

# ***Dismissal, distrust, and dismay: a phenomenological exploration of young women's diagnostic experiences with endometriosis and subsequent support.***

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## **Abstract**

Endometriosis is associated with extensive physical and emotional difficulties, yet there is little research investigating the impact of the diagnostic journey particularly for younger women. Using semi structured on-line interviews and an interpretative phenomenological analysis, this study explored nine young women's experiences of the diagnostic process and the significance of support during this period. Three main themes emerged: "the pursuit of a diagnosis", "adjusting to a new normality", and "the importance of effective support". These experiences revealed clinical shortcomings and potential improvements to current guidelines and practices to facilitate a more emboldening process for patients.

## **Introduction**

An estimated 1.5 million UK women have been diagnosed with endometriosis, with an approximate global figure of 6-8% in women of a reproductive age (Fuldeore, & Soliman, 2017; Reid et al., 2019; Singh et al., 2020). Endometriosis is a benign, gynaecologic disorder characterised by the relocation of endometrial tissue from inside the uterus to other organs, most commonly the reproductive system including the pelvic peritoneum, ovaries, and rectovaginal system (Giudice, 2010; Hsu, Khachikyan, & Stratton, 2010). Symptoms include progressive pain throughout the menstrual cycle affecting the lower abdomen, as well as pain during sexual intercourse, and bladder urgency (Moradi et al., 2014). The condition is diagnosed using a laparoscopy, and although a comprehensive cure has not yet been discovered, around 70% of cases can be treated using hormonal and pain management methods (Mettler, Ruprai, & Alkatout, 2014; Vercellini et al., 2014). As a complex condition, the cause of endometriosis remains unclear, although a key aetiological model suggests a 47% genetic contribution with a resulting 53% attribution to environmental factors (Saha et al., 2015).

## *Quality of Life*

Current research has largely focused upon the physical and emotional problems associated with the condition, often related to feelings of helplessness, disappointment, and frustration (Culley et al., 2013; Moradi et al., 2014; Rowlands et al., 2016). This emotional distress also includes increased anxiety, frequent depressive episodes, and diminished self-confidence (Culley et al., 2013; Facchin et al., 2017; Moradi et al., 2014). As a long-term reproductive condition, endometriosis also impacts identity, often as a result of infertility concerns, and a reduced physical and emotional capacity (Facchin et al., 2018; Moradi et al., 2014; Nnoaham et al., 2011). Research suggests that this change in physical capabilities has a negative effect on general wellbeing (Grogan, Turley, & Cole, 2018), as well as reduced job productivity, an increased number of sick days, and pain-related work disturbances (Hansen et al., 2013; Moradi et al.,

2014; Soliman et al., 2017). Furthermore, persistent fatigue often leads to self-pacing behaviours, to conserve energy, resulting in a decreased quality of life due to missed opportunities (Culley et al., 2013; Facchin et al., 2015; Grogan et al., 2018). To effectively manage these consequences, women often employ a number of problem and emotion based active coping strategies, including adopting a positive outlook, changes to daily activities, and evoking spirituality (Roomaney & Kagee, 2018; Zarbo et al., 2018). Recent literature suggests that these methods may reduce the frequency of depressive episodes and improve self-management within stressful situations (Roomaney & Kagee, 2018; Zarbo et al., 2018).

### *Diagnosis*

Contemporary literature has also begun to explore the efficacy of current diagnostic processes and clinical practices, which are based on the 2015 NICE guidelines (Dancet et al., 2014; National Institute for Health and Care Excellence (NICE), 2015; Young, Fisher & Kirkman, 2017). These provide an outline of key indicator symptoms, as well as recommended treatment plans depending on the stage and development of the condition (NICE, 2015). However, the average period between the initial presentation of symptoms and an official diagnosis, remains an average of 8 years (*Endometriosis UK*, 2011; Moradi et al., 2014; Staal, Van Der Zanden & Nap, 2016). The explanation behind this delay is complex, with suggestions that diversity in the presentation and severity of symptoms may act as key factors in preventing a timely diagnosis (Dunselman et al., 2014; Ghai et al., 2020; Moradi et al., 2014). Other contributory factors may include limited access to gynaecology services, a lack of clinician awareness or understanding of the condition, and concerns surrounding the use of a laparoscopy as an invasive surgery particularly in younger women (Ballard, Lowton, & Wright, 2006; Dunselman et al., 2014; Moradi et al., 2014). A recent exploration of the experiences of GPs and gynaecologists suggested that clinicians were aware of the condition but suggested that a lack of training resulted in a limited understanding of some reproductive disorders (Young, Fisher & Kirkman, 2017).

This delay was described as a 'battle for an accurate diagnosis' by those affected, with an emphasis on the lack of accurate information and conflicting advice from healthcare professionals (Grogan et al, 2018, p.1369; Moradi et al., 2014; Young, Fisher & Kirkman, 2015). Patients have also reported the misdiagnosis of endometriosis as other reproductive conditions, including ovarian cysts and pelvic inflammatory disease (Moradi et al., 2014). Women commonly report that before receiving an accurate diagnosis, clinicians repeatedly normalise and dismiss their symptoms as 'painful periods' (Grogan et al., 2018, p.1369; Johnston, Reid, & Hunter, 2015). Research suggests that a delay in diagnosis may foster disease progression therefore exacerbating painful symptoms, and increasing the risk of infertility (Brosens, Gordts & Benagiano, 2013; Coxon, Horne, & Vincent, 2018; Unger, & Laufer, 2011).

### *Support*

For many women, an effective support network is key in managing the emotional and physical effects of the condition, throughout the diagnostic journey. Current NICE guidelines provide recommendations for physical care, primarily conducted by endometriosis specialists or

gynaecology services (NICE, 2015). The ESHRE guidelines published in 2013, offer further recommendations for pain and hormone management, and are often used in conjunction with the NICE standards to form a treatment framework (European Society of Human Reproduction and Embryology, (ESHRE), 2013). However, these provide little guidance on emotional support, and as such, patients commonly report a dissatisfaction with clinical care (Grogan et al., 2018; Moradi et al., 2014; Rogers et al., 2013). This results in a 'lost faith' with healthcare professionals, and in the face of such clinical neglect, many women rely on alternative methods of support (Grogan et al., 2018, p.1369; Hu et al., 2012; Roomaney & Kagee, 2018). This includes family and peers to support daily functioning, as well as online support groups to share experiences, receive advice and empathise with others (Hu et al., 2012; Roomaney & Kagee, 2018; Shoebbotham & Coulson, 2016;).

Despite a growing understanding of endometriosis in women of all reproductive ages, current research within the adolescent population is limited. Research suggests that any stage of the condition, including deep endometriosis (DE) can occur during young adulthood, and thus presented symptoms are similar to those in adult women (Janssen et al. 2013). Contemporary literature has largely focused on surgical and clinical outcomes for young women, and the effectiveness of different treatment plans (Dowlut-McElroy & Strickland, 2017; Saridoğan, 2017). However, endometriosis indicator symptoms are often ignored or dismissed in adolescents, predominantly due to the normalisation of symptoms during puberty (Dunselman et al., 2014; Johnston et al., 2015). Adolescence is a key period of transition, development and identity formation, and research suggests that individuals are at increased risk of developing emotional and behavioural problems during this time (Kroger et al., 2010; Lerner & Steinberg, 2009; Steinberg, 2005). Research suggests that adolescents with endometriosis symptoms will experience multiple obstacles during this time, thus often reducing their quality of life (Le Roux et al., 2021). This is further illustrated in recent literature exploring the impact of living with other long-term health conditions on adolescents; teenagers with juvenile idiopathic arthritis (JIA) described the physical and psychological burden of living with the condition, and the need to develop a level of resilience to overcome these barriers (Cartwright et al., 2015). Furthermore, nearly half of young adult cancer patients also expressed their experiences of distress associated with the diagnostic journey, as well as ongoing concerns surrounding treatment decisions, work/school issues and sadness (Chan et al., 2018).

Despite evidence surrounding preferred treatment plans for adolescents, there remains very little academic research into the impact of endometriosis for this population. Recent research priorities, suggest that improvements to the diagnostic process and effective psychological management methods should be at the forefront of current research (Rogers et al., 2017). Current literature also offers little understanding of the importance of support during this diagnostic period, and thus a greater understanding of these experiences may inform future practices within a clinical setting and improve current care structures for younger women. Such methods of family and social support are key for healthy development, body awareness and self-identity during adolescence and young adulthood (Colarossi & Eccles, 2003; Kia-Keating et al., 2011). This is corroborated by extensive research into adolescent teenage cancer patients, suggesting that effective support from peers may improve experiences, particularly within an

education setting, also causing them to feel more encouraged during this period (Pini, Gardner, & Hugh-Jones, 2013; Cho, & Park, 2017). Furthermore, a study investigating responses to a HIV diagnosis, found that adolescents and young adults receiving are also more likely to openly discuss their diagnosis, with a higher level of perceived social support (Lee et al., 2015). The aim of this study is to explore young women's experiences of an endometriosis diagnosis, in order to gain a better understanding of the impact of this process and the role and importance of support structures.

## **Methodology**

### *Design*

This study gained ethical approval from the University's ethics panel. A qualitative study using semi-structured on-line interviews was designed, and an interpretative phenomenological analytic (IPA) approach was adopted. This approach was most appropriate to understand each individual experience and to pursue in-depth discussions surrounding the diagnostic journey (Pietkiewicz & Smith, 2014; Smith, 2003). This method of data collection also enabled vulnerable participants to speak freely without pressure from the researcher, in a safe and comfortable environment to encourage an open dialogue (Biddle et al., 2013; Jamshed, 2014; Low, 2013). The use of video interviews was based on the geographical dispersion of participants across the UK and therefore the impracticality of in-person interviews (Janghorban, Roudsari & Taghipour, 2014). This method also allowed the researcher to observe significant nonverbal and social cues (Janghorban, Roudsari & Taghipour, 2014; Nehls, Smith & Schneider, 2015). The use of focus groups for this sample was also considered, however potential emotional distress elicited when discussing personal topics may have been uncomfortable in a group setting (Gill et al., 2008; Willig, 2013).

### *Participants*

In line with IPA recommendations, a small homogenous sample of 9 women was recruited from two endometriosis Facebook support groups, with a cumulative 67,000+ members (Alase, 2017; Smith, 2003). Inclusion criteria for this study specified that all individuals must be aged 18-30 years old and current UK residents. Those pre-clinical diagnosis via a laparoscopy and/or suffering from another chronic condition were excluded to maintain a focus on the idiosyncrasies of the endometriosis diagnostic journey. The focus on UK residents was to enable an exploration of the diagnostic experiences within a single healthcare system (National Health Service, NHS), which is free and available to all UK residents, regardless of wealth status, age, or background. The referral process and specialist provisions within the NHS are similar across the UK, and therefore participants' accounts of their care all stemmed from the same baseline access to free healthcare. This is unlike other countries such as the US where access to healthcare is based on health insurance and therefore fundamental care provisions may differ based on location or individual circumstances. The age range of 18-30 was chosen as this study focused on exploring young women's diagnostic experiences, with a specific focus on the impact of this journey on significant life events during young adulthood. This age range encompassed likely

periods of substantial life adjustments, including moving to university, starting full time employment, financial changes, and/or starting a family (Lewinsohn, Rohde, & Gau, 2003). To protect participants, all individuals were allocated a participant number for identification purposes and referred to using pseudonyms within all other discussions. All other names referred to within the discussions were changed and any reference to geographical locations was omitted. All identifiable details, participant information and data were stored on the University OneDrive system, accessible only to the researchers if necessary.

### *Data Collection*

Participants were recruited from both Facebook groups over a four-week period, and individuals interested in participating were asked to contact the researcher via email. Participants were then provided with a detailed information sheet and consent form, describing the aims of the study, potential risks, details surrounding withdrawal, anonymity and confidentiality, and a reminder of the inclusion criteria. Following the return of the completed written consent form, a 30–40-minute video interview was organised at a mutually convenient time.

The interview schedule for these discussions was based on relevant literature; after establishing a basic understanding of the participant's endometriosis history, this schedule focused on more specific issues using a number of open questions and prompts to elicit rich participant-led discussions (Galletta, 2013; Gill et al., 2008; Smith, 2003). The questions posed provided opportunity for descriptive accounts of the diagnostic experiences with reference to the importance of support, and the role of clinicians and health services during this period (Moradi et al., 2014; Rowlands et al., 2016).

Individual interviews were carried out over a two-week period using the video meeting platform 'Zoom', during which time the researcher made notes of any poignant discourse for later reference, and all interviews were audio recorded using a mobile phone then subsequently transcribed. Participants were then emailed a debrief form, as well as a £10 online voucher in thanks for their time. Within 6 weeks post-interview, participants were emailed the transcript and were asked to review the text within a two-week period to confirm the accuracy of the details discussed.

### *Data Analysis*

The interviews were transcribed verbatim and analysed by G.W. based on the IPA framework from Smith et al. (1999). The first interview was read and re-read, and initial considerations were noted in the left-hand margin, based on a preliminary interpretation of the discussion. The right-hand margin was then used to note emerging themes, and this process was repeated for all other interviews. These emerging themes were then collated, followed by a search for connections and thus potential patterns across the datasets to develop superordinate themes (Smith et al., 2009). To ensure validity throughout this process, G.W. produced regular commentary to reflect on key areas of interests, the participants' choice of language, and any unique interactions (Biggerstaff & Thompson, 2008; Rohleder & Lyons, 2014). Furthermore, to

minimise bias within this analysis the researcher continuously evaluated and reflected on their role within the study, as well as evaluating the research practices with vulnerable participants (Ngai & Chan, 2020; Rohleder & Lyons, 2014).

### *Data Sharing Statement*

The current article includes the complete raw data-set collected in the study including the participants' data set, syntax file and log files for analysis. Pending acceptance for publication, all of the data files will be automatically uploaded to the Figshare repository.

## **Results**

Three superordinate themes were established: the pursuit of a diagnosis, adjusting to a new normality, and the importance of effective support. All superordinate themes are described below, with each sub-theme explained in detail, with reference to illustrative quotes. These themes are also summarised in Table 1.

### *The pursuit of a diagnosis*

A key theme amongst young women with endometriosis, was the prolonged diagnostic process, from the initial reporting of symptoms, often during early puberty, to the diagnostic laparoscopy. This delay was largely attributed to failures within reproductive clinical practices and guidelines, and consistent age-based dismissal. Two sub-themes were identified: ineffective clinical practices, and age-based dismissal.

#### *Ineffective clinical practices*

The responsibilities of healthcare professionals to appropriately advise suspected endometriosis patients throughout this journey was at the centre of the concerns, and the lack of comprehensive guidance often resulted in a distrust of clinicians.

*"I think I would have actually kind of wanted someone to spend 10 minutes actually explaining you know what endometriosis is and what that means for you and you know the actual journey you're about to take because I literally felt like at the time I was going in blind" (Florence, 338-345)*

Many participants expressed that they had experienced painful symptoms for a number of years, prior to attention from clinicians. Once symptoms were presented to their GP, some participants remained confused about the nature of the condition and the proposed treatment plans. As the only official method of diagnosis, a laparoscopy often became particularly important to individuals within this experience, and the long journey often centred around this surgery, as described by Inez and Natalie.

*"I kind of saw the surgery as like the light at the end of the tunnel" (Natalie, 341-343)*

Furthermore, following the presentation of endometriosis related symptoms, clinicians remained hesitant to refer these women to specialist care routes. Instead, treatment plans offered orientated around the long-term use of hormone and pain management methods. This reliance of pharmacological methods to curtail painful symptoms, was frustrating for many participants, and this often lengthened the diagnostic process. Inez believed that healthcare professionals had little concern for the origin and potential exacerbation of symptoms and were primarily focused on the use of regular medication.

*"...I knew for a fact, but they were just throwing any tablet at me to try and not focus on what it actually was" (Inez, 435-438)*

#### *Age-based dismissal*

Participants often attributed this necessary persistence with clinical staff, to the continuous dismissal by healthcare professionals, with crucial endometriosis indicator signs frequently disregarded, typically based on the younger age of participants at the first presentation of symptoms. The age range of participants from 18-30 allowed participants to discuss their experiences of ineffective healthcare practices throughout their diagnostic journey, which for most began in adolescence. Both Molly and Natalie alluded to experiencing age-based bias within gynecologic clinical care.

*"...it annoys me that you kind of get labelled with the crazy girl, teenager looking for attention before you've even opened your mouth" (Molly, 706-708)*

*"I think as well being so young, they don't really take you seriously" (Natalie, 512-513)*

Some participants also discussed the need for persistence with clinical staff, in order to 'feel heard', and to eventually establish access to specialist gynecology services. Inez discussed her advice to a peer who was experiencing endometriosis-related symptoms, emphasising the need for persistence in the face of dismissal from clinicians.

*"...I've said, 'you just have to keep going and saying like I want the laparoscopy because I need answers' and eventually, they do take you seriously, but it does take time" (Inez, 495-499)*

#### *Adjusting to a new normality*

As the diagnostic journey progressed, many participants emphasised the importance of creating a new sense of 'normality', to make sense of their experiences. This was particularly important with regards to the ages of participants during this diagnostic process; many individuals described the need to develop a new-found sense of identity during adolescence and young adulthood. These adjustments as represented by three subthemes: fertility-based decision making, a lack of shared understanding, and the duty of care.

#### *Fertility-based decision making*

As part of their developing identity, many participants developed their understanding of what it means to be a 'woman', by expressing concerns surrounding potential future. These worries often centred around the dismissive attitude of healthcare professionals, and the frequent delay of surgery unless the individual's upcoming plans included conceiving. As such, participants felt as if their day to day decision making should consider future family planning, which often had a negative impact on emotional wellbeing.

*"...my only goal in life that's been like stable throughout my entire life is wanting to have a family I was like it's literally going to be taken" (Penelope, 516-520)*

Furthermore, Ruby's experience presents a particularly alarming case of indiscretion and subsequent emotional distress and clearly illustrates the crucial role of clinicians to provide informed guidance within fertility-based decision making.

*"...this doctor told me I was never gonna get pregnant, so in my head 'okay why would the doctor say (inaudible)' I'm having unprotected sex and then the next thing you know I'm pregnant" (Ruby, 297-301)*

#### *A lack of shared understanding*

This indifferent attitude from healthcare professionals is also highlighted in the limited clinical knowledge surrounding the condition. As the first point of contact prior to a specialist gynecology referral, participants expressed that GPs often offered little informed guidance about endometriosis and the potential impact on daily life. Participants expressed their subsequent feelings of isolation and frustration, which was exacerbated by the lack of public awareness of the condition.

*"It's just ridiculous, like one in ten people that have endometriosis then why is there no knowledge about it and why is there no support?" (Ella, 665-668)*

Despite this lonely experience, many participants began to accept endometriosis as part of their normal functioning, and the physical and emotional consequences became part of the life. Molly expressed this sentiment, when discussing the growing awareness of the condition and the importance of understanding abnormal symptoms.

*"...it's quite nice that people are kind of like revaluating their normal and thinking 'is it actually normal or is it just what I'm used to?'" (Molly, 616-619)*

#### *The duty of care*

Although the condition was accepted as the 'new normality' by many participants, some acknowledge a persistent sense of responsibility for their own care, as opposed to the usual clinicians' duty of care. Often associated with the current stigma surrounding reproductive health and lack of understanding about endometriosis, participants expressed a sense of obligation to be informed about the condition and advise clinicians themselves. Ella highlights

this need for individual research and the importance of self-management practices due to the lack of comprehensive clinical guidance.

*"it's not classed as a specific thing it's not like it's a condition not disease type of thing and different things like that so um that kind of puts me in more of a position where I have to do my own research a little bit more" (Clare, 772-777)*

Furthermore, even when accessibility provisions were available, participants found that clinicians were reticent to refer or publicise potentially useful resources. As such, participants' individual research also included an autonomous pursuit of self-management methods; these included a range of holistic therapies and avoidance diets in an attempt to alleviate painful symptoms and manage the condition long term. However, some participants depicted this search as more of a burden, as illustrated by Inez below.

*"...there wasn't really that much like offered like I thought there would be some sort of support afterwards or like some ideas on how to take care of myself and maybe things I shouldn't be eating, drinking just things to manage" (Inez, 387-393)*

#### *The importance of effective support*

A key component within the diagnostic journey for all participants, was the utilisation of complex support structures to alleviate emotional distress and improve overall wellbeing. These networks included family, friends, and online support, such as Facebook groups. All participants emphasized the significant role of their own support networks in their diagnostic journey, often improving both their emotional and physical wellbeing. However, these support methods often stemmed from a lack of clinician support or informed guidance. The three sub-themes represent these distinct channels: the role of social support, utilisation of online platforms and concerns surrounding clinical care.

#### *The role of social support*

The importance of peers and family members was emphasised by most participants, and discussions often revealed an increased dependence on these networks during periods of extreme stress or anxiety. These narratives illustrated the impact of endometriosis on the lives of all those involved. Participants spoke of the sacrifices made by others in order to provide reliable support, including changes in employment and relocation.

*"my Dad or Mum would like she just like drop anything and like come and pick me up" (Penelope, 333-335)*

Some peers and close friends were also able to effectively support participants, particularly when away from home (e.g. at university), and many expressed an interest in knowing more about the condition to offer specific care.

*"I was able to talk to my close friends and my uni course mates about the situation and about what I had and what the future could be looking like and things, and they were*

*really supportive like they were open to wanting to know and understand a bit more” (Clare, 381-388)*

#### *Utilisation of online platforms*

Some participants also revealed the importance of online support during their diagnostic journey including Facebook groups and other social media platforms. These offered the opportunity to share their experiences, ask for advice, and gain empathy from others affected by endometriosis. Florence illustrated the significance of these online channels, as she described the feeling of safety when interacting with others within these Facebook groups.

*“...I kind of felt just a bit more security cause it was like a little network of people who actually kind of know what you’re going through” (Florence, 319-322)*

Conversely, some avoided these online support channels due to the intensity of this form of communication. Natalie expressed the importance of an ‘endometriosis free space’ within her social media channels, in an attempt to avoid constant thoughts and to develop a feeling of ‘normality’ as previously discussed.

*“I don't really like seeing it all the time, it just makes me think about it so it's quite nice to just have Instagram as like not stuff you don't want to think about all the time” (Natalie, 532-537)*

#### *Concerns surrounding clinical care*

However, the use of these complex support structures including online channels, peers, and family, primarily stemmed from a lack of comprehensive care within a clinical setting. Feelings of frustration and disappointment were rife amongst participants, as described by Natalie with reference to the limited long-term support for her emotional wellbeing throughout the diagnostic journey

*“...I do think there needs to be more support surrounding that, especially for younger women because I just think it's really really daunting knowing that there's something that you could be living with for the rest of your life” (Natalie, 471-477)*

Some participants also explained that as a younger patient, clinicians in fact offered scaremongering advice to dissuade the search for a diagnosis, instead of providing impartial support throughout this period. This lack of care from a clinical perspective is highlighted in Ella’s experience, during which a clinician suggested the possibility of psychological harm if she were to pursue a diagnosis.

*“...this NHS person said to me ‘oh I’ve got women here who are now in psych wards because of endometriosis’ like they were just very negative and it made me feel so awful that I just I just couldn’t do it anymore” (Ella, 243 – 249)*

## **Discussion**

The issues, frustrations and experiences discussed by participants, brought light to a complex and nuanced journey prior to receiving a diagnosis. Analysis of patients' accounts revealed ongoing frustrations with clinical care, centred around feelings of dismissal when presenting symptoms to healthcare professionals. Similar to previous research, these experiences stemmed from a limited understanding and a lack of informed guidance surrounding endometriosis for both patients and clinicians (Grogan et al., 2018; Moradi et al., 2014). Many participants were also mistreated on the basis of age, and literature suggests that symptoms are regularly dismissed in younger women as 'painful periods' (Grogan et al., 2018, p.1369). Such experiences frequently resulted in a distrust of clinicians, and this was labelled as a frustrating 'battle' in similar exploratory research (Grogan et al., 2018, p.1369; Moradi et al., 2014). These experiences were also part of a wider, complex relationship between patients and healthcare professionals. The lack of support and guidance available, resulted in a distrust with clinicians, and a 'lost faith' with GPs specifically. Subsequently, research suggests that patients often feel clueless about their condition, and as such, many feel responsible for their own care through pursuing independent research (Roomaney & Kagee, 2018; Zarbo et al., 2018). Many participants expressed a similar sense of obligation to employ self-management methods and make significant lifestyle changes, including holistic therapies and avoidance diets. These changes align with previous research, with a recent study suggesting that over 75% of women affected by endometriosis, regularly use such techniques (Armour et al., 2019). Following these new coping strategies, participants reported decreased pain and a greater confidence in managing their own condition, thus reducing the frequency of depressive episodes (Zarbo et al., 2018). However, this study presented contrasting experiences, with participants depicting this responsibility as a burden, particularly during adolescence. To encourage long-term, effective self-management techniques, literature suggest that psychoeducation may play an important role (Bitzer, 2011; Van Niekerk, Weaver-Pirie & Matthewson, 2019).

Those interviewed also highlighted concerns surrounding the lack of awareness and understanding for those affected by endometriosis, as participants had become frustrated with the limited information available in the public domain. Research suggests that this may stem from the stigma surrounding reproductive health, particularly within mixed-gender educational settings (Gupta et al., 2018). This is paired with a current lack of comprehensive clinical guidance for diagnosing and signposting those presenting with endometriosis indicator symptoms, resulting in the label 'missed disease' (Overton, & Park, 2010). A risk associated with this delayed diagnosis is that patients experience feelings of isolation, especially during crucial periods of identity development during young adulthood (Cole, Grogan & Turley, 2020; Marschall et al., 2021). This was particularly evident in participants' concerns surrounding fertility, with many questioning their role as a woman based on social and cultural expectations. Recent literature suggests that infertile women with endometriosis struggle to maintain a 'feminine identity' (Cole et al., 2020), as well as anxiety and worry surrounding future family planning (Hudson et al., 2016). Participants in this study also emphasised the role of clinicians in fertility-based decision

making to provide informed guidance, alongside the emotional support from within their own support network.

The importance of this intricate support network was emphasised by all participants, in order to improve emotional wellbeing and mitigate the physical effects of endometriosis. Literature suggests that this support system also allows women to be alleviated of their day-to-day responsibilities, as well as encouraging them to access specialist care (Roomaney & Kagee, 2016). This social support has also been highlighted as a key factor in improving endometriosis patients' psychosocial wellbeing for reproductive health specialists (Culley et al., 2013; De Graaff et al., 2013; Dunselman et al., 2014). Other forms of support included social media channels and Facebook support groups, utilised by participants to discuss surgery and lifestyle-based advice. According to a recent study, these groups create a safe network to share experiences, although many users substantiated concerns surrounding the accuracy of the information and the need to avoid constant reminders of the condition (Shoebotham & Coulson, 2016).

The current study presents several strengths, including the use of semi-structured video interviews which allowed for an in-depth exploration of participants' experiences, accompanied by the use of a small, homogenous sample in line with IPA recommendations (Smith, 2003). This sample allows for a detailed understanding of a sub-group of women diagnosed with endometriosis aged between 18 and 30, however the capture of such niche experiences limits the generalisability of these findings to wider populations. This lack of generalisability is also highlighted in the predominantly English speaking, White British nature of the participants, revealing an opportunity for a more ethnically and culturally diverse population under study within future research. This group were all recruited as UK residents, and therefore all had access to the same free fundamental healthcare provisions under the public system of the NHS. This allows all individuals to access specialist services, regardless of their wealth status, background or age, and therefore these participant experiences can be directly compared. However, to better understand endometriosis healthcare services across a wider demographic, it is important to explore the experiences of patients for whom healthcare is based on their insurance status or wealth, for example the United States. Furthermore, the use of Facebook groups as the sole recruitment medium also presents particular challenges surrounding a limited scope of experiences, and a potential for those choosing to access the groups based on their more severe symptoms (Moradi et al., 2014; Shoebotham & Coulson, 2016). Individuals choosing to access these Facebook groups may also be more likely to seek out social support, and thus may lack sufficient support outside of social media platforms. Furthermore, many elements of the diagnostic journey were often discussed in retrospect, up to 10 years prior to the interviews, revealing potential challenges in the accuracy of particular details and experiences. These challenges are difficult to overcome within qualitative research, although such methods allow for crucial moments of synchronic reflection within the interviews (Abbott et al., 2016).

Within current literature surrounding the coding process in qualitative research, there is some discussion surrounding the measurement of coding reliability. Although this is a contested area,

there is scope for this in some instances, including approaches such as content analysis and synthesis of qualitative studies, where this type of assessment may be beneficial (O'Connor & Joffe, 2020). However, in methods such as IPA, this approach would not be advantageous, as it contradicts the interpretative agenda of this approach and diminishes the importance of the researcher's subjectivity and engagement with the data. The nature of IPA as a 'double hermeneutic', suggests that it is the role of the researcher to make sense of the accounts provided by participants, as their own interpretations of their experiences. According to the guidelines relating to establishing validity in qualitative research by Yardley (2000), a key part of this process is ensuring sensitivity to the individual experiences, and to offer accurate interpretations of these, with reference to existing literature. This is evident in this paper in the open-ended questions, prompting a participant-led discussion of their poignant experiences, followed by a perceptive analysis of the data with the use of illustrative quotes to support the researcher's explanation. This is reinforced by a commitment to the topic and a deep understanding of the data; the primary researcher conducting the interviews also had their own experience of endometriosis, thus creating a 'shared reality' with the participant (Van Helsdingen & Lawley, 2012). This was disclosed to participants, and although not discussed in any detail, such a likeness allows for an empathetic approach to collecting and analysing this data. Furthermore, to avoid any 'unintended influence', the primary researcher used a semi structured interview schedule to focus on particular elements of the diagnostic journey relating directly to the research question, and consistently checked for false assumptions within the analysis process (Van Helsdingen & Lawley, 2012; Grant, 2014). The rigour of this IPA process was also enhanced by regular meetings between the researchers, to discuss ideas, and to ensure that the themes were an accurate reflection of the interpretation suggested by the primary researcher. This supports the suggestion by Smith et al. (2009), to include an 'independent audit' as a key element of validity in IPA, to continuously assess all the elements of the analytic process.

The guidelines by Yardley (2000) also suggest that the specific details of the analysis process must be outlined, as well as a 'fit' between the research question, and philosophical perspective (IPA). This research question and IPA research practices outlined in this paper, offer a focused and detailed interpretation of the experiences of young women with endometriosis, thus achieving transparency and coherence in ensuring the reader understands these accounts (Yardley, 2000). Finally, the impact and importance of these findings is highlighted in the discussion, with reference to changes in clinical practices, and opportunities to develop current support structures for these individuals.

Some discussions surrounding intimate aspects of the diagnostic process also had the potential to elicit emotional distress, and as such, the researcher avoided excessive sympathy and continual reassurance towards participants (Ashton, 2014). Furthermore, the use of video interviews as a synchronous form of data retrieval, allowed for face to face interaction which promoted comfort and a sense of control for the participants to discuss chosen topics of significance (Mealer & Jones, 2014; Nehls, Smith, & Schneider, 2015). This method aimed to

reduce potential emotional distress, by creating an open environment within which to discuss such personal experiences and topics (Janghorban, Roudsari & Taghipour, 2014; Salmons, 2009).

These discussions provide a basis from which to offer potential improvements to the diagnostic journey and subsequent support. Current guidelines provide generic clinical advice designed for women of all reproductive ages, therefore negating the particularities of the diagnostic process for younger women (NICE, 2015). The age-based dismissal discussed by many participants plays a central role in exacerbating the average period of 8 years prior to receiving a diagnosis (*Endometriosis UK*, 2011). This illustrates current shortcomings within clinical practices, often deriving from a lack of comprehensive information and understanding of the condition (Laufer, Sanfilippo, & Rose, 2003; Staal et al., 2016). Improvements to clinical guidelines may also incorporate more holistic advice including diet and lifestyle changes, alongside current recommendations for hormone and pain management (Mettler et al., 2014). The importance of introducing structured self-management techniques also highlights the need to provide a more comprehensive support structure within clinical care. This may include in-person support groups, information surrounding psychological wellbeing and therapy options for women both pre and post-surgery, to improve satisfaction with clinical care and develop the patient-clinician relationship (Grogan et al., 2018; Moradi et al., 2014; Rogers et al., 2013).

Future research in this area may further explore the specific experiences of younger women, with specific reference to the stigma surrounding the condition and the impact of this journey on identity development. Current findings reveal deep-rooted fertility concerns related to the perceived characteristics of 'womanhood' which suggests a more nuanced journey of self-identity which is not yet fully understood. Furthermore, this is one of the first studies to discuss the role of online support channels for these women, and thus highlights an important area for future research to explore interactions within these groups (Roomaney & Kagee, 2018).

## **Conclusion**

To conclude, this study used a phenomenological approach to provide an in-depth exploration of young women's experiences of an endometriosis diagnosis, and the role of support throughout this journey. The findings from this research highlight the importance of enhancing clinical guidelines to improve the diagnostic process, to facilitate a more emboldening treatment practises. Future research is necessary to understand the impact of a diagnosis on patients' identity, with particular reference to stigmatisation and fertility concerns, as well as the role of online support within this process.

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