



Self-managed dietary changes and functional gut symptoms in endometriosis: A qualitative interview study

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ABSTRACT

Objective: Endometriosis is a chronic gynaecological condition, often causing gastrointestinal symptoms and misdiagnosed as irritable bowel syndrome (IBS). Endometriosis guidelines do not formally endorse dietary changes and little is known about how they are self-managed. The objective of this study is to understand nutritional practices and management of gut symptoms in people with endometriosis.

Study design: Participants were recruited as part of a larger survey study via endometriosis support groups on social media. Eligibility criteria were: a self-reported physician-led diagnosis of endometriosis, over 18 years old and residing in the United Kingdom (UK). Semi-structured interviews were undertaken virtually via Zoom using a predefined interview guide. All interviews were transcribed and analysed using thematic analysis.

Results: 10 people with endometriosis were interviewed. All had made individual dietary changes to manage their gut-related endometriosis symptoms. Dietary changes were made based on advice from social media support, books, websites or professionals other than dietitians. Changes included the restriction and exclusion of multiple essential food groups, including dairy, grains (primarily gluten), vegetables, fruits, and animal products. These changes impacted participants' weight, nutritional status and relationship with food. Four strong themes were identified: 1) impact of pain 2) severe and unpredictable gut symptoms 3) dietary changes and their impact 4) seeking support for dietetic intervention. A common thread underlying and linking these four main themes was the feeling of being dismissed, care being delayed and lack of support. Overall the long delay waiting for a diagnosis, surgery and, at times, the re-occurrence of symptoms post-surgery led to unsupported trial and error with modifiable lifestyle factors, including diet.

Conclusion: Overall, participants demonstrated some patterns of restrictive eating behaviour and wanted more professional support to help manage their endometriosis-related gut symptoms. This highlights the need for dietitians to be involved in endometriosis care to help alleviate gut symptoms, whilst ensuring nutritional adequacy and offering weight management support where required

1. Introduction

Endometriosis is an incurable and chronic gynaecological condition characterised by significant pain and infertility [1]. It presents as a complex disorder of unknown aetiology, often defined by the presence of endometrial-like tissue, sometimes referred to as 'lesions' or 'adhesions', presenting outside of the uterus [2]. It is estimated to impact approximately 190 million women of reproductive age worldwide [1,3] with 2 million affected in the United Kingdom (UK) [4]. The symptoms of endometriosis include chronic pelvic pain arising from painful

ovulation, painful periods, and pain during or after sexual intercourse. Gastrointestinal symptoms, including bloating, abdominal pain and change in bowel movement, are also a common feature of endometriosis, affecting up to 36–38.5 % [5,6]. In a recent survey, 84 % of UK respondents reported bowel symptoms related to endometriosis [4].

There is no cure for endometriosis, therefore treatments namely analgesia, hormone treatment and surgery are given with the aim of relieving pain, slowing growth of the endometrial tissues, improving fertility and prevention of recurrence [7]. Due to the available treatment options being invasive with potential side effects, people with

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endometriosis commonly opt for self-care practices to complement their medical treatments [8,9]. These practices can include dietary changes, exercise, yoga, meditation, herbal medications, Chinese medicine and acupuncture [9]. The use of self-care strategies allows people to feel more in control of their symptoms, rather than the pain controlling their life [10,11].

Several systematic reviews have been undertaken exploring the impact of dietary changes on endometriosis symptoms. However, despite some potential for dietary strategies to reduce symptoms, overall the evidence base is weak [12–14]. As a result, lifestyle therapies are not endorsed by international guidelines [15,16] and, therefore, not routinely recommended by healthcare professionals. Often the primary source of information about lifestyle and dietary changes is the internet/word of mouth [17], and self-administration of dietary changes is common [11,18,19].

Registered dietitians are the only nutrition professionals to be regulated by law in the UK, however dietetic interventions in endometriosis are currently minimal [6,20,21]. A recent survey undertaken by our group revealed a lack of training, resources and investment in staff, alongside a need for nutritional information from endometriosis patients [6]. The aim of this qualitative research was to follow up on our survey study and learn more about people's experience with different dietary approaches in endometriosis and their perspective on the impact of those approaches, particularly on gut symptoms. It also aims to explore in more detail preferences regarding sources of advice and healthcare professional support.

2. Methodology

2.1. Study design

A qualitative approach with semi-structured interviews and thematic analysis was used.

2.2. Participants and setting

Participants were recruited as part of a larger survey study [6], via endometriosis support groups on social media. The inclusion criteria were those with a self-reported physician-led diagnosis of endometriosis, over 18 years old, residing in the UK, with the ability to read, understand and speak English. Eligible participants were invited to participate in a virtual interview at a convenient time. The interviews were performed between Jan 2022 and August 2022 by one of the authors (KK) using Zoom and an online transcription service Otter. There was no fixed sample size and interviews were conducted until saturation of themes was reached.

All participants had undertaken individual dietary changes as a self-management approach to cope with their endometriosis symptoms, alongside their medical management. These dietary changes involved increasing or decreasing their intake of different foods or adding or removing foods from their daily diet.

2.3. Data collection

Data were collected via semi-structured interviews using an interview guide, which was developed on the basis of previous literature and the results of our group's survey (see [Supplementary file 1](#)) [6,11,20]. The contents of this interview topic guide may have been revised in light of themes identified through on-going analysis of interview data. This is a standard procedure in a qualitative study employing an emergent design. The participants answered the question freely in their own words, and follow-up questions were used to clarify any unclear descriptions. Recapitulation was used with individuals who stopped talking; directing them back to previous comments to clarify or elaborate on any descriptions. The interviews were conducted in English and were digitally recorded.

2.4. Data analysis

All interviews were transcribed and analysed using thematic analysis. The research team consisted of two registered dietitians (KK and KM). The analysis was data-driven and based on the conceptual framework proposed by Braun and Clarke [22], with the following steps: 1) initial reading; 2) preliminary identification of codes; 3) identification of themes; 4) review of themes; 5) allocating the themes into categories; 6) final study synthesis. Analysis, the hierarchy of themes, and final categories of data were discussed amongst authors and results decided by agreement.

2.5. Ethical considerations

Ethical approval was obtained from the University of Plymouth Faculty of Health Research and Integrity Committee (ref. 2809). Participants received oral and written information and were asked for written consent. To ensure confidentiality, the characteristics of the participants are presented at a group level, and the quotations are labelled with IP1 to IP10 to maintain anonymity.

3. Results

Ten people with endometriosis were interviewed, all were between 18 and 55 years and resident in the UK. Interviews lasted between 36 minutes and 64 minutes. The analysis of the interviews determined 4 main themes: 1) impact of pain 2) severe and unpredictable gut symptoms 3) dietary changes and their impact 4) seeking support for dietetic intervention. A common thread underlying and linking these four main themes was the feeling of being dismissed, care being delayed and lack of support, as shown in [Fig. 1](#).

3.1. Theme 1: impact of pain

It was collectively evident from the interviews the extent to which chronic pain disturbed the quality of life of the participants. Pain and distress followed a cyclical pattern for most around their menstrual cycle. Some of the participants described gastrointestinal symptoms as pain as it caused them severe distress. The impact of pain and gastrointestinal symptoms on their academic, career, exercise and life choices was reflected in their comments. Some reported to have given up their work, due to the exhaustion caused by the symptoms requiring sleep every few hours. One of the participants reported that though she has had 6–7 laparoscopic surgeries she continues to have residual pain (IP6). Though there was a high degree of pain and distress reported, there was a tendency for this to be taken as normal by many participants. However when they raised the concern, there was often the undesirable outcome of feeling unheard or their symptoms not being important ([Table 1](#)).

3.2. Theme 2: variability and severity of gut symptoms

The reported gastrointestinal symptoms included diarrhoea, abdominal pain, constipation and extreme bloating, which were very disruptive on daily life and could occur suddenly (see [Tables 2 and 3](#)). There was a trend of the symptoms being cyclical around menstruation in some of the women, but in others the symptoms were unpredictable and varied over time. Some experienced faecal impaction requiring hospital attendance and/or rectal bleeding. Some were told they had irritable bowel syndrome (IBS), but not offered further support.

3.3. Theme 3: dietary changes made and their impact

A multitude of factors were taken into consideration prior to making dietary changes. When asked specifically about changes made to diet and their impact on gastrointestinal symptoms, the primary change noted was to restrict food groups and components, such as dairy and

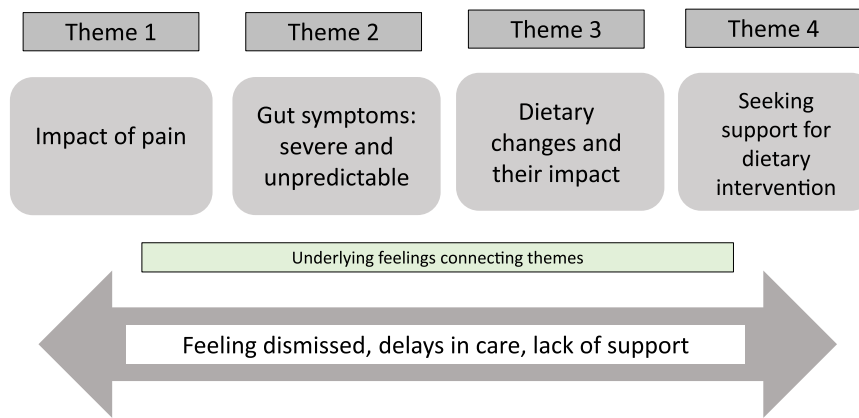


Fig. 1. Main themes identified.

Table 1
Quotes illustrating impact of pain theme.

Participant	Quote
IP1	“... during my period, where I would be, like, just genuinely unable to move in almost calling an ambulance kind of pain and pain in the abdomen, and all down the legs, and kind of almost head to toe really just sort of taking over the whole body”
IP3	“...I had to give up my job as I wasn't physically able to do it. I suddenly ran back and forth to the toilet or you know what I mean? It was just a horrible, horrible circle”
IP10	“...I've been going to the doctor for years complaining of the pain and telling them you know, could this be and we're asking them could this be endometriosis and every single one saying no”
IP8	“I continue to experience problems with painful periods, pelvic and abdominal pain outside of my period, the so heavy periods, and IBS type symptoms, fatigue, the whole host of kind of your standard endometriosis symptoms.... I went backwards and forwards to my GP. was referred to an NHS gynaecologist, who wasn't really interested in listening to what my symptoms were like, he just wanted to know whether I was planning to have any babies”

gluten. A summary of dietary changes made and any impact noted is shown in Table 3.

An attempt to find a dietary cure for endometriosis was explored by many. Most quests led to being exposed to approaches such as “anti-inflammatory diet” and “foods to reset hormones”. A higher intake of fruits and vegetables and use of organic foods was noted as an attempt to have an “anti-inflammatory diet”, as was avoidance of refined sugars. Several of the participants were very conscientious with trying to eat healthily and avoid processed foods, aiming to “cook from scratch” all the time (see Table 4).

Most of the participants were aware of there being no cure for endometriosis, indeed one stated that despite all the dietary changes endometriosis recurred post surgically. Some reported to have undergone a food intolerance test to identify foods they should restrict. Some

Table 2
Quotes illustrating theme of gastrointestinal symptoms.

Participant	Quote
IP2	“I bled for days, I was bloated to hell. And I bled for days and I had to deal with it. And that was quite frequent when travelling”
IP3	“So that's what I got told for years it was IBS and that was constant as IBS, IBS”.
IP4	“IBS type of symptoms come on quite suddenly.... One minute I could have really quite severe diarrhoea. A couple of hours later, I could be completely constipated”
IP5	“And then I used to get really bad bloating, I'd look like six months pregnant. And it within five minutes of the pain started and my stomach would balloon”
IP7	“I had constipation with big loss of rectal bleeding. So I was always anaemic, but received no help”

felt that despite adhering strictly to specific dietary restrictions, there wasn't any noticeable improvement in symptoms, leading to frustration and lack of hope. Others noted negative side effects, including losing too much weight and becoming anxious about reading and following food labels (IP8). One of the participants (IP6) was given advice to follow a liquid diet with nutritional supplement drinks pre and post surgery, which left her feeling extremely tired and depleted.

3.4. Theme 4: seeking support for dietary changes

The most common source of nutrition information was social media and online forums, although books were also mentioned. Online platforms provided considerable support for many; IP1 spoke of “joining a community of women who feel their voices have not been heard”. However the downside identified was unreliable and potentially unsafe information – IP6 spoke of potentially harmful advice to try the ketogenic diet (see Table 5).

All participants found it very difficult to source dietetic support, despite asking for referrals. IP5 spoke about seeking new advice from

Table 3
Summary of dietary changes made and their impact.

IP	Gastrointestinal symptoms	Individual food restrictions/additions	Impact noted
IP1	Bloating, diarrhoea prior to periods, slight constipation before and after period. Described it like it was a faecal impaction	Restricted dairy, white wine, sultanas, green grapes, beetroots. Health shop suggested vitamin B12 and D deficiencies based on the intolerance test described above. Included prune juice to help with constipation.	Food restrictions helped improve bloating to a great extent. Felt prune juice almost worked as a "miracle cure".
IP2	Bloating, diarrhoea, constipation	Excluded gluten and lactose, alongside reduced caffeine intake.	Feels has helped out bloating and faecal impaction, but has lead to her increasing the number of times opening bowels. Not sure of impact.
IP3	Mixed symptoms - constipation and diarrhoea (both reported at extreme levels), lack of energy, severe abdominal pain.	Excluded gluten, dairy, lactose, chocolate, fizzy/energy drinks, onion, tomatoes.	No impact on symptoms.
IP4	Mixed symptoms on the same day- diarrhoea, constipation, severe bloating and abdominal pain. Severe cramping.	Reduced dairy intake, alcohol, coffee and meat.	Gluten and dairy restrictions helped with bloating. Unsure of benefit of gluten free diet. Liquid diet helped gut symptoms, but caused fatigue. Unsure whether it helped
IP5	Severe bloating, diarrhoea.	Reduced dairy, sugar, red meat and spices.	Helped symptoms, but became underweight and anxious about restrictions. Lactose-free diet had a lasting and immediate impact on constipation.
IP6	Bowel and bladder pain, urgency	Gluten free diet. Liquid diet pre and post surgery	Helped improve overall symptoms and reduced fatigue.
IP7	Constipation	Excluded gluten, dairy, soy, caffeine, chocolate, beans, tomato puree.	
IP8	Abdominal and pelvic pain, fatigue	Reduced most carbohydrates (pasta, bread, potatoes) and excluded refined sugars	
IP9	Painful defecation, smelly stools, constipation and extreme fatigue.	Excluded lactose, red meat and soya.	
IP10	Faecal impaction leading up to period, followed by diarrhoea, bloating.	Reduced gluten intake.	

online endometriosis forums every time she had a symptom. However when she asked for a referral to a dietitian, she was advised that she would have to pay to access private healthcare. IP8 mentioned being told to google different dietary interventions and felt there was a strong need for: "regular check ins on how they're getting on with it, what their relationship is, like with food, because an exclusion diet is a very extreme form of diet".

4. Discussion

The aim of this study was to explore people's experience with different dietary approaches in endometriosis and the potential impact of those approaches, particularly on gut symptoms. We also aimed to understand further how people with endometriosis wanted to be supported by healthcare professionals in managing their endometriosis symptoms with diet. This was in the context of our recent published

Table 4
Quotes illustrating dietary changes and impact theme.

Participant	Quote
IP1	"...with it being an inflammatory condition. I mean, I really don't know. But I just thought surely if I try and cut out anything that's causing me inflammation, that's probably a good idea"
	"And some of them do fall off in the rabbit hole of restrictions and then associating food with negative aspects and then it starts controlling the life because they can't eat anything"
IP3	"After stopping gluten, lactose, sugar, coke, and chocolate... whether or not they're working I honestly don't know"
IP5	"I kind of I'm very strict about what I eat anyway. And you know, I cook every day I'm not someone who has like ready meals and things like that and just easy meals, kind of, I make sure I get like the raw ingredients and cook everything from scratch so I know what's going on in it"
IP6	"My bowels have just been a disaster for me since all the surgery. I did it for about six months really well. And I can't honestly say I noticed a massive difference.... It was just a bit frustrating because I tend to trust what I'm being told that yes, this is gonna work. This will be amazing. And it wasn't quite that way for me."
	"I'm told to go on a liquid diet (for up to a week). So when I go on a liquid diet, I do start to feel better. But obviously it's not sustainable.... Well, it's a lot of effort. And when I'm working, I get you know, if you're not eating and you haven't got nutrients, you just feel exhausted. And in my job, I can't be exhausted. I've got to be on my game. So it's it's never what I want to do...."
IP8	"And I lost, I lost a lot of a lot of weight. So I've never, I've never been overweight. So for context, I'm five foot six, I weigh about nine stone. But at the time I was following that diet, when I've been following it potentially for maybe six months, only weighed about seven stone. So I was quite tiny. And I didn't know that. I wouldn't necessarily say it helped my symptoms, enough to continue pursuing it to the impact that it then had on my mental relationship with food"
	"the restrictions in terms of constantly looking at food labels and the stress and anxiety that caused around what I couldn't eat"

Table 5
Quotes illustrating seeking support for dietary changes.

Participant	Quote
IP3	<i>“So I might maybe see a dietitian that we know. But I mean, I have been on that waiting list for almost two years”.</i>
IP7	<i>“I did ask for dietitian I did call the GP several times ... there is no help. And I mean, there is no help”</i>
IP5	<i>“... but it was really difficult, it will be a lot easier if I was able to be have like access to a dietitian. And I don't think anyone I've spoken to has had much help in that way. Yeah. So like I said, a lot of it is just your own self of like research and trying out different things”</i>
IP4	<i>“I think just having I don't know if there is a regulatory body, that for sort of things like that for endometriosis. And, you know, sort of listed to say whether it's been proven or not to help”</i>
IP6	<i>“I know someone who was on the keto diet, because she was told that would help her. But I literally watched her lose about a stone. I don't know, 10 days or something, whatever it was, and I just can't do that. If that cannot be healthy for you”.</i>
IP8	<i>“No he didn't give me a leaflet. But he told me to Google anti inflammatory diet or the endo diet”</i>
	<i>“you can't just say as a GP, you need to try the low FODMAP diet, go away and Google it. That's just not it's not a helpful approach is it? They should at least be some form of leaflets or even potentially an additional referral to someone like a dietitian who can help you to start to make those changes in a healthy way?”</i>
IP10	<i>“And it's one thing that my family keeps saying to me, like, you know, go and find a dietitian, and then speak to someone and actually, you know, check that you're not eliminating stuff that you're trying to that you actually do need that's going to, that is going to help you”</i>

survey [6], which demonstrated that only a quarter of respondents had satisfactory relief of gut symptoms, only 13.2 % had seen a dietitian regarding their gut symptoms, yet 57.7 % would find it useful to. Although our survey study provided quantitative data about access to nutritional information and advice from a large sample of respondents (n = 1385), it did not provide sufficient experiential understanding of the difficulties people with endometriosis in the UK face, which this present study aimed to do via semi-structured interviews.

Overall the four themes identified – impact of pain, severe and unpredictable gut symptoms, dietary changes and their impact and seeking support for dietetic intervention, underlined by a common thread of delay in diagnosis, being dismissed and lack of support; are similar to those identified by other international studies. Young et al. [23]

undertook a systematic review assessing experience of endometriosis summarising studies from the UK, Australia, New Zealand, Canada and France. Although they did not specifically focus on diet/nutrition, they explored women's experience of different treatments sources of information, underlining the profound effect of endometriosis symptoms on wellbeing and the need to improve healthcare professional knowledge of endometriosis management.

A more recent Swedish qualitative study [10], which did specifically focus on dietary changes, found that participants experienced an increase in wellbeing and a decrease in symptoms following their dietary and lifestyle changes. Although most of the participants interviewed (n = 12) excluded or decreased gluten, dairy products, carbohydrates, or those considered to increase inflammatory processes; as was the case in this study, their perception of the impact of these changes on their symptoms was considerably more positive than what we observed. This difference in experience in the effectiveness of dietary change may be due to the sampling of participants or variation in the type or severity of symptoms. Because endometriosis is a spectrum condition with wide heterogeneity [2], there is considerable variation in presentation and it is not yet known why treatments are more effective in some people than others [24]. Of note the average time to diagnosis in the UK is approximately 8 years [4] and the present study took place in 2022, following the COVID-19 pandemic, which further limited healthcare access and lead to worsening of symptoms including anxiety and depression [25]. Although the delay in diagnosis does not necessarily have a direct impact on gut symptoms, the chronic stress of not feeling heard could negatively impact wellbeing and perception of symptom relief. Similar to our study, Vennberg et al. [10] reported weak or non-existent support from healthcare professionals, however support from family and friends were identified as important in implementing and sustaining the dietary changes – an influential group to consider for any future interventions.

Nutrition could be perceived as one of the easiest modifiable factors in endometriosis management - with nutritional decisions being taken multiple times per day. However the increased stress, food preparation time and financial costs of following an exclusion diet should not be underestimated [11]. Those with endometriosis who want to self manage their symptoms can be vulnerable to poor nutritional practices that may be recommended online, this is particularly worrisome for those who follow restrictive diets at a time when they are looking to conceive. It was concerning to note that some participants experienced weight fluctuations, chronic anaemia and disordered relationships with food, due to following unfounded nutritional advice. Given the severity of gastrointestinal symptoms mentioned, it is understandable that they were increasingly desperate to implement dietary changes independently when unable to access healthcare professional support. Fortunately most participants were wary of information available online and recognised the importance of seeking reputable and reliable information, rather than falling down the “rabbit hole of restrictions”. A recent cohort study has identified an association between IBS, eating disorders and endometriosis, using validated screening tools, albeit in a small sample (n = 54) [26]. Although the association and overlap of IBS and endometriosis has long been established [27], the observation that eating disorders may also be more prevalent in endometriosis that in the general population, provides even more emphasis that those with endometriosis should receive nutrition and dietetic care as standard and be monitored regularly to ensure overly restrictive dietary patterns are not followed for too long unnecessarily.

4.1. Strengths and limitations

To our knowledge, it is the first qualitative study to explore diet and endometriosis in a UK-based population. A qualitative method was used to identify and describe dietary experiences and their consequences, providing a detailed insight into the phenomenon from the perspective of the person with endometriosis. Although the sample was relatively small (n = 10) the interviews generated a large amount of rich data,

which was sufficient to achieve both depth and width in the analysis and to reach saturation, with no new themes or subthemes being identified. The first author had strong insight into endometriosis and dietary intervention, having worked as a specialist gastroenterology and fertility dietitian, which enriched the themes, however may have been a source of interviewer bias. Weaknesses of the study are the reliance on recruitment via social media group, which may bias the respondents' viewpoints and that diagnosis and medical history were all self-reported.

5. Conclusion

This qualitative study exploring experiences of dietary changes in endometriosis management, has highlighted the severity and unpredictability of gut symptoms experienced and the absence of healthcare support. Overall the long delay waiting for a diagnosis, surgery and, at times, the re-occurrence of symptoms post-surgery led to unsupported trial and error with diet, which varied in its effectiveness. Participants demonstrated some patterns of restrictive eating behaviour, alongside nutritional depletion and wanted more professional support to help manage their endometriosis-related gut symptoms. Further research is needed to understand the effectiveness of dietary approaches in endometriosis and to streamline and standardise dietetic care.

Declaration of Competing Interest

None of the authors declare a conflict of interest.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.eurox.2023.100219](https://doi.org/10.1016/j.eurox.2023.100219).

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