (Dunselman et al., 2014; La Rosa et al., 2020; Vitale, La Rosa, Rapisarda, & Laganà, 2017). Several studies have explored the psychological impact of infertility for women, noting that for some, this made them question their role in society, as a woman without children (Facchin, Buggio, Dridi, & Vercellini, 2019; Riazi et al., 2014; Young, Fisher, & Kirkman, 2016). Beyond the struggle with infertility, women with endometriosis describe a disrupted sense of identity; whereby the chronic illness of endometriosis interrupts their regular experience and prompts them to re-examine their identity (Bury, 1982; Trusson, Pilnick, & Roy, 2016). This can occur

in terms of their body image, sexuality, and gender identity (Cole, Grogan, & Turley, 2020; Facchin, Saita, Barbara, Dridi, & Vercellini, 2018).

Endometriosis also has an impact on employment. A recent study found that women with symptomatic endometriosis were less likely to have a job, compared with those who have asymptomatic endometriosis and women who do not have the condition (Facchin, Buggio, Ottolini, et al., 2019). For women who are employed, several studies report a negative impact on work performance and absenteeism (Fourquet, Báez, Figueroa, Iriarte, & Flores, 2011; Nnoaham et al., 2011; Soliman, Coyne, et al., 2017).

When considering the symptoms of endometriosis and the profound impact this can have on a woman physically and socially, it is understandable that this can also have a negative impact on wellbeing and mental health. Women have reported feeling isolated due to their symptoms; specifically, they feel silenced due to a stigma surrounding menstruation (Grogan et al., 2018). Seear (2009b) describes how societally there is an impetus on all women to conceal any negative consequences arising from menstruation, this includes hiding the impact from other women. This is relevant for women with endometriosis, as an early symptom of the condition is painful menstruation. As a result of this stigma, women feel inhibited, and some are unable to be honest about their symptoms.

When women do speak about their pain, they are met with pain being normalised by both their doctors and their family, and are told that period pain is to be expected (Bullo, 2019; Facchin et al., 2018; Grogan et al., 2018; Moradi et al., 2014). Studies have found that normalising pain was a cause for further delay in diagnosis, as women were more likely to

believe their pain was normal if those around them also believed this (Hudelist et al., 2012; Moradi et al., 2014).

The Present Study

A review by Inocente and Soares (2019) found that medical intervention is still the primary treatment offered to women with endometriosis. A multidisciplinary approach has been advocated by both health professionals and those receiving care, with 90% of women surveyed by the All Parliamentary Party Group stating they would have liked access to psychological support (Amess et al., 2020). A recent update to guidance for chronic pain by NICE, recommends psychological intervention in the support of pain (National Institute for Health and Care Excellence, 2021). Several authors make note of the importance of treating endometriosis holistically; acknowledging the impact of endometriosis on relationships and wellbeing, they state that psychological and sexological support should be offered (Buggio et al., 2017; La Rosa et al., 2020; Leroy et al., 2016; Quinlivan et al., 2020). To this end, psychological interventions were identified as an area of research priority for The Endometriosis Priority Setting Partnership in 2017 (Horne, Saunders, Abokhrais, & Hogg, 2017).

Despite these drivers, Van Niekerk, Weaver-Pirie, and Matthewson (2019) noted that evidence for psychological intervention is currently determined to be weak. A review by Evans, Fernandez, Olive, Payne, and Mikocka-Walus (2019) explored the psychological and mind body interventions studies to date, some of these include yoga, mindfulness, cognitive behavioural therapy, and Chinese medicine. They highlight the wide variation in approaches and the need for further research before stating that psychological interventions are effective

in alleviating distress in women with endometriosis. Additionally, it is not known how women with endometriosis experience such support.

The purpose of this study is to privilege the experiences and meaning making of women accessing psychological support; knowing what has been helpful in these interactions can help guide clinicians and endometriosis services. This research also aims to contribute to the growing evidence base and understand further the potential role for clinical psychologists in managing this condition. This study aims to understand the experience of women who have accessed psychological care for support with their endometriosis.

Method Section

Design

A qualitative methodology was chosen to gain insight into the unique experience of women who had received psychological support for endometriosis. Specifically, the study used Interpretative Phenomenological Analysis (IPA). IPA was chosen over other qualitative analysis methods such as grounded theory or discourse analysis due to its focus on the lived experience. IPA was developed within the field of psychology. Therefore, it has a concern with how experiences and meanings are related to cognition and behaviour. Unlike discourse analysis, it assumes a chain of connection between what a person says, with what they think and how they behave. An underlying position of IPA is that individuals are actively engaged in a process of sense-making regarding their experiences (Smith & Osborn, 2015). The double hermeneutic results when the researcher engages in an interpretation of the participant's sense-making. It is idiographic in its approach as it is concerned with detailed analysis of each case before moving onto the next and in showing in the final analysis how patterns meet and differ across participants.

The early development of the IPA approach focused on chronic illness and the transition to motherhood (Smith, 1996, 1999). More recently IPA has been used to explore women's experiences of vulvodynia, miscarriage, breastfeeding and gynaecological surgery (Charlick, McKellar, Gordon, & Pincombe, 2019; Meaney, Corcoran, Spillane, & O'Donoghue, 2017; Phillips, Archer, Montague, & Bali, 2019; Shallcross, Dickson, Nunns, Taylor, & Kiemle, 2019). This indicates that it is well placed to explore women's experience of accessing psychological care for endometriosis.

Interviews are the primary, most efficient way of eliciting data in IPA research. The use of semi-structured interview allows flexibility, so that participants will be able to fully explore their lived experience. This included their thoughts and feelings about working with mental health professionals to understand their endometriosis in a psychological way (Smith, Flowers, & Larkin, 2009).

Sampling and Participants

Recruitment was conducted via a registered charity, Endometriosis UK. The poster for this study was advertised within the local Endometriosis UK support group mailing list and their associated Facebook group (see Section 4). If interested, participants were then invited to contact the author directly, via email. The author then discussed the project and sought any further details necessary to establish inclusion in the study.

IPA aims to have a homogenous sample so as to explore the convergence and divergence within the sample (Alase, 2017). Criteria for inclusion in the study was as follows; women between the ages of 18-50; while endometriosis is a condition which can affect women of any age, the condition is less common in adolescents and symptoms are thought to ease during and after the menopause, the age range was chosen for this reason (National Health Service,

2020). Participants must have a confirmed diagnosis of endometriosis from a gynaecology department or Endometriosis Clinic. They must have accessed psychological care regarding their endometriosis; for this study psychological care is understood as any formal support from a trained mental health professional (e.g. Psychologist, Cognitive Behavioural Therapist, Psychological Wellbeing Practitioner, Psychiatrist, Nurse, or Social Worker). This support must be within the last five years; and have been based in the UK. Requiring that the support was accessed within the last five years was done to limit the potential impact of recall bias (Althubaiti, 2016). Exclusion criteria included women who did not have a diagnosis of endometriosis, or who had not accessed psychological therapy.

In total 11 women were interested in participating in the study, interviews were conducted between August and December 2020. Six met the inclusion criteria, five were interviewed and one was unable to attend their interview; it was not possible to reschedule. Participants were all female and were aged between 28 and 49; the women had been diagnosed with endometriosis between 2-11 years before taking part in the study. The psychological care was provided by clinical psychologists, psychodynamic psychotherapist, and counsellors. Participants accessed care ranging from six months – five years before the study. They were referred for care by their gynaecologist (n=3) and self-referred (n=2). See Table 1 for participant demographics, and pen portraits for additional contextual information (see Appendix 2-A).

INSERT TABLE 1

Reasons for exclusion were: not having accessed psychological support (n=2), and accessing psychological services, but this was not for support with their endometriosis (n=3). The decision was made to exclude these three individuals, in order to maintain the

homogeneity of the sample (Pietkiewicz & Smith, 2014). All those who were not included were offered a summary of the findings.

Sample size in IPA studies can range from 1 to 10 (Starks & Brown Trinidad, 2007). The sample size of five in this study was deemed appropriate; it was felt that this number and quality of data represented a sufficient sample for the in-depth analysis required in IPA. Smith et al. (2009) note that a sample size of five to six participants is appropriate for doctoral research.

Data Collection

The interview schedule was developed by the lead researcher; this was completed by reviewing the previous literature and reviewing guidelines by Smith et al. (2009) (see Section 4 for copy of schedule). The schedule was reviewed by supervisors, as well as one woman with endometriosis who was known to the researcher, she did not take part in the interviews. Based on feedback the schedule was amended to include a question about the referral for psychological support. The interview schedule included prompts surrounding how and when the diagnosis of endometriosis was achieved, when psychological support was accessed, what difficulties were experienced at the time, the experience of the support and the individual's perception of their endometriosis afterwards. After the first two interviews the interview schedule was reviewed by the author and their supervisor. No changes were made to the content or the order.

If inclusion was confirmed, women were informed by the author about the purpose of the study and the interview process. They were provided with copies of the participant information sheet and consent form. Once these were completed, the interview was arranged via the participant's chosen method of communication. Due to COVID-19 restrictions at the

time of recruitment, the options presented to participants included online technology (e.g., Skype/ Teams/ Zoom) or telephone only. Saberi (2020) notes that within the COVID restrictions, using online video conferencing technology can replicate as closely as possible an in-person interview. It was considered that not all participants might have access to technology or consistent Wi-Fi, and therefore the option of telephone was also provided (Sevelius et al., 2020).

Consent was obtained in advance of the interview via email, with the exception of one participant; in this case the consent form was recorded via reading this aloud and the participant agreeing to take part in the study. Before commencing the other interviews, the author revisited the participant information details and consent form to ensure participants were happy to go ahead.

The average length of the interviews was 86 minutes (ranging from 73 – 95 minutes). Four interviews were carried out using Microsoft Teams video conferencing technology and one was conducted on the telephone. At the end of the interview participants were reminded that they could opt out of the study within 2 weeks, after this their information would be pooled and be more difficult to remove. Participants were provided with a debrief sheet outlining contact details for the author and other support available. Participants were encouraged to make contact if they had any further questions or concerns (see Section 4).

Analysis

The audio from each interview was transcribed and analysed using guidelines outlined by Smith et al. (2009) and Murray and Wilde (2020). Due to the idiographic nature of IPA analysis is conducted on a case-by-case basis, then across the sample. The first stage involves a thorough reading and re-reading of the transcripts to aid with familiarisation. The second

stage involved making notes regarding participant's descriptive, linguistic, and conceptual comments. In stage three emergent themes were developed for each transcript; an example of initial notes and emergent themes can be seen in Appendix 2-B. This is followed by step four, searching for connection across the emergent themes to create participant level superordinate themes. At this stage of the analysis narrative summaries were written for each participant theme, to aid with elucidating the core meaning as recommended by Murray and Wilde (2020) (see Appendix 2-C). This process was done for each interview before moving on to the next case and finally searching for connections across cases. Appendix 2-D outlines the main themes across all participants.

Ethics

Before research commenced ethical approval was sought from the Faculty of Health and Medicine in Lancaster University (see section four of this thesis for approval letter). A shortened version of the research protocol, ethics documentation and interview questions were provided to Endometriosis UK. The study was reviewed within the organisation prior to advertising.

A protocol for managing distress was established. This was as follows: If participants became distressed during the interview the interview would be stopped, they would be given time to recover and then they would be presented the option to continue the interview, reschedule or withdraw from the study. Details for support services were sent as part of the initial information pack and after the interview. The protocol was not needed in the interviews.

Reflexivity

Smith et al. (2009) argues that IPA requires researchers to be attentive to their own assumptions so that they can put this aside when engaging in the process of making sense of the participant. A reflective diary was maintained throughout to continually engage in reflexivity as suggested by Shaw (2010) see Appendix 2-E. Relevant to this study is that the lead researcher is a female trainee clinical psychologist in her late thirties, who has family and friends with endometriosis. Themes and analysis were discussed with supervisors to reduce the potential for bias. In the development of the materials for the project a woman with lived experience of endometriosis was consulted; this was done to address any potential assumptions the lead researcher may have had.

Results

Four superordinate themes were identified: (1) Therapeutic alliance; (2) Permission to speak; (3) Therapy can be empowering; (4) Managing endometriosis means managing mental health. See Table 2 for the full breakdown of themes, noting which participants contributed. All names are pseudonyms and quotes have had identifiable details removed. Participants accessed support from various psychological professionals; for the purpose of clarity, the professionals will be referred to as 'therapist' for the remainder of the paper.

Theme One: Therapeutic Alliance.

The therapeutic alliance has been defined as, "...agreement on the goals of the treatment, agreement on the tasks, and the development of a personal bond made up of reciprocal positive feelings." (Ardito & Rabellino, 2011, p. 2). When considering whether to avail of psychological therapy several of the participants spoke about the value of empathy, feeling listened to and having someone advocate on their behalf. This is reflected in the subtheme; relationship makes all the difference. For others, the tasks and goals did not align,

and the therapeutic alliance was not established. This is evidenced in the subtheme, dashed hopes and broken trust.

Relationship makes all the difference.

Violet described a strong therapeutic alliance with her therapist, arising from feeling valued and understood. Violet had spent thirty years struggling with endometriosis before she received her diagnosis. This came quickly and required surgery; after which she experienced a serious medical complication and endured a significant amount of trauma. As a result, Violet's interactions with medical professionals had left her feeling dismissed and unsafe. Within the therapy Violet felt heard for the first time, and not only heard but believed. Her relief at this is palpable in this statement: "I thought Oh my God, someone is listening to me, someone is listening to me."

The trust between Violet and her therapist increased further when they evidenced that they took time to research her condition or advocate on her behalf. She recounted an experience where the therapist accompanied her to a medical review appointment and advocated for her.

"She asked, 'is it alright then if I come into your session and see', because I've always said that I struggle speaking with these doctors, because they don't listen to me all that much... she spoke on my behalf, 'no that's not what Violet is saying, I think this is what Violet is saying'..."

Having a therapist who advocated was also something that Mary valued. She felt her therapist identified her needs and ensured that she got the right support, for the right amount of time.

“And there was, I think the amount of, minimum you know, 8 weeks or 12 weeks, anyway, she kept me for as long as she could, so it ended up being 21 weeks or something... she's one of the best therapists I've ever had.”

For Jessica, finding a therapist who she felt at ease with, was something rare, which once found must be held on to. “I've seen a couple of other counsellors before, but I just felt a lot more comfortable talking to her...And then when I found out I was like, I'm not letting go.”

For Sarah, the trust was twofold, first in terms of accessing the right support and then within the relationship itself. It was important to Sarah that she find a therapist who understood her. As a Black woman she had at times felt disconnected from the endometriosis community, and it was important to find support that would be specific to her. This was a responsibility that Sarah took on, so that she could feel safe in the therapy. She reached out to trusted friends and asked their advice on where to look. Finding an organisation with Black, Asian and Minority Ethnic (BAME) therapists, meant that Sarah could speak about her whole experience, without the additional step of having to explain her perspective as a Black woman with endometriosis. She summarises this by saying, “And I think, it makes you, some things you just don't have to state.” Feeling seen and understood by her therapist contributed to an increased sense of trust in their relationship, which strengthened their therapeutic alliance.

“I think, she kind of saw that in me quite early on, which was quite surprising. You just want something, or sometimes people get you...But I look back on it and she was, she was great you know, we really got on. And it was a really important three months.”

Dashed hopes and broken trust.

For some of the participants there was no trust in the therapeutic relationship. Sarah spoke about having been referred for Cognitive Behavioural Therapy (CBT), where she did not feel comfortable with the therapist. "I didn't really warm to that woman and I didn't really get anything out of it, and I didn't finish the sessions." This statement contrasts with her previous remarks about the importance of those three months. Without a solid therapeutic alliance Sarah did not feel connection to the therapist or a commitment to the process.

Brooke spoke about her hopes for the therapeutic relationship and how, for many reasons, these were not met. Her therapy was disrupted, due to work constraints and then Covid-19. This is likely to have had some impact on the relationship, but it also appeared that Brooke did not feel secure with her therapist. She did not feel like her therapist had entered her world; they felt apart, and this impacted on the strength of their relationship.

"You know, showing a bit of empathy, put yourself in his or her shoes. In this kind of situation, what would I do if I were her? And that helps because it feels a bit more, closer; feels like the therapist is OK, is with me on this journey, because she puts herself in my situation."

For Mary, trust was broken when her therapist crossed boundaries. She accessed therapy at a time when she was vulnerable and still recovering from major surgery. Mary was met with a therapist who behaved inappropriately and prioritised her own needs in the interactions. She was forced to end the therapy and make a complaint to the organisation. This was in the context of having already felt very let down by the medical system; this presented even further disappointment.

"I think I maybe went to three sessions, but each one got weirder. And yeah, that last one I just was like. This woman really, really shouldn't be in a position where she can

be saying these things... I was just like, I'm really sorry, but I don't feel comfortable anymore and I'm gonna go home.”

Overall, when the women felt listened to and respected, they were more likely to feel secure in the relationship and value the therapy. When these factors were not in place, the women were less likely to feel the benefit of therapy.

Theme Two: Permission to speak.

Participants spoke about how therapy was able to facilitate a space, both physically and mentally, which gave permission for difficult conversations. Three participants spoke about a lost opportunity to address their struggles when this was not facilitated.

Space to facilitate discussion.

Four participants spoke about the value of therapy to process trauma, the diagnosis, and the impact of endometriosis.

In the past Mary was forced to cope with her health difficulties alone; as a result, she did not have the time to think about the impact of the endometriosis. Mary noted that having therapy in the hospital setting meant that she was given permission to speak about her endometriosis.

“And it was in that context, that I'd been referred. It meant that I just felt like I wanted to tell her what was going on with my endo... so I think that being, seeing her in that context meant that I wanted to speak a bit more about that, and actually thinking about it, I hadn't before, dedicated any therapy or counselling time really to any of my health issues.”

For Violet, therapy allowed her to think about the impacts of trauma; to process what had happened to her. This was something that she had been looking for in her interactions with the medics but had not found. "I have to come to terms with living with this. But the therapy, so important, and my experiences are so important."

Sarah also found that therapy gave permission for her to process trauma from medical interventions, the diagnosis, and the ongoing management. Sarah spoke about the struggle to cope with the change that comes with a diagnosis, while also maintaining regular life commitments.

"Have those discussions and have that space to do it for me. It's also that space, like I'm very busy, I'm doing a million things and it's that time when you say I'm doing this now and you can take time out."

For Jessica and Brooke, therapy provided an opportunity to talk about how they were really feeling, without fear of judgment. Brooke talked about holding emotions inside, and therapy allowing for these emotions to be let out. Jessica found therapy to be a safe space where no conversation was off limits, "Yeah she created a space where I felt, not judged, or you know, even say anything."

Lost opportunities.

While some participants valued the space in therapy, others also experienced that there was a lost opportunity for certain conversations. This occurred when the priorities of the participants differed from the therapist. Brooke spoke about feeling silenced when speaking about the consequences of endometriosis, namely painful sex. This was the symptom which indicated to her that something was wrong and remained the most difficult element of the

illness. Therapy for Brooke focused on taking control in her life and not on the psychological impact of this pain.

“They have never asked hey girl like how do you feel, when you feel low or all of this pain, you know...sex that causes me a lot of discomfort, and a lot of pain, and a lot of psychological damage.”

Mary experienced differing priorities when she accessed CBT. Within this therapy she was encouraged to make a goal to work towards; this was not the type of support she was hoping for. Mary wanted space to be able to speak about her struggles, but she did not get this. As a result, she was left feeling dismissed and frustrated.

Sarah acknowledged that she did not speak about her struggles with fertility in therapy. This was a reluctance that perhaps arose from both herself and the therapist. Here she expresses a hope that future therapists will recognise this reluctance in their patients and take the initiative to start these conversations.

“So, I think that's also a major factor that some people might not want to talk about. And I probably didn't for a long time myself; but I think maybe that's something that can be really, kind of, factored into the clinician's discussion.”

In summary, talking about their difficulties was recognised as important; the space created by the therapist gave permission for this. When this space was not available it was experienced as a lost opportunity.

Theme Three: Therapy can be empowering.

Three participants spoke about how they found therapy empowering. Psychological empowerment in health care settings has been described as “...feelings of power, control, and

self-esteem.”(Sak, Rothenfluh, & Schulz, 2017, p. 2) Prior to accepting support both Jessica and Violet had worries that their experiences were psychological. This worry subsided when they were provided with psychoeducation; this took the form of explaining how the body reacts physically to anxiety and pain. Understanding that there is a physical role in how we respond had a normalising effect for both women as outlined below.

Violet had been dismissed by medical professionals when she tried to highlight her ongoing physical pain; instead of addressing this, they recommended that she needed mental health support. In therapy she was able to explore and understand how the body and mind responds to pain; this helped her make sense of her reactions.

“And that is exactly what I needed with the psychology aspects of that. But it just all made sense to me then, it was all making sense to me...the interpretation of how the brain will always still remember that you were covered in endometriosis for years. So that you know you're not going crazy.”

Having this knowledge empowered Violet to become a more active participant in her health decisions “I would just be more confident with what I was saying when I went to see medical experts.”

Jessica also felt a relief in knowing that her response to anxiety and pain were not solely psychological; having the awareness that the brain plays a role had a normalising effect. “It's not just me going crazy, it's a process that is happening, it just happened in my brain and I think that really helps.” This meant that not only did they understand their body better, it reduced their self-criticism and allowed them to see that they were not alone, “But it's nice to know that you're obviously not the only person that feels like that.” The impact of the

psychoeducation was that the participants felt more in control and were able to take another perspective to their situation.

For Sarah, the psychoeducation increased a feeling of power and control as it allowed for independence by providing skills that she could use outside of therapy. This was an independence that was encouraged by her therapist also. Sarah's therapist helped her to reconnect to her strengths as a motivated, businesswoman and athlete; which had been overshadowed by the diagnosis and resulting trauma. Reconnecting with these increased her self-esteem and helped her feel empowered. "I felt that with her, she saw, probably some of the strengths that I forgot I had at that point."

For one of the participants, Brooke, the psychoeducation tools were experienced as disempowering. The tools were introduced to help gain perspective, but the work was interrupted. As a result, Brooke was left questioning if she was ready or able to make the necessary changes.

"She showed me this pyramid. So basically, I should be on top of the pyramid. I should be the leading lady really, in life and not, and not be on the reverse pyramid... OK, so I need to be on top of the pyramid, so I need to do more, you know? But the thing is, how can one, do the things that they should do in their lives. Make the decisions they should?"

In summary, understanding themselves better, having their feelings normalised, and having a new perspective, increased participants sense of power, control and self-esteem; resulting in the participants feeling empowered.

Theme Four: Managing endometriosis means managing mental health.

For three of the participants, their endometriosis and mental health were inextricably linked. Managing their endometriosis means managing their mental health also. This link was conceptualised in two ways; firstly, mental health difficulties are a part of the illness, and secondly, they can exacerbate endometriosis physical symptoms. This is represented in the subtheme, “Anxiety, it does affect my endometriosis a lot.” Five of the participants identified a need for ongoing psychological support. This stemmed from accepting that endometriosis is a chronic condition. This is evidenced in the subtheme; endometriosis is a chronic illness and support may be ongoing.

“Anxiety, it does affect my endometriosis a lot.”

Sarah describes the importance of understanding that mental health is part of the illness, and how this might aid with earlier diagnosis, “It is hormonal issues as well, so it could be, you know extreme lows, extreme highs that all need to be part of the diagnosis.” When describing this link between the physical and the psychological, Sarah used medical terminology to comprehend her psychological struggles, “Because you do kind of put them in the background when you have a flare up, but actually sometimes the psychological flare ups, we need to kind of take note of as well.”

Managing the psychological flare ups means managing anxiety and stress, as this exacerbates the physical symptoms of endometriosis. Jessica described getting stuck in a vicious cycle whereby stress causes a flare up of endometriosis pain, then the pain causes her to feel more stressed. She was able to reflect that because of therapy she can now intervene in this cycle and believes that as a result she is better able to manage her pain.

“Well actually, in way more pain now, but because in general I'm in a stronger place mentally, for the most part I have not taken any time off work and I can, I think I can deal with the pain.”

Endometriosis is a chronic illness and support may be ongoing.

For Violet, accepting a chronic condition meant a changing identity; a shift from fighting against endometriosis to recognising it is a disability. This allowed her to focus on finding balance in the long term.

“I'm not sure where, I have had it for so many years, because it is a disability of the highest level, and it may be more so because of all the other impacting things that happened after the operation.”

Due to endometriosis, Mary experienced a fraught relationship with her own body. She speaks of an ongoing psychological battle to maintain perspective in the face of a physical organ which is causing enormous pain.

“I have this, in my mind diseased, messed up spiky painful thing in me that I don't want... It's like 16 years, it's like they don't understand that the psychological stuff around, like literally, the relationship between me and my mind and this literal physical organ...it's really difficult to live with.”

Inherent in Mary's plea for HCPs to understand the complexity of this relationship, is the feeling that support has not been maintained throughout her journey.

For Jessica and Sarah, knowing that endometriosis is a chronic condition brought its own distress. Sarah viewed this as an ongoing 'battle' and Jessica noted that it felt overwhelming to think that there is no cure. Both women experienced periods of low mood

and lost hope in the past. Preventing these feelings was a strong motivator for them continuing to access psychological support. The support offered hope that they do not have to experience those moments. It also offered a way to exert some control over their situation. “You can go to some dark places with it still. And I have accepted that. I think that's why I still have that ongoing support, trying, you know, maintain my mechanisms.” (Sarah).

Brooke described a pervasive feeling of uncertainty arising from the chronic nature of endometriosis. She hoped that connecting with others who had similar experiences might help manage the uncertainty.

“I would have wanted the doctor to refer me to a group session like and be able to talk to other women. Being able to help each other emotionally. I think this helps the most. The therapist does help, but I suggested the lady as well that I would want to talk to other people.”

In summary, the women recognised endometriosis as a chronic condition that requires ongoing support, which may be in the form of therapy, peer support or via HCPs having a better understanding of their condition. Accepting this allowed them to ensure that they were managing their mental health too.

Discussion

This research aimed to understand the experience of accessing psychological support for women with endometriosis. The first theme centred around the concept of the therapeutic alliance. This term originated within the psychoanalytic discipline, where it was first identified that the strength of the therapeutic working alliance impacted on the success of therapy (Bordin, 1979). Factors which have been found to increase the strength of the therapeutic alliance, are the therapists' use of 'we' behaviours, where the therapist and

patient are on a 'therapeutic journey' together to reduce distress (Ackerman & Hilsenroth, 2003; Horvath & Luborsky, 1993, p. 567). Osborn and Smith (2008) found that participants with chronic pain felt less isolated and better able to manage their pain because of the therapeutic alliance. Some key skills which have been identified as improving physical therapists' patient relationships are active listening, empathy, and encouragement (O'Keeffe et al., 2016). These skills were also highlighted as valuable within this study. This is particularly relevant for women with endometriosis, as previous studies have found that they do not feel listened to within their healthcare encounters (Grogan et al., 2018; Grundström, Alehagen, Kjølhede, & Berterö, 2018; Moradi et al., 2014; São Bento & Moreira, 2017; Zale, Lambert, LaNoue, & Leader, 2020). Having a HCP who was supportive was experienced as new and refreshing.

Another quality highlighted by the participants in the present study was the role of advocate. This referred to the psychologist advocating within medical systems for the participants. The British Psychological Society (2007) and the American Psychological Association (2021) both state that it is the role of a psychologist working within a team to promote effective participation for patients; this can be done by helping raise their voice. One way to achieve this is to prepare women in advance of their physical health appointment (Parker, Davison, Tishelman, & Brundage, 2005). However, a review by D'Agostino et al. (2017) found that while patients who had training in preparation for their health appointments received more information, this did not correspond with improved psychosocial wellbeing. Further research into the benefit of providing training for patients would be beneficial.

Delivering training to staff around good communication is another way for psychologists to advocate for patients (Neo, 2011). Studies exploring the perspectives of HCPs working with endometriosis have found that they experience the condition, and the women they work with, as challenging (Bach, Risoer, Forman, & Seibaek, 2016; Grundström et al., 2016; Leow, Szubert, & Horne, 2018; Young, Fisher, & Kirkman, 2018). Facchin et al. (2018) calls for psychologists to work directly alongside gynaecologists to improve patient communication for women with endometriosis, and Nadal (2017) notes that the psychologist-activist can also incorporate learning opportunities into team meetings or reflective sessions.

Similar to not feeling heard, previous studies have shown that women with endometriosis regularly encounter HCPs who do not believe them (Bullo, 2018; Denny & Mann, 2008). In previous studies some women self-silenced for fear of being labelled a 'hypochondriac' or 'mad' (Grundström, Danell, Sköld, & Alehagen, 2020; Young, Fisher, & Kirkman, 2020). The findings in theme two of this study indicate that some of the women experienced therapy as a safe space, where they were given permission to speak about their difficulties. Chochinov et al. (2013) found that the creation of a safe therapeutic space relies on both the physical environment, and the skills of the therapist to be present while maintaining a pace that is in line with the patient. It is the role of the therapist to provide a therapeutic 'frame', whereby the patient can feel free to speak about stigma (Kearns, 2018). The findings in this paper indicate that for some participants certain stigmas were not inside their frames; this included communication taboos surrounding painful sex and infertility (Denny & Weckesser, 2019; Griffith, 2017). Previous research surrounding these communication taboos has focused on HCPs, including psychologists, working in cancer care. They found that HCPs report a lack of confidence, lack of training, lack of time and personal

discomfort as reasons for not discussing sex and infertility with patients (Logan, Perz, Ussher, Peate, & Anazodo, 2018; Ussher et al., 2013; Vermeer et al., 2015).

The findings in the third theme of this study indicate that psychoeducation surrounding the body's response to pain and anxiety was empowering. Psychoeducation can be any of the following: brief flyers, multiweek group interventions, or individualised support (Donker, Griffiths, Cuijpers, & Christensen, 2009). A review by Van Niekerk et al. (2019) found that psychoeducation may be beneficial for women with endometriosis, but highlighted a lack of research into the form this should take. This study demonstrated that psychoeducation in the 1:1 therapeutic relationship was normalising and empowering. Previous studies have found that psychoeducation reduced distress in patients with physical health diagnoses such as gynaecological cancer, breast cancer, heart disease and sexual dysfunction (Bashiri, Aghajani, & Alavi, 2016; Brotto et al., 2008; Chow et al., 2020; Horn, Kaneshiro, & Tsui, 2020; Lungulescu et al., 2018). Research has also shown that incorporating psychoeducation can reduce pain catastrophising in women with chronic pelvic pain and in general surgery (Horn et al., 2020; Katz, Fransson, & Patterson, 2021).

Stress and anxiety were identified as significant factors in the ongoing management of endometriosis. Research in animal studies has shown that stress can exacerbate endometriosis; with a recent review recommending targeting stress as a treatment option to reduce inflammation and pain (Appleyard, Flores, & Torres-Reverón, 2020). Given the chronic nature of endometriosis, the need for access to support at times of increased stress was identified by the participants. The Improving Access to Psychological Therapies (IAPT) service within the NHS also recognised this need and have developed a framework for working with individuals with long term health conditions (Roth & Pilling, 2015).

Clinical Implications

The clinical implications of these findings suggest that women with endometriosis may benefit from having a dedicated therapeutic space to consider the impacts of their endometriosis. The women in this study valued ongoing support, recognising that there would be times in their life where they would need to re-access services. Given the chronic nature of endometriosis, the role for psychological support is likely to extend beyond adjustment to diagnosis.

Therapists working in healthcare settings should consider the context in which women present for support, namely having felt dismissed by the medical system and experiencing stigma (Markovic, Manderson, & Warren, 2008; São Bento & Moreira, 2017; Seear, 2009b). In particular within services where women have been referred for psychological support by their gynaecologist, this usually occurs at the end of a long road to diagnosis. Therefore, extra consideration should be given to the setting of the therapeutic frame and establishing a strong therapeutic alliance (Kearns, 2018).

This study also highlights a need for additional training for all HCPs, including therapists, to increase confidence in overcoming communication taboos surrounding sex and infertility.

Limitations and Future Research

One potential limitation of this study is in relation to the sample. The aim of an IPA study is to achieve a homogenous sample, which is a well-defined group of individuals for whom the topic is relevant (Smith & Shinebourne, 2012). This study focused on the experiences of women accessing psychological care for support with their endometriosis. By

adhering to this homogeneity, this study was able to explore psychological support, where endometriosis was the key feature of the work. While the included participants were able to achieve homogeneity, it excluded women who had accessed psychological care but not specifically for endometriosis support, as well as those who were never offered psychological support but would have accessed if possible. Given that 81% of women surveyed by the APPG noted that endometriosis impacted their mental health, and 90% would have liked referral for psychology but were not offered this, these criteria may have excluded women (Amess et al., 2020). Future research should explore the experiences of women with endometriosis who access psychological support for multiple needs. Combined with the results of this study, it may highlight what the target of psychological interventions should be.

Another limitation of this research is in relation to psychological care. For the purpose of this study, care could be delivered by numerous professionals and was not restricted by therapeutic modality. This resulted in the participants having accessed a range of therapies, each with its own orientation. While the themes that were identified could be described as pan-theoretical, future research exploring the features and efficacy of specific interventions would be beneficial (Horvath & Luborsky, 1993; Morris, Fitzpatrick, & Renaud, 2016).

Differences have been reported in terms of race and a diagnosis of endometriosis. A recent review indicating that Black women are less likely to receive a diagnosis of endometriosis, compared with white women; Asian women were more likely to receive a diagnosis compared with both (Bougie, Yap, Sikora, Flaxman, & Singh, 2019). Due to a lack of racial and ethnic specific research, the review was unable to assert the reasons for this discrepancy. This could be understood in the context of a historical attitude which believed endometriosis to be a condition that only white women experienced (Farland & Horne, 2019;

Jacoby, Fujimoto, Giudice, Kuppermann, & Washington, 2010). For one of the participants in this study, finding BAME support was beneficial. Future research is needed to ensure that the experiences of all women with endometriosis are respected, and their needs met.

Conclusions

This research identified four themes relevant to the experience of accessing psychological care for women with endometriosis. Findings have highlighted the importance of using the key skills of empathy, listening, encouragement and advocacy to establish a strong therapeutic alliance. Providing a therapeutic frame allowed participants the space to speak about trauma; when this was not in place, the women could not speak about stigma. When psychoeducation was delivered at the right time it was experienced as empowering. This research also demonstrates the chronic nature of endometriosis and the value in having access to ongoing support to manage this condition.

Acknowledgments

The author would sincerely like to thank all the women who took part in this study.

Notes

The term 'patient' is used in this paper; this is for consistency and clarity purposes only. The author recognises that in psychological therapies this term is not always preferred. The author has also used 'woman' to describe patients with endometriosis; the author recognises that not all individuals with endometriosis identify as women.

Funding Declarations

None

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Table 1- Participant Demographics

PARTICIPANT	PSEUDONYM	AGE	DIAGNOSIS	PSYCHOLOGICAL PROFESSIONAL ACCESSED	REFERRED
1	Sarah	48	39	Clinical Psychologist	self
2	Violet	49	42	Clinical Psychologist (individual & group)/ Counselling	via gynaecologist/ work
3	Mary	28	16	Psychodynamic Psychotherapy/ Clinical Psychologist/Counsellor	via gynaecologist
4	Brooke	34	31	Clinical Psychologist	via gynaecologist
5	Jessica	30	28	Counsellor	self

Table 2- Table of Themes

Super ordinate Themes	Participants contributing	Sub themes	Participants Contributing to sub theme	<i>Additional Example Quotes</i>
Therapeutic alliance	5/5	Relationship makes all the difference.	Sarah, Violet, Jessica, Mary	<ul style="list-style-type: none"> • <i>“I don't want to recreate the wheel, start Googling all these- its just overwhelming for someone who doesn't know. So that was actually also a referral” (Sarah)</i> • <i>“I think it was quite, um, for me to be I'm at the BME aspect was always there. I was usually only black person that would have attended.” (Sarah)</i> • <i>“You know if you feel like sometimes you don't even you don't know who you should trust, your sort of doctor to do because I've had, I've seen three consultants and have different advice from every single one” (Jessica)</i> • <i>“Said I'm telling you now you can go back to your GP and this is what you're going to do. You can go back and say you are still in pain and you are insisting that you get back to your gynaecologist” (Violet)</i> • <i>“And that was the only way I get in, through, by speaking about the counsellor saying this is his belief, that he believed me, that I actually got through them to the next stage.” (Violet)</i>
		Dashed hopes and broken trust.	Sarah, Mary, Brooke	<ul style="list-style-type: none"> • <i>It felt like I have to please the person I'm having therapy with (Brooke)</i>
Permission to speak	5/5	Space to facilitate discussion.	Sarah, Violet, Mary, Jessica	<ul style="list-style-type: none"> • <i>“When I was and so I think that that therapy with X at the hospital came at the perfect time, really because...and then when we got those like. Oh yeah, it's actually. Yeah, this this is I should probably deal with this.” (Mary)</i>

			<ul style="list-style-type: none"> • <i>“So, I did end up talking more about my endometriosis and stuff with X the hospital one. But she never restricted me to that.” (Mary)</i> • <i>“Can we just talk about my experience? And this is what I'm feeling. And if you listen, let me speak.” (Violet)</i> • <i>“And I think we go through a lot of that denial of what you are going through.” (Violet)</i> • <i>“I felt it's what I needed then, to kind of get out of a really difficult time...It's always those questions of why, how, what, how you know, how did you know how did it get to this and we know it could have been things I could have done to prevent.” (Sarah)</i> • <i>“So, it was all really managing pain, managing the trauma, managing the effects of the relationship ending, so there was a lot in that 3 months.” (Sarah)</i> • <i>“It was like it was away for me to speak someone and feel that even if I could just talk, unload and have someone to talk to impartially.” (Jessica)</i> • <i>that Lady and I had, you know, I had her to let out, to talk...you'll let out some emotions that maybe you want to let out.” (Brooke)</i>
	Lost opportunities	Brooke, Sarah, Mary	<ul style="list-style-type: none"> • <i>“I think it's really, really, really damaging and it can be just seen as a kind of by product, but it's really affects people and then even post, as you say, post when you made that decision or you know physical it's been made for you and you've got to deal with it and then but still having to deal with the endometriosis.” (Sarah)</i> • <i>“Let's go ice skating. She's like great, but I was like I've just got [physical health limitations], I'm not going ice skating like that's not.” (Mary)</i>
Therapy can be empowering	4/5	Sarah, Violet, Brooke, Jessica	<ul style="list-style-type: none"> • <i>“I would just be more confident with what I was saying when I went to see medical experts.” (Violet).</i>

				<ul style="list-style-type: none"> • <i>“So, it's my madness again. I must have been really mad. So basically, I'm mad. I just going around I'm mad, and everything I'm seeing is not really happening because no one is listening.”</i> • <i>And I remember a thing she said, she said, ‘oh you'll remember things we've said in the future and you'll kind of use them’ and I did. I really did. And I still kind of remember things she said. (Sarah)</i> • <i>And so I think that helps with that really not know it happened like so how are you going to manage it from here in, you know with the effects of it in a way. (Sarah)</i> • <i>“I'm going to the group. And listening to help other women battle in society with this illness.” (Violet)</i> • <i>“The hormonal issues, and then the interpretation of how the brain will always still remember that you were covered in endometriosis for years. So that you know you're not going crazy so you're at home going.” (Violet)</i> • <i>“But I think I'm definitely more aware of, my sort of way of thinking, I guess in an it helps keep me in check” (Jessica)</i>
<p>Managing endometriosis means managing mental health</p>	<p>5/5</p>	<p>“Anxiety, it does affect my endometriosis a lot.”</p>	<p>Sarah, Violet, Jessica</p>	<ul style="list-style-type: none"> • <i>“But yeah, so I've actually, so when I was in X I had another life change, and with anxiety it does affect my endometriosis a lot, I know that and I kind of manage it.” (Sarah)</i> • <i>“When you're in pain as well, then you stress about the pain so you get in this cycle.” (Jessica)</i> • <i>“You know there is. It's not completely hopeless. There are things that I can do, just need sometimes snap myself back into that headspace.” (Jessica).</i> • <i>“Pain, but my understanding is pain will always be recorded in my brain. So it is about adjusting my life always knowing that this could happen and stress does really affect me” (Violet)</i>

Endometriosis is a chronic illness and support may be ongoing.

Sarah, Violet,
Mary, Brooke,
Jessica

- *“I think that's part of the distress of it is knowing that like it'll never, there's no cure so this is something that you've got to learn to live with, and that that's a lot sometimes.” (Jessica)*
 - *“I'm not sure where it would have had it for so many years, because it is a disability of the highest level and it may be more so because of all the other impacting things that happened after the operation...they thought sometimes depending on where I was because it's always on the mental health and physical health at the same time trying to be congruent and it was always one was. Out of kilter compared to the other” (Violet)*
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Section 2 Appendices

- 2-A Pen Portraits**
- 2-B Excerpt coding for Violet evidencing initial notes and emergent themes**
- 2-C A Narrative Summary of a clustered notations- extract from Violet**
- 2-D Participant level superordinate themes mapped onto final themes**
- 2-E Reflective diary excerpt**

Appendix 2-A: Pen Portraits

Sarah

Sarah is a 48-year-old Black woman; she is a businesswoman and an athlete. Sarah was diagnosed with endometriosis at the age of 39 under emergency circumstances. Receiving the diagnosis under these circumstances and the resulting serious health complications had a profound impact on her; Sarah accessed psychological support to help adjust to the diagnosis and the end of her relationship. At that time, she accessed 3 months of therapy with a clinical psychologist through a third sector organisation supported by the NHS. Several years later, after a difficult flare up in her condition, Sarah accessed cognitive behavioural therapy (CBT) but did not find this helpful. Sarah has a supportive partner and one year ago, she sourced support privately with a clinical psychologist and this is ongoing.

Violet

Violet is a 49-year-old white woman; she is married with children. She received her diagnosis at age 42, after many years of painful periods. Once she was diagnosed, Violet had surgical intervention within a short period of time. She suffered serious complications arising from surgery and persistent pain. Violet's endometriosis made it very difficult at times for her to work in the same roles she had done previously. It was a difficult transition for her to accept that she may not be able to work full time in the future. She initially accessed psychological support from a counsellor via her workplace, and later from a clinical psychologist within the NHS. Through the NHS, Violet was also able to attend a psychology group programme for managing pain.

Mary

Mary is a 28-year-old white woman who received a diagnosis of endometriosis at the age of 16. While she notes that she was young receiving this diagnosis in comparison to others, this was still after several years of experiencing painful periods. Mary has experienced multiple surgical

investigations; she accessed therapeutic support at several points, to help manage the resulting trauma and ongoing pain. Mary's endometriosis and related health difficulties have greatly disrupted her education, career, and relationships. She has accessed support from a counsellor via her university and CBT from a clinical psychologist; neither of these therapies were beneficial. Mary then accessed support with a psychodynamic psychotherapist within the NHS, and this therapy was beneficial.

Brooke

Brooke is 34-year-old white woman who received her diagnosis at the age of 31, after several years of difficulties with painful periods and experiencing painful sex. These symptoms placed a great deal of strain on Brooke and her relationships. Brooke's endometriosis has meant that she has had to choose employment that allows flexibility, rather than pursuing a career as she had hoped. Brooke was automatically referred for psychological support with a clinical psychologist as part of the diagnosis process. She identified that this was welcome news. Brooke was unable to finish all the sessions with her therapist, due to work commitments. When she re-accessed to commence the work again, COVID-19 prevented this; she hopes to restart the sessions as soon as the pandemic allows.

Jessica

Jessica is a 30-year-old woman who received her diagnosis at 28. She received the diagnosis because of investigations for other conditions. Jessica had been experiencing many symptoms of endometriosis from a young age, but the connections were not made. Jessica noted she is fortunate to have a supportive family, partner, and employer, and this helps her manage when the endometriosis symptoms are difficult. She accessed therapy to help support with the uncertainty of endometriosis, and gain perspective on her situation. She accessed support from a private counsellor, which is still ongoing. She values the flexibility and notes that she accesses support in advance of upcoming difficulties.

Appendix 2-B : Excerpt coding for Violet evidencing initial notes and emergent themes

Emergent Themes	Original transcript	Exploratory Comments
<p>Therapist provided vital information.</p> <p>Therapy to understand own responses.</p> <p>Therapy to process what's happened.</p> <p>Relationship with therapist- valued insight and encouraged to share story.</p> <p>Therapy as a space to talk about feelings.</p> <p>Therapy helped to make sense</p> <p>Power dynamics- information/ knowledge withheld</p>	<p>P: Yeah, yeah, so she was from, obviously in X there's a few hospitals at all linked up in the same trust so she would come over, she's actually a specialist at Pain Clinic in the heart. Her thing without heart transplants, but because she was psychologist refer to different pain collects. She took me up from the Pelvic pain clinic. <i>She was amazing straight away.</i> Told explained absolutely everything what was going on, and that's what I needed to hear. None of them ever spoke about how you, how your brain process is pain, how it holds on to pain and I have to like come to terms with living with this. <i>But the therapy, so important, and my experiences are so important.</i> So it was like the cognitive behaviour therapy I did with her, and obviously she did diagnose me straight away. So 20 minutes apart from post traumatic stress and but it was the way she spoke to me; because obviously led by me, but obviously she was in it and I did 8 sessions with her and then she turned round and said, right I have a suggestion and I don't know whether not you want to participate, which says I would love you to participate, she said. I'm going to be running group sessions and the focus is compassionate therapy and she says it will be with other people who have chronic pain. And but she said, I'll be very truthful with you now you are the first person who's had endometriosis that we would ever have come to this group. So she says I would love you to come to educate people or the people who suffer this out. Or she said, how would you find talking about all of this scenario situation? You don't have to, you can just come to the group and you learn an. I said I'd be up for that, and that was amazing as well, because it was about. So the how you look after yourself and the understanding of what goes on in your body when you have chronic pain. That it was bizarre none of the doctors would ever really go into that detail. It was always medication. And then where is that was what I was always requesting from day one. Can we just talk about my experience? And this is what I'm feeling. <i>And if you listen, let me speak.</i> Then you know then what is the outcome? And that is exactly what I needed with the psychology aspects of that. But it just all made sense to me then, it was all making sense to me. And I was like. Why have I been denied this? I've been to, you know. Seeing these experts' gynaecologist, but they're not the experts to explain what happens afterwards and how your body copes, and manages with pain after such a a massive operation.</p>	<p><i>She explained everything.</i></p> <p>Psychoeducation made a difference. Understood her own responses.</p> <p><u>Your experiences matter.</u></p> <p><u>Come to terms with living with this.</u></p> <p>Recognised the PTSD.</p> <p><u>Valued her insight/ participation in group.</u></p> <p>Share your experience- educate others. <u>Role/ meaning</u></p> <p>Come and learn. <i>Amazing group support.</i> Knowing more about body and pain felt empowering.</p> <p>Trust- why not told before now.</p> <p>Therapist listened to experiences/ feelings.</p> <p>Angry why denied this.</p>

	<p>I: So it sounds like she was helpful in that she gave that there was that space and it was led by you and you were able to have those conversations about how you felt. But also there was an element of it where she explained actually this is what's going on for you that helped you make sense of what was what had been happening.</p> <p>P: Then yeah, because that's obviously my learning style. I just don't want somebody to tell me. because I think it all comes back, obviously she said I question everything because for 30 years I kept questioning and I'm being silenced where she just gave me loads of information. And said, is this how you like information or like clarity and putting A to B? I like factual information as well. So basically my understanding through all my experiences is that because, um she actually fought, she was amazing.</p>	<p>Therapy fitted with learning style- <u>wanted to be involved in the conversations.</u></p> <p>Practical information but also pulling it all together.</p>
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Appendix 2-C: Narrative Summary of a clustered notations- extract from Violet

Information is power			
<ul style="list-style-type: none"> Power dynamics- information or knowledge is withheld 	25/8	And I was like. Why have I been denied this?	<p>Violet had access to psychoeducation regarding pain and how the body responds to pain. This information was freeing, it allowed her to feel that she wasn't 'going mad' and that the pain was an understandable reaction to 30 years of endometriosis. Prior to this she had experienced dismissal from the medics that her ongoing pain wasn't real and that it was psychological. It appears that having a scientific, and in part, biological explanation to understand the pain liberated Violet from this worry that there was something psychological 'wrong'. This removed an element of blame, her body was 'holding onto' the pain, this wasn't a choice for her.</p> <p>While this information was freeing it was also a source of frustration, as she felt that she had been denied this knowledge and suffered for many years without knowing the reasons why. There was anger that this wasn't known earlier. For Violet felt that withholding this information meant that the medical system didn't respect her or other women with endo. Withholding meant that they didn't think she was intelligent. The therapist however recognised the need for knowledge and delivered it in a way that felt respectful and empowering. The therapist also valued Violet's experiences and showed this by encouraging her to take part in the psychology group. This provided a role for Violet, where she could have her experience normalised but also where she could offer support to others.</p>
<ul style="list-style-type: none"> Respect women by sharing power/ knowledge 	44/1	While I was there is an incredible conversation and it's like giving respect for women that they're intelligent enough to understand these things	
<ul style="list-style-type: none"> Therapist provided vital information 	24/5	She was amazing straight away. Told explained absolutely everything what was going on, and that's what I needed to hear.	
<ul style="list-style-type: none"> Therapy helped to make sense 	25/6	And that is exactly what I needed with the psychology aspects of that. But it just all made sense to me then, it was all making sense to me.	
<ul style="list-style-type: none"> Therapy to understand own responses 	24/6	None of them ever spoke about how you, how your brain process is pain, how it holds on to pain	
<ul style="list-style-type: none"> Psychology group has normalising effect 	39/2	I'm going to the group. And listening to help other women battle in society with this illness.	
<ul style="list-style-type: none"> Psychoeducation normalised post op struggles 	43/18	The hormonal issues, and then the interpretation of how the brain will always still remember that you were covered in endometriosis for years. So that you know you're not going crazy so you're at home going	
<ul style="list-style-type: none"> Intimidated in medical meeting 	14/19	And I built myself up and went in and then it wasn't him	
<ul style="list-style-type: none"> Knowledge = confidence to self-advocate 	45/5	So and and I would just be more confident with what I was saying when I went to see medical experts	
<ul style="list-style-type: none"> Therapy increased confidence 	19/1	So the GP says right then she said yeah I will send you back to the gynaecologist and when I did go to the gynaecologist I said I'm not leaving here now until we discuss whether I've still got an endometriosis	
<ul style="list-style-type: none"> Therapy met need 	25/20	Then yeah, because that's obviously my learning style. I just don't want somebody to tell me. because I think it all comes back, obviously she said I questioned everything because for 30 years I kept questioning	
<ul style="list-style-type: none"> Therapy as an ongoing need 	28/14	They will always remember those bad days because it gets restored in there, but obviously every day I try and	

		<p>change the pathways with all the strategies but pain is in there and that's how your body does interpret it.</p>	<p>Through therapy Violet developed a better understanding of her responses to pain, and how to manage this on an ongoing basis. She began to view this as a chronic condition. Initially accepting this was very difficult for Violet, as this was contrary to her identity, but the more information she received (strategies to manage) the more she was able to have self-care by recognising her limits.</p> <p>Having this information and understanding how their body works also meant that Violet felt more confident when dealing with doctors. In the past she found these encounters to be intimidating, and invalidating. After she learned more about their response, and feeling believed, she was able to better self-advocate.</p>
--	--	---	---

Appendix 2-D: Participant level superordinate themes as associated with final themes

	Theme One: Therapeutic Alliance	Theme Two: Permission to Speak	Theme Three: Therapy can be empowering	Theme Four: Managing endo means managing mental health
Sarah	<i>Tailored Support</i>	<i>The space for difficult conversations</i>	<i>Therapy enables strength and coping</i>	<i>Endo is ongoing, so therapy is ongoing</i>
Violet	<i>Therapist as advocate</i>	<i>Therapy to process</i>	<i>Information is power</i>	<i>Changing identity- disabled not a negative anymore</i>
Mary	<i>Broken Trust</i>	<i>Differing Priorities & Right time and place for therapy</i>		<i>Endometriosis makes you vulnerable</i>
Brooke	<i>Expectations of therapy</i>	<i>Silenced – no one wants to talk about sex</i>	<i>Therapy equals change</i>	<i>Seeking connection to help with uncertainty</i>
Jessica	<i>Support must come from a trusted source</i>	<i>Support must come from a trusted source</i>	<i>Therapy helps with perspective</i>	<i>Therapy can be preventative & Uncertainty is hard to tolerate</i>

Appendix 2-E: Reflective Diary Excerpt

Reflective diary excerpt, this was recorded after all interviews were conducted and transcribed.

Having completed the transcription of all the interviews, I have been overwhelmed by a sense of anger. I cannot help but feel it is unfair that women must suffer for so long before getting the appropriate medical support. Not least to say, in several cases where the women had to research and access their own psychological support. I can't help but wonder why this is? The psychosocial implications are really apparent, and well-articulated by the women themselves. This is making me question why the medical professionals don't consider a referral for psychological support?

My initial thoughts are that all the interviews were punctuated with a sense of mistrust or doubt in systems. This was something I had read in the literature, but I was surprised at how powerful this was when hearing it applied to the individual circumstances. I'm finding myself quite in awe of what the women have been through, and how they have coped. This is really making me consider further the role of psychology in this context, as there are larger systemic and societal narratives impacting on the type of care and how it is accessed.

It feels important at this point that I consider my reaction to the material before starting the analysis to ensure that my approach is measured. I want to ensure that I am not bringing this sense of mistrust, to the participants. In my clinical work when I feel this way, I find it helpful to pause and try take a wider view, to understand some of the larger influences at play, and to increase compassion. What might be some of the barriers for medics in responding to the pain? Is it stigma? Time constraints? It's likely they are also aware of how the system is letting patients down, what must it be like to work in this way? Do they feel powerless at not being able to cure endometriosis?

I'm noticing that my focus at this point is thinking about how psychology can also support medics understanding. This because I want to help the women; I'm perhaps also feeling a sense of powerlessness. I think I'm maybe also jumping ahead here, considering the extended role of psychology

is not the primary aim of this paper. This is making me aware of my world view, in that I can readily see the role for psychology here, others may not. Which raises the question what am I not seeing because psychology is my lens?

Appendix 2- F: Journal Submission Guidelines

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Section 3 - Critical Appraisal

Reflections on conducting research exploring the experiences of women with endometriosis.

Samantha Harpur

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count: 3,979

(Excluding references, tables, figures and appendices)

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This critical appraisal summarises the empirical paper presented in section two of the thesis; it will also offer a reflective account of my research journey. This paper will discuss the following: a review of the main findings, reflexivity and my interest in the topic, the impact of Covid-19 and finally recommendations for future research. In this paper I will explore the challenges encountered conducting health research during a global pandemic and outline the decision-making process in this regard.

Summary of Research Paper

The empirical paper explored the experiences of psychological care for women with endometriosis. Five women with endometriosis were recruited; interviews were transcribed and analysed using interpretative phenomenological analysis. Four superordinate themes were identified: (1) Therapeutic alliance; (2) Permission to speak; (3) Therapy can be empowering; (4) Managing endometriosis means managing mental health. Women experienced psychological support as beneficial when there was a strong therapeutic alliance. This was facilitated by the therapist's ability to provide an adequate therapeutic frame; allowing the women to explore the full consequences of their endometriosis, now and in the future. When the therapeutic alliance was not adequate, the women felt unable to speak about stigma. Future research should consider the efficacy of specific psychological interventions, as well as individualised, culturally specific support.

Why I chose this topic.

Reflecting on one's motivations for conducting research is recommended in order to increase reflexivity; Mortari (2015) describes this as "...a practice that a researcher should carry out to make the politics of research transparent." (p. 2). To that end, what follows is a reflection of my decision to explore this topic. I decided early in my DClinPsy journey that I would like to do research on women's health. My previous studies highlighted that there are elements of women's health which are not regularly discussed. When considering my thesis topic, I had a conversation with a friend who had recently received their diagnosis of endometriosis. I was aware of the condition as there are several

members of my extended family who also have endometriosis. What I was not aware of was the long journey to diagnosis. Nor did I have an insight into the difficult relationships with healthcare professionals.

My initial scoping highlighted the full extent of the delay in diagnosis. When I explored the topic further there appeared to be a clear call for multidisciplinary working, although research in this area appeared to be lacking (Amess, Doyle-Price, Hardy, Bardell, & Furniss, 2020; Endometriosis Task Group, 2018; Facchin, Saita, Barbara, Dridi, & Vercellini, 2018). From my personal experiences of endometriosis with my friends and family, I had a level of insight into the psychosocial impact on women's lives. Based on my reading it did not appear that psychological support was routinely offered. Several studies explored psychological interventions and their effectiveness for supporting women with endometriosis (Evans, Fernandez, Olive, Payne, & Mikocka-Walus, 2019). These studies were outcome based and this made me wonder what elements of the therapeutic input had been beneficial. I was more interested in understanding what the experience was like for women to be supported with their endometriosis. I did not find research that explored the women's perspectives on their therapy. Endometriosis has been linked (for good and bad) with mental health, and I wanted to understand women's experiences of thinking about their physical health and if this had changed through the process of therapy.

Reflexivity

Acknowledging that I had a personal connection to the material of this thesis required that I pay close attention to my own pre-understandings and potential biases. Interpretative phenomenological analysis (IPA) requires researchers to engage in "bracketing" these pre-understandings in order to privilege the participants' experiences (Biggerstaff & Thompson, 2008; Chan, Fung, & Chien, 2013; Hopkins, Regehr, & Pratt, 2017). Shaw (2010) argues for embedding reflexivity into psychological research and defines it as "...an explicit evaluation of the self." (p. 234). While it is important to acknowledge that prior experience or understanding of the phenomenon may present as a barrier to

the work, it can also be a valuable resource. Finlay (2008) describes how the researcher must strike a balance "...between bracketing pre-understandings and exploiting them as a source of insight." (p. 3). For me, these pre-understandings centred around a lack of priority for women's health and difficulties in access to healthcare or psychological support. Outlined below is the development of my understanding in these factors, as well as the methods used to achieve sufficient bracketing.

Maintaining a research diary throughout the process helped to separate out those experiences, thoughts or feelings that were 'mine', as opposed to those originating with the participants. This diary illuminated the wider context in which this project took place. Conducting this research during a worldwide pandemic, and the tragic death of George Floyd, brought my attention to conversations about positionality that I had not fully considered before. Both personally and professionally, I found myself paying more attention to my privilege and position. See Appendix 3-A for an excerpt of my research diary.

Recognising this potential 'blind spot' helped me to consider further the role of race for my participants and prompted me to consider what frameworks I could avail of to help monitor this bias. While it is not possible to be fully removed from our own position and bias, taking note of it means we can understand our influence in the work (Finlay, 2008). Throughout conversations with colleagues, and the use of a research diary, I utilised the social GRRRAACCEESSS (SG) to examine my social position (Burnham, 2012). This mnemonic stands for Gender, Geography, Race, Religion, Age, Ability, Appearance, Accent, Class, Culture, Ethnicity, Employment, Education, Sexuality, Sexual Orientation, And Spirituality (Burnham & Nolte, 2019, p. 121). The purpose of exploring this is to give voice to those elements of ourselves that bring us together or set us apart. The SG which influenced me personally in this project were, I am a white, cisgender woman (race, gender) from an Irish working-class background (class, ethnicity, geography), who has had access to third level education (education) and has worked and lived in Ireland, UK and Canada (geography, employment). I have worked alongside women who have been survivors of mother and baby homes (Ireland) and

residential schools (Canada). I have also worked with families experiencing homelessness. Through these experiences I have witnessed women struggle to have access to appropriate information and healthcare. As a result, I take a strong position on advocacy for women's health and safety. Understanding the experiences that have shaped me and my work was vital in order for me to be able to "bracket" my pre-understandings of endometriosis and women's healthcare (Starks & Brown Trinidad, 2007).

I began using the diary at the beginning of the project and maintained it until writing up the project. At each stage of the process, I engaged in reflexivity. Chan et al. (2013) outlines strategies for conducting bracketing in research; they note that this begins with considering the topic through to data analysis. I experienced the greatest challenge to bracketing between having finished the interviews but before starting analysis. At this stage of the project, I had spent approximately seven hours with the women, hearing their stories. I had read about the invalidating experiences they encountered within healthcare systems, but I was not prepared for how this made me feel. I was angry on their behalf, and I struggled to have empathy for the professionals they encountered. This arose from my belief (and research) that women's pain is invalidated regularly (Nicola, Correia, Ditchburn, & Drummond, 2021). At the same time, I encountered a study titled: '*Attractiveness of women with rectovaginal endometriosis: a case-control study*' (Vercellini et al., 2012) which added to the sense of invalidation. My diary served as a productive space for me to explore some of the thoughts that had come from the women's stories and from the research above. The mere act of writing them out on paper made me consider the time and place for the analysis. I recognised that it would be difficult for me to bracket my frustration and anger, and as a result I took time to step away from the work before moving onto the next phase. When I returned to the material, I felt more able to enter the world of each participant at a time; and I was better able to bracket my views. See Appendix 2-E for excerpt from diary exploring this challenge.

Remote Interviewing

Another challenge that I experienced while conducting the research project was in relation to conducting the interviews remotely; this was required due to covid 19 restrictions at the time of recruitment. The options for conducting the interviews included telephone, or video conferencing. The participants were offered the choice so that I could ensure they felt as comfortable as possible. Four participants chose video conferencing and one chose the telephone. Saberi (2020) notes that during covid video conferencing can closely replicate the in-person interview. Farooq and De Villiers (2017) found that it is important for the researcher to feel confident in using the telephone for research interviews. Due to covid-19 all my clinical work had also moved to remote methods, therefore, by the time I conducted my first research interview I had gained experience of using technology.

The research interview, however, is different from clinical interactions, so while I was comfortable with the technology, I noted some different dynamics in terms of trying to build rapport. This started from sending the first email with the details of the study. I aimed to have an approachable and conversational tone to all my communications with participants. McGrath, Palmgren, and Liljedahl (2019) suggest that rapport building begins from this early stage and that adequately preparing participants for the interview can assist with building rapport more quickly.

I planned my time to ensure that there was space for 'informal' discussions at the beginning of each interview to help put the participants at ease. It also allowed time for any questions or concerns to be addressed before starting. Wherton, Shaw, Papoutsis, Seuren, and Greenhalgh (2020) refer to this as 'social talk', in face-to-face meetings this usually occurs when the participant enters the building, or during the walk to the interview room.

For the video calls I ensured I was in a room where I wouldn't be disturbed, where there was good lighting so I could be seen clearly on camera. This is recommended as Archibald, Ambagtsheer, Casey, and Lawless (2019) found that participants who had been interviewed via Zoom valued being able to see the researcher clearly and read their non-verbal cues; they noted this helped with maintaining

rapport. I found that this was helpful for me to be able to communicate nonverbally that I was listening and that I appreciated the seriousness of the content of our conversations. Considering the themes that emerged from the SLR, being dismissed and not being heard, it felt additionally important for the participants to know that I was listening.

For the interview that was conducted on the telephone, maintaining rapport was slightly different. Advice for qualitative researchers generally is to 'talk less and listen more' (McGrath et al., 2019); but in the instance of using the telephone there is a lack of visual cues and silence may be interpreted as disapproval or absence. Throughout my clinical work on the telephone, I became aware of the negative impact this could have on rapport. There is a need to communicate presence in order for allowing the participant/ client to know that I am listening and interested (Farooq & De Villiers, 2017). Irvine, Drew, and Sainsbury (2013) highlight the important of using 'acknowledgement tokens' such as '*yeah*', '*uh*', '*okay*' to communicate presence. I noted that I used these more frequently in the telephone interview than I did in the video interviews.

When reflecting on their PhD research Deakin and Wakefield (2014) found that personality of the participants made a difference in terms of building rapport. They noted that individuals who were more comfortable with video conferencing developed rapport quicker. Given in my study that participants had the choice of video or telephone, it would be reasonable to assume they chose the video platform as this was more comfortable for them. Therefore, rapport was established.

One limitation to using video conferencing or telephone to conduct the interview, is that it could have excluded participants who preferred to have face-to-face contact. One individual expressed an interest in taking part in the research project and stated a preference for face-to-face meetings; due to the restrictions in my region in United Kingdom at that time, this could not be facilitated. I explained this to the participant via email; stressing that it was as much for their safety as mine. I offered a phone call to discuss further but they agreed to a video conferencing call. Unfortunately, they did not attend, and they did not make contact despite several emails from myself after the fact. While there are many

reasons why an individual may change their mind about participating in research, I was left with the sense of a missed opportunity. Disappointment arising from the missed online interviews was also observed by Deakin and Wakefield (2014); they noted that in their studies that face-to-face interviews were more likely to go ahead than Skype interviews.

Impact of Covid-19

Covid-19 did not just impact on the recruitment methods, it may also have contributed to the wellbeing of the participants. The practical impacts of covid-19 was discussed in both the 'social talk' when starting the interview and throughout. Some of the participants spoke about the benefits of working from home and how this flexibility helped them manage their condition. Several studies and advocates have noted the positives that can come from women with endometriosis being able to work from home namely being able to manage their symptoms, and in effect they are more productive (Endometriosis Foundation of America, 2021; Evans, Dowding, Druitt, & Mikocka-Walus, 2021; Krsmanovic & Dean, 2021; Leonardi et al., 2020).

Participants also mentioned concerns about how the National Health Service (NHS) was coping; specifically referencing headlines stating that the NHS was over capacity. This increased concerns that their physical health needs might not be met if they had a flare up. For others, the concerns were related to previously scheduled appointments and whether these would be going ahead. These appointments were essential to answering on going questions about their fertility, the need for further surgery and for second opinions. This was also noted by participants in the study by Ramos-Echevarría et al. (2021), women in Puerto Rico noted that covid-19 had impact their ability to access appointments and prescriptions. In Australia 60% of women with endometriosis (n= 98) surveyed had their healthcare disrupted (Evans et al., 2021). Australia has been less impacted by covid-19 when compared with other countries (Moss et al., 2020). In the UK, in May 2020 there were 4.4 million fewer outpatients appointments when compared with May 2019 (National Health Service, 2021). Due to

these concerns, consideration was given to the appropriateness of conducting this research during covid-19.

Hensen et al. (2021) discuss the importance of considering whether research should go ahead in the context of covid-19. Specifically, they refer to considering the additional impact that this may have for individuals who are likely to have the interview at home and may be balancing competing demands. The British Psychological Society produced guidance for psychologists doing research during covid-19, these are in addition to regular ethical considerations and approval; they note that the research should be respectful of individuals, have scientific integrity, it should have social responsibility, and should maximise benefit and minimise harm (British Psychological Society, 2020). I will now outline how each of these considerations were addressed in my project.

Scientific Integrity: As is the case for research in general, the BPS recommend that studies should "... be designed, reviewed and conducted in a way that ensures its quality, integrity and contribution to the development of knowledge and understanding." (p. 2). Any changes to protocol because of covid-19 need to be justified. For this study there was always a plan to offer video conferencing or telephone interviews as an option. This meant that consideration had already been given to the impact of conducting the interviews remotely. This included ensuring there was a plan to manage sensitive issues; by having contact information for myself and other services readily available for participants. Further information about the distress protocol is included in part 4 of this thesis.

Social responsibility: Research conducted in the time of covid-19 must have high social value. Habets, van Delden, and Bredenoord (2014) describe social value as research that has benefits to the participant and to society. The participants in this study noted that they felt encouraged by the fact that someone was conducting research about the psychological support for endometriosis, and they hoped that this could help others. This is in line with findings by Agarwal et al. (2007), who noted that that women involved in endometriosis research were strongly motivated to be a part of scientific advancement and supporting others.

Maximise benefit and minimise harm: The aim of research of this kind is that participants would not be exposed to any further distress than they would in normal life. The women in this study are managing a chronic condition. They are accustomed to having to discuss their conditions with employers, friends, family and healthcare professionals (Culley et al., 2013; Roomaney & Kagee, 2015).

Several papers explore the changing landscape of women's healthcare post covid-19; they note the importance of innovation in structuring services to meet women's needs (Ball, Willmott, Rivas, & Talati, 2021; Bruno, Shalowitz, & Arora, 2021; Karavadra, Stockl, Prosser-Snelling, Simpson, & Morris, 2020). The evidence from the systematic literature review and empirical paper, shows that there is an immediate need for women with endometriosis to have access to supportive healthcare encounters. There is an imperative for the findings of this research to be considered in the context of any post covid-19 restructure. I felt that there was social value in completing this research at this time.

Clinical Implications

Research exploring the impacts of endometriosis has greatly increased in recent years, in which the psycho-social implications of the illness have been made abundantly clear (Culley et al., 2013; Young, Fisher, & Kirkman, 2015). The two papers in this thesis demonstrate the potential role of a psychologist within the multidisciplinary team (MDT); highlighting how they can provide support to both the MDT and women with endometriosis.

In order to support women with endometriosis, psychologists need to have an understanding of women's healthcare encounters. The systematic review in section one of this thesis makes note of the fractured relationships women with endometriosis can have with their healthcare professionals (HCPs); whereby they experience feeling dismissed and routinely have their expertise ignored. The review has provided evidence for points of intervention within these challenging encounters. It specifically calls attention to the role of psychologists to provide education for other HCPs surrounding the impact of stigma, a psychological understanding of pain, power imbalances and the psycho-social implications of endometriosis.

Knowledge regarding these encounters is essential for psychologists, as the findings in the empirical paper of this thesis identify the ways in which these fractured relationships may be compounded upon in therapy. Specifically, this is in relation to stigma and communication taboos surrounding menstruation, sex and fertility. If therapists do not allow sufficient space for these discussions, the women may continue to experience being silenced. Having an awareness of these troubled relationships means that therapists should be prepared to prioritise creating a space which gives permission to speak. In turn, the empirical paper in this thesis provides evidence regarding the benefits for women having the time and space to process their diagnosis. It indicates that this space was facilitated by the therapist, and therefore may be an important consideration for all HCPs, particularly given the feelings of dismissal identified in the systematic literature review. In order for women to feel adequately supported, consideration should also be given to the timing and location of any therapeutic intervention.

The empirical paper showed that women accessed psychological care for support with adjustment to their diagnosis, trauma arising from medical interventions, and psychosocial implications of endometriosis. Support at this stage was primarily delivered within secondary services associated with their physical care; namely therapists working in the hospitals. There are debates about whether chronic pain should be treated within primary care, or if it requires specialist referral to secondary services; this is due to the level of complexity. Research shows that while primary care physicians may not receive extensive training in the management of chronic pain, they are able to provide care and treatment for individuals with complex chronic pain (Cano-García, González-Ortega, Sanduvete-Chaves, Chacón-Moscoso, & Moreno-Borrego, 2017; Fink-Miller, Long, & Gross, 2014; Mills, Torrance, & Smith, 2016). With further argument being made that most chronic pain patients will only present to primary care services (Smith, Hopton, & Chambers, 1999).

The results of this study highlight that having psychologists based within primary care, specifically within GP services could provide several options for intervention; both for women with endometriosis

and the health care professionals they encounter. First having psychologists as part of general practice would allow for them to act as educators for GPs, to increase awareness of the psychosocial implications of endometriosis. Several of the women in this study experienced a dismissive attitude from HCPs, resulting in a delay in diagnosis. Providing education can improve interactions between HCPs and patients with chronic pain (Fisher & Dickinson, 2014). Secondly, this would offer the opportunity for psychologists to intervene and offer support earlier in the diagnostic pathway. The women in this study valued having space to process and consider their diagnosis, having access to a psychologist prior to this may help with the transition. And finally, having psychologists placed within primary care may allow for a greater ease of access (Durcan, 2020). This is relevant as women in the study identified the need for ongoing support, particularly when they were experiencing flare ups in their endometriosis. Having access to a psychologist within primary care or GP practices might reduce barriers for women to access support in a timely manner.

Future research

The participants within this project accessed various therapies, such as CBT, psychodynamic psychotherapy, and counselling. These therapies were provided in several different settings, for example within both primary and secondary care, within their workplace and with private therapists. Future research which explored specific therapies and specific settings would be beneficial. A recent survey of mental health clinicians found that psychologists were more likely to use Acceptance and Commitment Therapy (ACT) than other therapies, for women with chronic pelvic pain (Brooks, Sharp, Evans, Baranoff, & Esterman, 2021). There is growing evidence that ACT can be a beneficial intervention for managing chronic pain (Casey et al., 2020; Gentili et al., 2021; Hann & McCracken, 2014; Rickardsson et al., 2020; Simpson, Mars, & Esteves, 2017). Although Endometriosis is considered a chronic pain condition it could be argued that there are further implications to the illness, such as the link to infertility, that are not present in other chronic pain conditions (National Institute for

Health and Care Excellence, 2021). Therefore, further research is needed to assess the appropriateness of ACT for women with endometriosis.

Conclusion

In conclusion, this critical appraisal explored the challenges I encountered while conducting this research during a global pandemic. The steps taken to counter these challenges are also discussed. This paper also explored the importance of reflexivity in qualitative research. My journey with reflexivity is documented to monitor for any potential bias. Services offering psychological support for women with endometriosis are not currently widely available. It is hoped that this research will contribute to understanding the important therapist factors essential to offering good quality support, as well as highlighting the opportunity for psychologists within primary care to support women before and after their diagnosis.

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Appendix 3-A : Excerpt From Research Diary

“I’ve just read a news article about how black women are five times more likely to die in childbirth than white women in the UK. In the article a woman is speaking about how her pain was dismissed and how the doctors almost missed a life-threatening condition because of it. This is making me think about the women in my study, and how many of them only found out about endometriosis when it was an emergency. How did race factor into this? And why hadn’t I considered this before? I think this is because I am white, and personally haven’t experienced discrimination and disbelief due to racism. My focus throughout the thesis is broadly on the interplay between the condition and healthcare/support, but perhaps I need to keep a closer eye to race and how that impacts the support received?”

Section 4 - Ethics

Ethics Documentation

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Word Count: 4,398

(excluding references, tables, figures and appendices)

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Approval Letter



Applicant: Samantha Harpur
Supervisor: Craig Murray, Claire Hardy
Department: Health Research
FHMREC Reference: FHMREC19054

29 April 2020

Dear Samantha

Re: The Experience of Psychological Care for Women With Endometriosis.

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "R.E. Case".

Becky Case
Research Ethics Officer, Secretary to FHMREC.

Ethics Application Form

**Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University****Application for Ethical Approval for Research**

Title of Project: The Experience of Psychological Care for Women With Endometriosis.

Name of applicant/researcher: Samantha Harpur

ACP ID number (if applicable)*:

Funding source (if applicable)

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [\[link\]](#).**

Type of study

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, two and four of this form**

Includes *direct* involvement by human subjects. **Complete sections one, three and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Student

2. Contact information for applicant:

E-mail: s.harpur@lancaster.ac.uk

Telephone: 07472389785 (please give a number on which you can be contacted at short notice)

Address:

3. Names and appointments of all members of the research team (including degree where applicable)

Samantha Harpur, Trainee Clinical Psychologist

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#))

PG Diploma Masters by research PhD Thesis PhD Pall. Care
 PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD
 DClinPsy SRP [if SRP Service Evaluation, please also indicate here:] DClinPsy Thesis

4. Project supervisor(s), if different from applicant: Dr. Craig Murray; Dr. Claire Hardy

5. Appointment held by supervisor(s) and institution(s) where based (if applicable): Lancaster University- Senior Lecturer (CM); Lancaster University- Lecturer in Organisational Health and Well Being (CH)

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date: _____ End date: _____

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' no

4c. If yes, where relevant has permission / agreement been secured from the website moderator? no

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage

period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain?

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Endometriosis is a chronic health condition which affects 10% of women. It occurs when endometrial tissue is found outside the womb on organs such as the ovaries or the bowel. The symptoms can severely impact on a woman's health and wellbeing, such as difficulties with quality of life, employment, personal relationships, and fertility (Culley et al., 2013; Young, Fisher, & Kirkman, 2015). Given this impact, there appears to be many opportunities for clinical psychologists to support women. Indeed, recent recommendations from a government review in Wales, encouraged more professionals, including psychologists, to work together to support women (Endometriosis Task Group, 2018).

The researcher will interview women who have a diagnosis of endometriosis and who have accessed psychological care for support with this. For this study psychological care is understood as any formal support from a trained mental health professional. By exploring the experiences of women who accessed psychological care, this study aims to understand the role of clinical psychology.

2. Anticipated project dates (month and year only)

Start date: February 2020

End date: March 2021

Data Collection and Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

As is consistent with the IPA methodology, purposive sampling will be used to recruit between 8-12 participants in the United Kingdom. Inclusion criteria for participants: a) will be women between the ages of 18-50 in the UK, who have a confirmed diagnosis of endometriosis from a gynaecology department or Endometriosis Clinic, and b) who have accessed psychological care regarding their endometriosis within the last 5 years. For this study psychological care is understood as any formal support from a trained mental health professional (e.g. Psychologist, Cognitive Behavioural Therapist, Psychological Wellbeing Practitioner, Psychiatrist, Nurse, or Social Worker).

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Recruitment for this study will be from within the UK. This may increase the homogeneity of the sample, as participants will have had access to very similar health systems and supports. Recruitment will be from Endometriosis UK via their website and their local support group in Manchester. The support group has an associated Facebook group with over 500 members; I hope to be able to advertise the study in this group also. Once ethical approval is received, I will email Endometriosis UK, seek permission to advertise the study on their website, in their support group in Manchester and within their associated Facebook Group. Once permission is granted, I will circulate the poster with contact details for lead researcher, including email address to make contact if interested in taking part in the study. Expressions of interest will then be screened to see if they fit the inclusion criteria. If they are appropriate for the study, they will be invited to take part in an interview lasting approximately 30-60 minutes.

If the required sample cannot be recruited from this source, then it will be extended outside of the UK to charities based in Australia and Canada. Extending recruitment outside of the UK may increase the limitations of the study, due to the differing health systems and support on offer. While the services offered in Australia and Canada may differ to that in the UK, they both provide universal healthcare.

Other factors relating to an individual's experience of psychological support for endometriosis may be similar enough, in order to maintain homogeneity. This could include, type of therapy, age of onset, impact of symptoms, decision to access support, or experience of thinking psychologically about their difficulties.

In this instance recruitment will be from EndoActive based in Sydney, Australia has over 13,000 followers on Facebook and regularly promote research projects looking for participants. The Endometriosis Network Canada based in Toronto has an online Facebook support group with over 6,500 members. I can conduct the semi-structured interviews via online technology (eg. Skype, WhatsApp, Microsoft Teams) and audio record the interviews with an audio recorder. Participants will be informed about security of each option and can make an informed choice about the method of contact they would like to use. The procedure will follow all the same steps as for the UK except for the option for a face to face interview for participants.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

This study will be qualitative; using Interpretative Phenomenological Analysis (IPA). IPA is widely used in healthcare research as it offers the opportunity to gain insight into the unique experience of patients and how they make sense of these experiences (Biggerstaff & Thompson, 2008). Given the nature of IPA as an idiographic approach, Smith, Flowers, and Larkin (2009) recommends small, homogenous samples; noting that this allows for in-depth analysis of the transcripts in order to identify common themes. As per the protocol for IPA this will be conducted via semi-structured interviews with women who have a diagnosis of endometriosis and who have accessed psychological care. The use of semi-structured interview allows flexibility so that participants will be able to fully explore their lived experience. This includes their thoughts and feelings about working with mental health professionals to understand their endometriosis in a psychological way (Smith et al., 2009). The research aims to understand the unique meanings that participants attribute to accessing psychological support in relation to their illness, and how this support was experienced.

The participants will be given the option of conducting the interview via online technology, telephone or face to face. I am willing to meet with participants face to face in the Greater Manchester area. If participants choose to meet face to face the interview will take place at a location convenient to the participant.

In the course of the interview demographic data will be collected from participants. Data collected may include age, approximate time from symptom onset to diagnosis, time since diagnosis, and psychology support accessed. Participants will be assigned an ID and this data will be stored in a separate encrypted word document on a secure online server. These details will be collected to explore the homogeneity of the sample and consider whether themes are influenced by these factors. I will transcribe each interview and follow the protocol for analysis, as laid out by Smith et al. (2009). Smith describes how the process of data analysis is completed on a case by case basis, then looking across the sample. The research outlines a common approach: a line by line reading of the transcript, followed by making notes regarding the use of language, context and descriptors; then pulling out emerging themes, to finally looking at themes across all cases. Throughout the process I plan to keep a note of my own reactions and responses, as well as access support from my supervisor regarding the themes and interpretations, as is recommended (Pietkiewicz & Smith, 2014).

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Data will be stored on a secure online server, specifically One Drive. Physical copies of consent forms will be scanned and stored on the personal H drive, with the physical copy then being destroyed (shredded). Anonymised transcripts will be transferred to the research co-ordinator within the Doctorate in Clinical psychology and will be stored in a secure location by the university for 10 years (e.g. One Drive, Department servers); after this time, they will be deleted. University procedures will be followed to ensure safe transfer of this data at the end of the project. Any files containing identifiable details, including names, email addresses and/or phone numbers, will be encrypted and stored separately to the anonymised transcripts on a secure online server; an ID will be created to match the detail to the transcripts. These files will be deleted post viva.

7. Will audio or video recording take place? no audio video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

The researcher will record the interview on an audio recorder. Once the interview is complete, the files will be immediately transferred to One Drive.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Digital recordings will be stored on personal drive on Lancaster University server and will be destroyed upon completion of the Thesis post viva.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

All data will be stored electronically and will be encrypted, and password protected. On completion of the Thesis data will be transferred to the research coordinator for long term storage.

8b. Are there any restrictions on sharing your data?

Due to the sensitive nature of the interviews, the small sample size and recruitment via one charity in the UK, there may be the potential for participants to be identified even after the transcript is anonymised. Therefore, the data will only be available to the researcher and supervisors.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Prior to commencing the interview, the participant will be provided with the Participant Information Sheet, detailing the aims of the project and informing them that they do not have to take part. The Participant Information sheet will also detail the procedure and timeline for having their data removed from the project if they change their mind later. Once they have confirmed that they have read the participant information sheet they will be requested to sign the consent form. If the interview is taking place face to face these will be completed in person. If the interview is taking place over the phone the Participant Information Sheet and consent form will be emailed in advance. The consent form will need to be signed and returned by email before the interview takes place. If the consent form has not been returned before the interview, consent will be recorded verbally at the beginning of the interview by the researcher reading through the consent form with the participant. This will then be kept as an additional audio file. Any files containing identifiable details will be encrypted and stored separately to the anonymised transcripts; and ID will be created to match the detail to the transcripts. These files will be deleted post viva.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Participants may experience discomfort with regarding to discussing their wellbeing and experiences with endometriosis. As part of the initial pack of information about the project participants will be provided with details of organisations where they can access support after the interview if they become distressed. Participants will also be encouraged to contact their GP if they feel distressed. If participants become distressed during the interview the interview will be stopped, they will be given time to recover and then they will be presented the option to continue the interview, reschedule or withdraw from the study.

Participants can request to withdraw at any time for 2 weeks post interview. The reason for this time limit, is because it can be difficult to take out data from one specific participant when this has already been anonymised or pooled together with other people's data.

Due to recent government guidelines regarding unnecessary travel and enforcing social distancing protocols, face-to-face interviews will not be offered until such a time as the government deems it safe to resume normal working procedures. Until this time all interviews will be conducted via online technology or telephone. This is to ensure the safety of both the researcher and the participant.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

Potential for the researcher to be distressed by the interview content. Researcher will avail of the support of research supervisors.

If the interview is conducted face to face, this will take place at a location that is convenient and accessible to the participant, as a result this may take place in their home. The interview will be conducted on a one-to-one basis with the participant and myself. I will therefore adhere to the Department of Health and research lone Worker policy and avail of both a Lone Researching Safety Partner (a fellow Trainee Clinical Psychologist from Lancaster), and technology namely SkyGuard. SkyGuard is an alarm system with an external company, I can activate the SOS button and the

company can provide police and medical assistance if needed. I will check in and check out of my interviews by activating the SkyGuard alarm, and by notifying my Lone Researching Safety Partner. I will ensure that my Lone Researching Safety Partner is aware of the time and location of the interview in advance, via an encrypted word document on a shared folder on the H drive. I will provide my Safety Partner with a password for this and I will contact them before and after the interview to report that I am safe.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There is the potential for participants to benefit from having time to speak about their experiences. Whilst the results are not generalisable they may inform future practice, there is the potential for participants to feel included in this process via this project.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Participant's travel costs to interviews will be reimbursed up to £20; receipts will need to be provided for this.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? **yes**

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Participants demographic details will not be stored alongside transcripts. Each participant will be assigned a pseudonym. The participant information sheet will inform participants that while their contributions will be anonymised, the researcher plans to use exact quotes as part of the written paper but will ensure that names, dates, and place will be anonymous.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

One woman with Endometriosis was consulted in the design of all participant information details, poster and interview schedule. This individual is known to the researcher.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

I plan to submit this research for peer review publication in Human Reproduction Journal. This journal focuses on reproductive physiology, endocrinology (study of hormones) and psychology. The aim is to

expand the potential audience for these findings beyond psychology to include medical professionals (General Practitioners, Endometriosis nurses and Gynaecologists.)

I also plan to feed back the themes and potential understandings to Endometriosis UK and any local support groups.

The results of this research will be submitted as a thesis for Doctorate in Clinical Psychology which will be made publicly available within Lancaster University Library.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

SECTION FOUR: signature

Applicant electronic signature:

Date

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review

Project Supervisor name (if applicable):

Date application discussed

Submission Guidance

1. Submit your FHMREC application by email to Diane Hopkins (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
 - i. **FHMREC application form.**
Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.
 - ii. **Supporting materials.**
Collate the following materials for your study, if relevant, into a single word document:
 - a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
 - b. Advertising materials (posters, e-mails)
 - c. Letters/emails of invitation to participate
 - d. Participant information sheets
 - e. Consent forms
 - f. Questionnaires, surveys, demographic sheets
 - g. Interview schedules, interview question guides, focus group scripts
 - h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
 - i. Projects including direct involvement of human subjects [**section 3 of the form was completed**]. The *electronic* version of your application should be submitted to [Becky Case](#) **by the committee deadline date**. Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
 - ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. [**Section 3 of the form has not been completed, and is not required**]. Those involving:
 - a. existing documents/data only;
 - b. the evaluation of an existing project with no direct contact with human participants;
 - c. service evaluations.
3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

References

- Culley, L., Law, C., Hudson, N., Mitchell, H., Denny, E., & Raine-Fenning, N. (2013). The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Human Reproduction Update*, 19(6), 625-639. doi:10.1093/humupd/dmt027
- EndometriosisTaskGroup. (2018). Endometriosis care in Wales: Provision, care pathway, workforce planning and quality and outcome measures. Retrieved from http://www.wisdom.wales.nhs.uk/sitesplus/documents/1183/Endometriosis%20Care%20in%20Wales%20Report%281%29_2018.pdf
- Pietkiewicz, I., & Smith, J. (2014). *A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology* (Vol. 20).
- Smith, J. A., Flowers, P., & Larkin, M. H. (2009). *Interpretative phenomenological analysis : theory, method and research*: Sage.
- Young, K., Fisher, J., & Kirkman, M. (2015). Women's experiences of endometriosis: a systematic review and synthesis of qualitative research. *Journal of Family Planning and Reproductive Health Care*, 41(3), 225. doi:10.1136/jfprhc-2013-100853

Research Protocol

The Experience of Psychological Care for Women with Endometriosis.

Name of Applicant: Samantha Harpur

Supervisor: Craig Murray

Field Supervisor: Claire Hardy

Introduction

Endometriosis is a painful chronic gynaecological condition, effecting 10% of women worldwide. This occurs when endometrial tissue grows outside the womb, typically it is found in the pelvic area (EndometriosisUK, 2019). This tissue responds to monthly hormone release by swelling and bleeding; which can be the cause of significant pain for individuals. Common symptoms of endometriosis include pelvic pain, heavy or painful periods, dyspareunia, pain associated with bowel movements, fatigue and infertility. Research shows that there are numerous psycho-social implications for women with endometriosis including: difficulties with quality of life, employment, personal relationships, and fertility (Culley et al., 2013; Facchin et al., 2017; Grogan, Turley, & Cole, 2018; Roomaney & Kagee, 2018; Vitale, La Rosa, Rapisarda, & Laganà, 2017; Zarbo et al., 2018). A review by Culley et al. (2013) found that emotional distress was ubiquitous in the qualitative studies they reviewed. Several studies conducted since this review found that women with endometriosis were significantly more likely to struggle with anxiety and depression (Chen et al., 2016; Laganà et al., 2015; Roomaney & Kagee, 2015, 2018).

While the condition itself presents challenges for a woman's wellbeing, navigating the healthcare system can be an added difficulty. NICE guidelines have indicated that women can experience delays of 4-10 years from the first onset of symptoms to receiving a diagnosis (Kuznetsov, Dworzynski, Davies, & Overton, 2017). Reasons for this delay are on both the patient and doctor level. For patients research indicates that there is a stigma around menstruation which can impact on women feeling comfortable to disclose their difficult periods to both health professionals and family members (Grogan et al., 2018; Gupta et al., 2018; Riazi et al., 2014; Seear, 2009). Women also note

that their painful periods are frequently normalised by family and friends as well as by doctors; (Ballard, Lowton, & Wright, 2006; Young, Fisher, & Kirkman, 2015).

Factors involved in causing the delay on the doctor level are related to a lack of knowledge of endometriosis (Bach, Risoer, Forman, & Seibaek, 2016; Young et al., 2015). Misdiagnosis is also common with Hudelist et al. (2012) noting that 74% of patients in Germany and Austria received a minimum of one incorrect diagnosis.

There are many psychological and social implications of a delay in diagnosis. Staal, van der Zanden, and Nap (2016) found that women experienced the delay as traumatising. Women report that there is a high level of uncertainty surrounding not having a confirmed diagnosis (Grogan et al., 2018; Roomaney & Kagee, 2018). Once a diagnosis has been confirmed, women in several studies spoke about a relief and feeling of validation (Culley et al., 2013; Roomaney & Kagee, 2018). Others felt that they were not adequately supported post diagnosis (Grogan et al., 2018; Roomaney & Kagee, 2018).

Recommendations in both Wales and Australia specifically note that Clinical Psychologists should be included in multidisciplinary teams (MDTs) (Department of Health, 2018; Endometriosis Task Group, 2018). Several studies report that women feel their care would be better if they had greater access to a full multidisciplinary team including psychologists and patient groups (Facchin et al., 2017; Facchin, Saita, Barbara, Dridi, & Vercellini, 2018; Ugwumadu et al., 2017).

Given the extent of the psychosocial implications of endometriosis there appears to be many opportunities for clinical psychologists to support women. This may take the form of support accepting their diagnosis, coping skills, or helping families and health care professionals with the management of endometriosis. By exploring the experiences of women who accessed psychological care, this study

aims to understand the role of clinical psychology. Though not generalisable the results of this study may inform the development of psychology services for women with endometriosis.

Research Question

What are the experiences of women with endometriosis who have accessed psychological care?

Method

Design

This study will be qualitative; using Interpretative Phenomenological Analysis (IPA). IPA is widely used in healthcare research as it offers the opportunity to gain insight into the unique experience of patients and how they make sense of these experiences (Biggerstaff & Thompson, 2008). As per the protocol for IPA this will be conducted via semi-structured interviews with women who have a diagnosis of endometriosis and who have accessed psychological care. The use of semi-structured interview allows flexibility so that participants will be able to fully explore their lived experience. This includes their thoughts and feelings about working with mental health professionals to understand their endometriosis in a psychological way (Smith, Flowers, & Larkin, 2009). The research aims to understand the unique meanings that participants attribute to accessing psychological support in relation to their illness, and how this support was experienced. Once the first interview is completed the interview schedule may be amended if needed.

Participants

As is consistent with the IPA methodology, purposive sampling will be used to recruit between 8-12 participants in the United Kingdom. Given the nature of IPA as an idiographic approach, Smith et al. (2009) recommends small, homogenous samples; noting that this allows for in-depth analysis of the transcripts.

Inclusion criteria for participants: a) women between the ages of 18-50, who have a confirmed diagnosis of endometriosis from a gynaecology department or Endometriosis Clinic, and b) have accessed psychological care regarding their endometriosis within the last 5 years.

While endometriosis is a condition which can affect women of any age, the condition is less common in adolescents and symptoms can ease during and after the menopause, the age range was chosen for this reason (NHS, 2020). In order to limit the potential impact of recall bias, participants will also have accessed psychological care regarding their endometriosis within the last 5 years (Althubaiti, 2016). For this study psychological care is understood as any formal support from a trained mental health professional (e.g. Psychologist, Cognitive Behavioural Therapist, Psychological Wellbeing Practitioner, Psychiatrist, Nurse, or Social Worker)

Recruitment will be from Endometriosis UK via their website and their local support group in Manchester. The support group has an associated Facebook group with over 500 members; I hope to be able to advertise the study in this group also.

Materials

The following materials will be required:

- Participant information sheet (Appendix A)
- Consent Forms (Appendix B)
- Debrief sheet (Appendix C)
- Semi structured interview schedule (Appendix D)
- Poster to advertise the study. Once approval is granted by Endometriosis UK and group moderators, this will be shared electronically in the Facebook Groups and Twitter. It will be in paper format for the Endometriosis UK support group meeting. (Appendix E)
- Contact with agencies- email to Endometriosis UK. (Appendix F)
- Audio recording equipment

Procedure

Once ethical approval is received, I will email Endometriosis UK (see appendix F), seek permission to advertise the study on their website, in their support group in Manchester and within their associated Facebook Group. Once permission is granted, I will follow guidance from Endometriosis about who to contact (i.e. moderators or support group facilitators) in order to ask them to circulate the research poster within their support groups and Facebook Group (see appendix E). This includes details about the study and an email address to make contact if interested in taking part in the study. Expressions of interest will then be screened to see if they fit the inclusion criteria. If they are appropriate for the study, they will be invited to take part in an interview lasting approximately 30-60 minutes. The interview can be in person face-to-face, on the telephone or via online technology (eg. Skype, WhatsApp, Microsoft Teams) and audio record the interviews with an audio recorder. Participants will be informed about security of each online option and can make an informed choice about the method of contact they would like to use. If they choose face-to-face the interview will take place at a location convenient to the participant within the Greater Manchester area.

Prior to commencing the interview, the participant will be provided with the Participant Information Sheet (appendix A), detailing the aims of the project and informing them that they do not have to take part. The Participant Information sheet will also detail the procedure and timeline for having their data removed from the project if they change their mind later. Once they have confirmed that they have read the participant information sheet they will be requested to sign the consent form. If the interview is taking place face to face these will be completed in person. If the interview is taking place over the phone the Participant Information Sheet and consent form will be emailed in advance. The consent form will need to be signed and returned by email before the interview takes place. Consent will also be recorded verbally at the beginning of every interview by the researcher reading through the consent form with the participant. This will then be kept as an additional audio file.

Interviews will be recorded with an audio recorder. Once the interview is complete, the files will be immediately transferred to the secure online server One Drive. The recordings will be transcribed by myself. Digital recordings will be stored a secure online server (One Drive) and will be destroyed upon completion of the Thesis post viva.

In the course of the interview demographic data will be collected from participants. Information collected may include: age, approximate time from symptom onset to diagnosis, time since diagnosis and psychology support accessed.-Participants will be assigned a pseudonym and this information will be stored in a separate encrypted word document. These details will be collected to explore the homogeneity of the sample and consider whether themes are influenced by these factors.

Proposed Analysis

Each transcript will be transcribed by myself and will follow the protocol for Interpretative Phenomenological Analysis as laid out by Smith et al. (2009). IPA is an approach which aims to understand the unique meanings which participants attribute to their experiences. Cronin and Lowes (2016) note that IPA as a methodology provides the opportunity for researchers who are interested in understanding health difficulties from a patient centred perspective. In the context of this project IPA will allow the exploration of the participant's experience of endometriosis and psychological care.

Pietkiewicz and Smith (2014) describes how the process of data analysis is completed on a case by case basis then looking across the sample. They outlined a common approach as: a line by line reading of the transcript, followed by making notes regarding the use of language, context and descriptors, then pulling out emerging themes, to finally looking at themes across all cases. Throughout the process I plan to keep a note of my own reactions and responses and avail of support from my supervisor in terms of maintaining a dialogue around themes and interpretations, as is recommended.

Practical Issues

I aim to speak with Endometriosis UK about advertising for participants on their websites and through support groups. However, if the required sample cannot be recruited from this source, then it will be extended outside of the UK to charities based in Australia and Canada. Extending recruitment outside of the UK may increase the limitations of the study, due to the differing health systems and support on offer. While the services offered in Australia and Canada may differ to that in the UK, they both provide universal healthcare. Other factors relating to an individual's experience of psychological support for endometriosis may be similar enough in order to maintain homogeneity. This could include, type of therapy, age of onset, impact of symptoms, decision to access support, or experience of thinking psychologically about their difficulty.

In this instance recruitment will be from EndoActive based in Sydney, Australia has over 13,000 followers on Facebook and regularly promote research projects looking for participants. The Endometriosis Network Canada based in Toronto has an online Facebook support group with over 6,500 members. I can conduct the semi-structured interviews via online technology (eg. Skype, WhatsApp, Microsoft Teams) and audio record the interviews with an audio recorder. The procedure will follow all the same steps as for the UK except for the option for a face to face interview for participants.

For participants in the Greater Manchester area the interview will take place at a location that is convenient and accessible to the participant, this may take place in their home. The interview will take place on a one-to-one basis with the participant and myself. I will therefore adhere to the Department of Health and research Lone Worker policy and avail of both a Lone Researching Safety Partner (a fellow Trainee Clinical Psychologist from Lancaster), and technology, namely SkyGuard. SkyGuard is an alarm system with an external company, I can activate the SOS button and the company can provide police and medical assistance if needed. I will check in and check out of my interviews by activating the SkyGuard alarm, and by notifying my Lone Researching Safety Partner. I will ensure that my Lone Researching Safety Partner is aware of the time and location of the interview in advance, via an

encrypted word document on a shared folder on the H drive. I will provide my Safety Partner with a password for this and I will contact them before and after the interview to report that I am safe.

Due to recent government guidelines regarding unnecessary travel and enforcing social distancing protocols, face-to-face interviews will not be offered until such a time as the government deemed it safe to resume normal working procedures. Until this time all interviews will be conducted via online technology or telephone. This is to ensure the safety of both the researcher and the participant.

Participants can request to withdraw at any time for 2 weeks post interview. This timeline has been established as it can be difficult to remove data from one specific participant when this has already been anonymised or pooled together with other participants' data.

Ethical Concerns

Participants may experience discomfort with regard to discussing their wellbeing and experiences with endometriosis. As part of the initial pack of information about the project, participants will be provided with details of organisations where they can access support after the interview if they become distressed. Participants will also be encouraged to contact their GP if they feel distressed.

If participants become distressed during the interview the interview will be stopped, they will be given time to recover and then they will be presented the option to continue the interview, reschedule or withdraw from the study.

In order to protect confidentiality any identifiable information used during the interview, such as names or location, will be made anonymous in the transcript. Participants will be assigned a pseudonym for the final write up of the project.

Timescale

February 2020- Ethics application

April 2020- Begin recruitment

May 2020-December 2020- Conduct interviews, transcribe and analyse data

December 2020- March 2021- Write up final paper

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Appendix A: Participant information sheet

Participant Information Sheet***THE EXPERIENCE OF PSYCHOLOGICAL CARE FOR
WOMEN WITH ENDOMETRIOSIS.***

I am a Trainee Clinical Psychologist at Lancaster University and I would like to invite you to take part in a research study about the experience of psychological support for women with endometriosis. I would be interested in talking to you if you have had any formal support from a trained mental health professional to manage any difficulties associated with your endometriosis. A mental health professional might be a psychologist, cognitive behavioural therapist, psychological wellbeing practitioner, psychiatrist, nurse, or social worker.

Please take time to read the following information carefully before you decide whether you wish to take part.

What is the study about?

This study aims to understand your experience of seeking psychological support to manage any difficulties associated with your diagnosis of endometriosis. The study hopes to explore the ways in which endometriosis has impacted on your life and how psychology services can support with this.

What will I be asked to do if I take part?

If you decided to take part, this would involve an interview lasting between 30-60 minutes. This can be done locally in person (Manchester), online (eg. Skype, WhatsApp, Microsoft Teams) or on the phone. If you choose to have the interview using online technology, we will discuss the security for each system before we start.

What are the possible benefits from taking part?

If you take part in this study, your insights will contribute to our understanding of how psychology services might be able to support women with endometriosis.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Your participation is voluntary.

What if I change my mind?

If you change your mind, you are free to withdraw your participation in this study. If you want to withdraw, please let me know, and I will extract any ideas or information you contributed to the study and destroy them. However, it is difficult to take out data from one specific

participant when this has already been anonymised or pooled together with other people's data. Therefore, you can only withdraw up to 2 weeks after taking part in the study.

What are the possible disadvantages and risks of taking part?

Taking part will mean investing 30-60 minutes for an interview.

Will my data be identifiable?

After the interview, only my supervisors and I, will have access to the typed record of what you share with me. I will keep all personal information about you (e.g. your name and other information about you that can identify you) confidential, that is I will not share it with others. I will remove any personal information from the written record of your contribution.

How will we use the information you have shared with us and what will happen to the results of the research study?

I will use it for research purposes only. This will include, my DClinPsy thesis and potentially other publications, such as journal articles. I may also present the results of my study at academic conferences.

When writing up the findings from this study, I would like to reproduce some of the views and ideas you shared with me. I will only use anonymised quotes, so although I will use your exact words, you won't be identified in our publications.

If anything you tell me in the interview suggests that you or somebody else might be at risk of harm, I will be obliged to share this information with my supervisor. If possible, I will inform you of this breach of confidentiality.

How my data will be stored

Your data will be stored in encrypted files and on password-protected computers. I will keep data that can identify you separately from non-personal information (e.g. your views on a specific topic). In accordance with University guidelines, I will keep the data securely for a minimum of ten years. For further information please visit our webpage: www.lancaster.ac.uk/research/data-protection

What if I have a question or concern?

I hope that you have found it okay to be approached about this project. If you have any queries or if you are unhappy with anything that happens concerning your participation in the study, please contact:

Researcher

Samantha Harpur
Trainee Clinical Psychologist
Lancaster University
Furness College
Bailrigg
Lancaster
LA1 4YG
s.harpur@lancaster.ac.uk
07908613784

Supervisor

Claire Hardy
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Supervisor

Craig Murray
Senior Lecturer
Lancaster University
Furness College
Bailrigg
Lancaster
LA1 4YG
c.murray@lancaster.ac.uk
+44 1524 592730

If you have found any part of this experience to be distressing, you can contact your GP. There are also some organisations listed below that you can contact.

ENDOMETRIOSIS UK

Endometriosis UK provide a range of support services including a Helpline, information, an online forum and monthly support groups.

Website: www.endometriosis-uk.org

Online Forum: www.endometriosis-uk.org/online-community

Helpline: 0808 808 2227

SAMARITANS

Website: www.samaritans.org

Helpline: 116 123

If you have any concerns or complaints that you wish to discuss with a person who is not directly involved in the research, you can also contact:

Dr Laura Machin

Chair of Faculty of Health and Medicine REC

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YG

TelTelephone: +44 (0)1524 594973

l.machin@lancaster.ac.uk

Thank you for considering your participation in this project.

Appendix B: Consent Form

Consent Form**Study Title:** The Experience of Psychological Care for Women with Endometriosis.

We are asking if you would like to take part in a research project. This study aims to understand your experience of seeking psychological support to manage endometriosis. Before you consent to participating in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to Samantha Harpur.

- | | Please initial each statement |
|--|-------------------------------|
| 1. I confirm that I have read the information sheet and fully understand what is expected of me within this study | <input type="checkbox"/> |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 3. I confirm that the options for online technologies and the security of each has been explained to me. | <input type="checkbox"/> |
| 4. I understand that my interview will be audio recorded and then made into an anonymised written transcript. | <input type="checkbox"/> |
| 5. I understand that audio recordings will be kept until the research project has been examined. | <input type="checkbox"/> |
| 6. I understand that my participation is voluntary and that I am free to withdraw within 2 weeks of my interview by contacting the researcher or supervisor; without giving any reason. | <input type="checkbox"/> |
| 7. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data. | <input type="checkbox"/> |
| 8. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. | <input type="checkbox"/> |
| 9. I consent to information and quotations from my interview being used in reports, conferences and training events. | <input type="checkbox"/> |
| 10. I understand that the researcher will discuss data with their supervisor as needed. | <input type="checkbox"/> |
| 11. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor. | <input type="checkbox"/> |
| 12. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. | <input type="checkbox"/> |
| 13. I consent to take part in the above study. | <input type="checkbox"/> |

Print Name (Participant): _____

Signature: _____

Date: _____

Print Name (Researcher): _____

Signature: _____

Date: _____

Appendix C: Participant Debrief Sheet

PARTICIPANT DEBRIEF SHEET*THE EXPERIENCE OF PSYCHOLOGICAL CARE FOR
WOMEN WITH ENDOMETRIOSIS*

Thank you for participating in this interview. I hope that you have found it okay and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact:

Samantha Harpur

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

C16 Furness College

Lancaster University

Bailrigg, Lancaster

LA1 4YG

07908613784 or s.harpur@lancaster.ac.uk

You can contact your GP; there are also some organisations listed below that you can contact.

ENDOMETRIOSIS UK

Endometriosis UK provide a range of support services including a Helpline, information, an online forum and monthly support groups.

Website: www.endometriosis-uk.org

Online Forum: www.endometriosis-uk.org/online-community

Helpline: 0808 808 2227

SAMARITANS

Website: www.samaritans.org

Helpline: 116 123

This debrief form to be used if recruitment is extended to Australia.

PARTICIPANT DEBRIEF SHEET*THE EXPERIENCE OF PSYCHOLOGICAL CARE FOR
WOMEN WITH ENDOMETRIOSIS*

Thank you for participating in this interview. I hope that you have found it okay and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact:

Samantha Harpur (Trainee Clinical Psychologist)

Doctorate in Clinical Psychology

C16 Furness College

Lancaster University

Bailrigg, Lancaster

United Kingdom

LA1 4YG

07908613784 or s.harpur@lancaster.ac.uk

You can contact your GP; there are also some organisations listed below that you can contact.

ENDOACTIVE AUSTRALIA & NZ

Website: endoactive.org.au

ENDOMETRIOSIS AUSTRALIA

Support Groups: www.endometriosisaustralia.org/support-groups

BEYOND BLUE

Website: www.beyondblue.org.au

Helpline: 1300 22 4636

This debrief form to be used if recruitment is extended to Canada.

PARTICIPANT DEBRIEF SHEET*THE EXPERIENCE OF PSYCHOLOGICAL CARE FOR
WOMEN WITH ENDOMETRIOSIS*

Thank you for participating in this interview. I hope that you have found it okay and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact:

Samantha Harpur (Trainee Clinical Psychologist)

Doctorate in Clinical Psychology

C16 Furness College

Lancaster University

Bailrigg, Lancaster

United Kingdom

LA1 4YG

07908613784 or s.harpur@lancaster.ac.uk

You can contact your GP; there are also some organisations listed below that you can contact.

ENDOMETRIOSIS NETWORK CANADA

Website: endometriosisnetwork.com

Online Support Group: <https://www.facebook.com/groups/301016744454/>

CANADIAN MENTAL HEALTH ASSOCIATION

Website: www.cmhs.ca

Helpline: (416) 646- 5557

Appendix D: Interview Schedule

*THE EXPERIENCE OF PSYCHOLOGICAL CARE FOR
WOMEN WITH ENDOMETRIOSIS.*

Interview Guide

The following is a guide of potential questions for the semi structured interview:

- Can you tell me about when you received your diagnosis? *Possible prompts: How did it feel?*
- How did you decide to seek help with your endometriosis? *Possible prompts: Did you have to wait to see someone? How did it feel to make that decision? Where did this fit in your timeline?*
- What were the primary psychological or social difficulties you were experiencing at that time?
- How did it feel to talk about your difficulties?
- What did you work on? *Possible prompt: was it similar or different to other help you received?*
- How do you feel about your endometriosis now? *Possible prompt: has your perception/experience of endo changed?*
- *How has it felt talking about this today?*

Appendix E: Poster

ENDOMETRIOSIS & PSYCHOLOGICAL SUPPORT

Volunteers Needed For Interviews

What is the research about?

Endometriosis can impact on women's psychological wellbeing. I am interested in speaking with women who have accessed support to help manage this impact.

Are you...

- A woman 18-50 years of age with endometriosis.
- Have accessed psychological support, for example counselling, pain management, or cognitive behavioural therapy. This can be with a psychologist, or any mental health professional.



What, where, when?

It would involve a 30- 60 minute interview which can be done over the phone, via online technology (e.g Skype/WhatsApp/Teams) or in person in Greater Manchester.

If you think that you can help, please contact Samantha Harpur

s.harpur@Lancaster.ac.uk

Lancaster
University 

Appendix F: Email to agencies for recruitment

To Whom it May Concern

My name is Samantha Harpur, I am writing to you today to ask permission to advertise a research project within your support groups and Facebook group. I am aiming to explore women's experience of endometriosis and psychological care.

I am hoping to recruit a) women between the ages of 18-50, who have a confirmed diagnosis of endometriosis and b) who have accessed psychological care regarding their endometriosis within the last 5 years. (this is with a trained mental health professional e.g. Psychologist, Cognitive Behavioural Therapist, Psychological Wellbeing Practitioner, Psychiatrist, Nurse, social worker)

The research has received ethical approval from the Faculty of Health and Medicine in Lancaster University. Hopefully the findings from this research will inform clinical psychology about how best to support women with a diagnosis of endometriosis. Please don't hesitate to contact me if you have any questions about the research.

Kind Regards

Samantha Harpur

Trainee Clinical Psychologist

Furness College

Lancaster University

Bailrigg, Lancaster

United Kingdom

LA1 4YG

07908613784