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Nutritional practices and dietetic provision in the endometriosis population, with a focus on functional gut symptoms

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Abstract

Background: Endometriosis is a common condition causing chronic pain, fatigue and gut symptoms. Research suggests that dietary changes may improve symptoms; however, evidence is lacking. The present study aimed to investigate the nutritional practices and needs of individuals with endometriosis (IWE) and the management of endometriosis by dietitians in the UK, focusing on gut symptoms.

Methods: Two online questionnaires were distributed via social media: a survey of dietitians working with IWE and functional gut symptoms and a survey of IWE.

Results: All respondents to the dietitian survey ($n = 21$) used the low fermentable oligosaccharides disaccharides monosaccharides and polyols (FODMAP) diet in IWE, with the majority 69.3% ($n = 14$), reporting positive adherence and patient benefit. Dietitians recommended more training (85.7%, $n = 18$) and resources (81%, $n = 17$) for IWE. Of those who completed the IWE questionnaire ($n = 1385$), 38.5% ($n = 533$) had coexisting irritable bowel syndrome. Only 24.1% ($n = 330$) had satisfactory relief of gut symptoms. The most common symptoms were tiredness, bloating and abdominal pain, experienced by 85.5% ($n = 1163$), 75.3% ($n = 1025$) and 67.3% ($n = 917$), respectively. Some 52.2% ($n = 723$) had tried dietary modifications to relieve their gut symptoms; 36.7% ($n = 500$) ate a restricted diet at present; 13.5% ($n = 184$) experienced recent unintentional weight loss and 29.8% ($n = 407$) a decreased appetite. Some 13.2% ($n = 183$) had seen a dietitian regarding their gut symptoms. Of those who had not seen a dietitian, 57.7% ($n = 693$) would find it useful to.

Conclusions: Gut symptoms and dietary restriction are very common in IWE; however, dietetic input is not. More research on the role of nutrition and dietetics in the management of endometriosis is recommended.

KEYWORDS

dietetic provision, endometriosis, functional gut symptoms, irritable bowel syndrome

Key points

- Endometriosis is a common condition causing chronic pain, fatigue and gut symptoms.
- Research suggests that dietary changes may improve symptoms; however, the evidence is weak.

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- This survey study of dietitians and people with endometriosis found that gut symptoms and dietary restriction are very common in endometriosis; however, dietetic input is not.

INTRODUCTION

Endometriosis is an incurable and chronic condition estimated to impact approximately 190 million women of reproductive age worldwide,^{1,2} with 2 million individuals with endometriosis (IWE) in the UK.³ 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.⁴ Its symptoms are vast, including but not limited to debilitating pain, gastrointestinal issues, painful sexual intercourse, chronic fatigue, depression and subfertility.⁵ This can lead to decreased quality of life and interference with careers and relationships.^{3,6} In the UK, diagnosis is via multiple avenues including ultrasound, a blood test to detect serum CA125, magnetic resonance imaging and/or laparoscopy.^{7,8} Often prior to a formal surgical diagnosis, the route to diagnosis is one of elimination and referrals, taking an average of 8 years in the UK from the onset of symptoms,^{3,9} thus creating one of the largest barriers to receiving treatment, care and support.³ Treatments, such as pain medication, hormone treatment and surgery are given with the aim to relieve pain, slow growth of the endometrial tissues, improve fertility and stop the endometriosis from returning.⁵

Gastrointestinal endometriosis symptoms reported in the literature include abdominal pain, bloating, nausea, vomiting, painful bowel movements, constipation and diarrhoea, with one study suggesting that gastrointestinal symptoms are as common as gynaecological symptoms in IWE.¹⁰ Research has repeatedly shown that IWE has a three-fold higher prevalence of irritable bowel syndrome (IBS) than the general population.¹¹ Indeed, endometriosis shares several features of IBS, such as visceral hypersensitivity, low-grade inflammation and chronic stress, often leading to missed or delayed diagnosis.¹² Although the etiologies of both endometriosis and IBS are uncertain, multifactorial pathophysiology is hypothesised for each of them.

Recent research has suggested that dietary interventions may be beneficial in providing symptomatic relief in endometriosis. Systematic reviews have found that most dietary interventions, whether supplementation with selected vitamins, fatty acids or antioxidants, or exclusion of specific dietary components, reported a positive effect on symptoms.^{13–15} Specifically, the low fermentable oligosaccharides disaccharides monosaccharides and polyols (FODMAP) diet, proven to provide symptomatic relief in IBS patients,^{16,17} was effective in reducing recurrence of gut-related endometriosis symptoms.¹⁸

However, overall, the evidence was determined to be of low quality,^{13–15} with many unanswered questions remaining,¹⁹ including the role of dietetic care. In the UK, diet and nutrition are not currently listed as treatment options for endometriosis.⁷ Recent European recommendations²⁰ have advised that, although clinicians should discuss non-medical strategies (such as nutrition) to address quality of life and psychological well-being in women managing symptoms of endometriosis, no recommendations can be made for any specific intervention, as the potential benefits and harms are unclear.

The most recently updated National Institute for Health and Care Excellence (NICE) [NG73] guidelines on endometriosis care in the UK advocate for IWE to seek specialist healthcare professionals, and to make endometriosis treatment decisions together with their chosen professional via informed conversations about their health options.⁷ An extensive healthcare professional and patient survey conducted in 2016 in the UK and Ireland identified the need for self-management and non-surgical approaches as one of the top 10 priorities in endometriosis research.²¹ More recently, a UK government all parliamentary party report has called for more research, increased awareness of endometriosis symptoms amongst all healthcare professionals and better information provision and support for patients.³ The aim of the present study is therefore two-fold: one to investigate the management of endometriosis and functional gut symptoms by UK dietitians, and the second to explore nutritional practices and needs among the endometriosis population, especially in regards to functional gut symptoms.

METHODS

Overview of study

This research is concerned with pelvic endometriosis in humans, and will use the inclusive term 'individuals with endometriosis' (IWE). When referring to 'dietitians' we refer to UK registered dietitians.

Two separate questionnaire-based studies were carried out:

- A survey of dietitians working with IWE and functional gut symptoms (see Supporting information, File S1), and
- A survey of IWE (see Supporting information, File S2)

Development of questionnaires

Both questionnaires were developed for the purpose of this study and were hosted on the Jisc online survey platform (<https://www.onlinesurveys.ac.uk>). The dietitian questionnaire explored current practices, training, evidence base and confidence in managing IWE. It was piloted amongst a group of dietitians, with small changes made to improve readability and content.

The IWE questionnaire had five sections, which incorporated some previously validated scales:

1. Adapted questions from the British Society Gynecology Endoscopy (BSGE) Pelvic Pain Questionnaire (a standardised questionnaire administered in Endometriosis Centres of excellence, UK²²)
2. Gut symptoms including global symptom response, the Gastrointestinal Symptom Rating Scale (GSRs)²³ and the Bristol stool form scale.²⁴ The GSRs assesses the severity of abdominal pain, bloating, flatulence, burping, borborygmi, urgency, incomplete evacuation, nausea, heartburn, acid regurgitation and lethargy using a four-point scale (absent/rare, mild/occasional, frequent/moderate, continuous/severe).
3. General health: including information about appetite and weight.
4. Diet and lifestyle: including nutritional supplements, source of nutritional advice and dietary practices.
5. General demographic questions.

It was piloted amongst patient and professional representatives from Endometriosis UK (a national patient charity) and edited for clarity and content.

Recruitment

- A. Dietitian survey: The questionnaire was distributed online via the British Dietetic Association ezine and social media accounts of relevant specialist groups in July 2021. UK-based dietitians working with those affected by endometriosis and gut symptoms were eligible to participate.
- B. IWE survey: Participants were recruited through the social media accounts of the national patient charity Endometriosis UK in August/September 2021. Inclusion criteria were those with a diagnosis of endometriosis, aged over 18 years, resident in the UK with the ability to read and understand English.

Sample size

A formal sample size calculation was not performed because it was an exploratory study designed as preparatory work for a future intervention study. A pragmatic

decision was made to open both questionnaires for approximately 4–6 weeks, with a reposting on social media after 3 weeks to maximise recruitment.

Data analysis

Data was exported from Jisc online surveys to Excel (Microsoft Corp.) for data cleaning and then SPSS, version 24²⁵ for analysis. Individual symptom responses assessed by the GSRs were analysed in two ways. First, individual scores ranging from 0 to 3 for each symptom were combined into a composite symptom score.²⁶ The minimum possible score was 0 (no symptoms experienced at all) to a maximum of 33 (all 11 symptoms experienced continuously) Second, individual responses were collapsed into a dichotomous response to report the presence of 'rare/occasional' or 'frequent/continuous' symptoms as previously reported.²⁷ Stool frequency was classified into normal (once every three days to three times a day) or abnormal (less than once every 3 days or more than 3 times a day). Stool consistency was classified into normal (Bristol Stool Form types 3, 4 or 5) or abnormal (Bristol Stool Form types 1, 2, 6 or 7), as previously reported.^{26,27}

Data were checked for normality and analysed using descriptive statistics. Categorical responses were reported as frequencies and compared with chi-squared or Fisher's exact test. Continuous variables were compared using *t*-test or the Mann–Whitney test. Data on pregnant participants was excluded if likely to influence the responses (current gastrointestinal symptoms/weight), but included where pregnancy was not deemed relevant (e.g., source of endometriosis information).

Ethical approval was obtained from the University of Plymouth Faculty of Health Research and Integrity Committee (ref. 2809) for both studies.

RESULTS

Dietitian survey

Twenty-one participants completed the survey, of whom only 19% ($n = 4$) had a specific service level agreement for endometriosis patients. The majority of respondents specialised in gastroenterology (52.4%, $n = 11$) with a smaller proportion specialising in women's health/fertility (19%, $n = 4$). Almost half were working freelance in the private sector (42.9%, $n = 9$), rather than in the public sector. The largest source of referrals were gastroenterologists (47.6%, $n = 10$). Over half of respondents, 57.1% ($n = 12$), had completed specialist training in the management of functional gut symptoms. All respondents used the low FODMAP diet in this patient group, with the majority ($n = 69.3%$), reporting a positive patient

TABLE 1 Participant characteristics.

Variable	Category	% (n)
Age (years)	18–24	10.1 (140)
	25–35	40.2 (557)
	36–45	38.2 (529)
	46–50	8.4 (116)
	> 51	3.1 (43)
Ethnicity	Asian	2.2 (30)
	Black	0.5 (7)
	Other	0.2 (3)
	Mixed race	1.4 (19)
	White British	89.5 (1240)
	White other	6.1 (84)
Highest educational level	Postgraduate qualification	22.1 (306)
	University degree	33.4 (463)
	A levels or equivalent	19.5 (270)
	NVQ/HND/BTEC	13.5 (187)
	GCSE	10.0 (139)
	No qualifications	1.3 (18)
Occupational status	Full time work	63.8 (884)
	Part time work	17.9 (248)
	University/college	6.0 (83)
	Home	4.3 (60)
	Unemployed	0.8 (11)
	Unable to work due to sickness	7.1 (99)
Pregnant	Yes	1.4 (20)
When diagnosed with endometriosis	< 2 years ago	30.8 (426)
	3–5 years ago	26.5 (367)
	6–10 years ago	18.3 (253)
	>10 years ago	24.5 (339)

Abbreviations: BTEC, Business and Technology Education Council; GCSE, General Certificate of Secondary Education; HND, Higher National Diploma; NVQ, National Vocational Qualification.

benefit (> 6/10 on a scale with 10 being maximum benefit) and strong patient adherence to the diet (92.3% of patients > 7/10 adherent). However, 42.9% ($n=9$) rated their competence as low in providing any further input beyond management of functional gut symptoms (< 5/10 on a scale of 10). Dietitians recommended development of more training (85.7%, $n=18$) and written resources (81%, $n=17$) to enable them to better support IWE.

IWE survey

Participant demographic characteristics

In total, 1385 participants completed the questionnaire, for which details are shown in Table 1. The majority of respondents were white British (89.5%, $n=1240$) and were employed full time (63.4%, $n=884$). Over half of respondents were educated at university degree level or above (55.7%, $n=771$). Approximately one-fifth 20.2% ($n=280$) experienced a delay in diagnosis of 8–10 years and just 11.3% ($n=157$) were diagnosed in less than a year.

Gastrointestinal pain and symptoms

Overall, 38.5% ($n=533$) of respondents had been diagnosed with IBS. Of this group, 80% ($n=427$) had been diagnosed prior to being diagnosed with endometriosis. Table 2 shows gastrointestinal symptoms, stratified according to IBS diagnosis. Overall, all participants experienced gastrointestinal pain and symptoms, but they were significantly worse in those with IBS. In response to the global symptom question (do you currently have satisfactory relief of your gut symptoms), overall, only 24.1% ($n=330$) answered 'yes'. Pain opening bowels occurred in the majority of participants, both during their menstrual cycle and at other times (63.7% and 59.6%, respectively).

Details of the 11 symptom components of the functional gut symptom score are shown in Figure 1 and Table 2. The most common symptoms were tiredness, bloating and abdominal pain, experienced frequently/continuously by 85.5% ($n=1163$), 75.3% ($n=1025$) and 67.3% ($n=917$), respectively. Conversely, the least common symptoms were heartburn and acid regurgitation reportedly frequently/continuously by 23.2% ($n=315$) and 21.9% ($n=296$), respectively. All of the symptoms were significantly more likely to be experienced frequently/continuously in those with IBS, which the exception of heartburn (chi-square, $p < 0.05$ for all).

Weight status

Excluding pregnant respondents, the median body mass index (BMI) was 26.8 kg m⁻² (IQR, 8.5). An even proportion of respondents were classified as being in the healthy weight (30.3%, $n=414$), overweight (29.9%, $n=408$) and obese categories (31.2% $n=426$), with a smaller proportion of 7.7% ($n=105$) classified as underweight (BMI < 20 kg m⁻²). Half of participants reported unintentional weight gain in the last 3–6 months (50.4%, $n=688$). Conversely, 13.5% ($n=184$) experienced

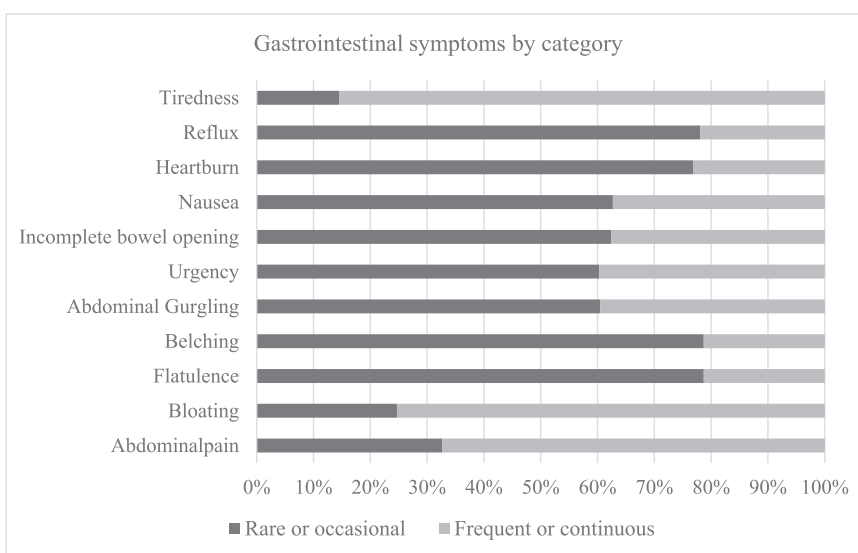
TABLE 2 Gastrointestinal pain and symptoms, stratified by IBS diagnosis.

	Participants with IBS (<i>n</i> = 524)	Participants without IBS (<i>n</i> = 840)	All participants (<i>n</i> = 1364)	2 sided chi squared <i>p</i> -value
Global symptom relief, % (<i>n</i>)	17.4 (91)	28.3 (238)	24.1 (329)	0.000
Pain when opening bowels during menstrual cycle, % (<i>n</i>)	65.5 (343)	62.5 (525)	63.7	0.004
Pain opening bowels at other times, % (<i>n</i>)	69.8 (366)	53.6 (450)	59.6%	0.000
Normal stool type, % (<i>n</i>)	44.7 (234)	50.5 (424)	48.3 (659)	0.039
Normal stool frequency, % (<i>n</i>)	76.9 (403)	84.8 (712)	81.8 (1116)	0.000
Abdominal pain, % (<i>n</i>)	75.8 (397)	37.9 (319)	67.3 (917)	0.000
Bloating, % (<i>n</i>)	82.6 (433)	70.4 (592)	75.3 (1025)	0.000
Flatulence, % (<i>n</i>)	54.2 (284)	39.2 (330)	45.1 (614)	0.000
Belching, % (<i>n</i>)	25.8 (135)	18.2 (153)	21.1 (288)	0.001
Abdominal gurgling, % (<i>n</i>)	45.4 (238)	35.3 (297)	39.3 (535)	0.000
Urgency, % (<i>n</i>)	48.9 (256)	33.8 (284)	39.6 (540)	0.000
Incomplete evacuation, % (<i>n</i>)	42.4 (222)	34.2 (288)	37.5 (510)	0.003
Nausea, % (<i>n</i>)	43.5 (228)	32.9 (277)	37.1 (505)	0.000
Heartburn, % (<i>n</i>)	25.8 (135)	21.4 (180)	23.2 (315)	0.055
Acid regurgitation, % (<i>n</i>)	24.4 (128)	20.0 (168)	21.9 (296)	0.050
Tiredness, % (<i>n</i>)	89.1 (467)	82.8 (696)	85.5 (1163)	0.020
Overall symptoms	79.8 (418)	67.4 (567)	72.3 (985)	0.000
Composite GSRS score, median (IQR)	16	14	15 (8)	0.000

Note: Pregnant participants (*n* = 20) have been excluded from this part of the analysis.

Abbreviations: IBS, irritable bowel syndrome; IQR, interquartile range; GSRS, Gastrointestinal Symptom Rating Scale.

FIGURE 1 Prevalence of functional gut symptoms.



unintentional weight loss in the last 3–6 months, with 29.8% (*n* = 407) experiencing a decrease in appetite. Of those who were underweight, the rates of unintentional weight loss and loss of appetite were 37.1% (*n* = 39) and 45.7% (*n* = 48), respectively.

Dietary practices

Details of dietary practices are shown in Table 3. The majority of respondents (63.4%, *n* = 878) reported consuming an unrestricted diet, 11.8% (*n* = 164) reported

TABLE 3 Dietary practices of participants.

Dietary characteristic	Category	% (n)
Eating pattern	Unrestricted	63.3 (878)
	Vegetarian	10.3 (143)
	Vegan	3.7 (51)
	Gluten free	11.8 (164)
	Dairy/lactose free	4.4 (61)
	Gluten and dairy/ lactose free	1.9 (27)
	Anti-inflammatory diet	1.1 (15)
	Low FODMAP	0.6 (9)
	Other	2.7 (37)
Nutritional supplement usage	Any nutritional supplement	50.0 (693)
	Combined multivitamin & mineral	31.6 (438)
	Calcium and vitamin D	10.1 (140)
	Vitamin D	27.5 (381)
	Folic acid	10.2 (142)
	Iron	15.2 (211)
	Omega 3 fatty acid	13.1 (182)
	Probiotics	13.3 (184)
Awareness of low FODMAP diet	Know what it is	21.0 (294)
	Have heard of it	41.5 (575)
	No	35.1 (487)
	Unsure	2.2 (30)

Note: Anti-inflammatory diet²⁸: gluten and dairy free, with low consumption of free sugars, and ultra-processed food. Inclusion of foods rich in omega-3 fatty acids, antioxidants, and dietary fibre.

Abbreviation: FODMAP: fermentable oligosaccharides, disaccharides, monosaccharides and polyols.

a gluten free diet and 10.3% ($n = 143$) reported a vegetarian diet. Although 21.1% ($n = 293$) knew of the low FODMAP diet, < 1% were following it at present (0.6%, $n = 9$). Just over half of respondents (52.2%, $n = 723$) had tried dietary modifications to relieve their gut symptoms. This was significantly higher in those with IBS (55.9%, $n = 298$ vs. 49.9%, $n = 425$).

Composite GSRs did not differ between those who had and hadn't changed their diet to relieve their gut symptoms (Mann–Whitney test, $p > 0.05$). Some 290 (21.2%) had another medical condition which affected their diet.

Dietary advice

Some 13.2% ($n = 183$) had seen a dietitian regarding their endometriosis and gut symptoms, of whom 58.5%

($n = 107$) were seen via the National Health Service (NHS), with the remaining 41.5% ($n = 76$) seen in private practice. A higher percentage of those with IBS had seen a dietitian (18.2%, $n = 97$ vs. 10.2% $n = 86$, $p = 0.000$), but those with IBS were more likely to have been seen in the NHS (12.2%, $n = 65$ vs. 4.9%, $n = 42$, $p = 0.013$). Of those who had not seen a dietitian, more than half (57.7%, $n = 693$) would find it useful to do so, with 32.4% ($n = 389$) 'unsure' of the benefit.

Some 11.2% ($n = 155$) had received nutritional/dietary information from another healthcare professional, including medical consultant, followed by nutritionist, endometriosis nurse and alternative therapist. Some 29% ($n = 402$) had received nutritional/dietary information from other sources, of which the most common source was Endometriosis UK (33.6%, $n = 134$), followed by Facebook groups (17.0%, $n = 68$), books (14.5%, $n = 58$) and general internet searches (12.0%, $n = 48$).

DISCUSSION

Endometriosis is a common inflammatory condition characterised by chronic pain, including, but not limited to, pelvic and gastrointestinal pain. Research suggests that endometriosis has nutritional implications that may be improved by dietary modification, although the quality of evidence is poor.^{13–15} The present study aimed to investigate the management of endometriosis by dietitians, and also the nutritional practices and needs among the endometriosis population in the UK, with a focus on functional gut symptoms. Although responses to the dietitian survey were low ($n = 21$), the results indicated that the low FODMAP diet was frequently used in IWE and gut symptoms to good effect. However, dietitians were not confident in managing the non-gastrointestinal aspects of endometriosis and more training and resources were recommended. The survey of IWE ($n = 1385$) demonstrated a very high prevalence of functional gut symptoms, even in the absence of an IBS diagnosis. Overall, only one-quarter (24.1%, $n = 329$) had satisfactory relief of their gut symptoms. More than half (52.2%, $n = 723$) had modified their diets to try to improve symptoms, approximately one-third (36.7%, $n = 500$) followed a restricted diet, yet only a minority (13.2%, $n = 183$) had seen a dietitian for their symptoms, with even less (7.7%, $n = 76$) accessing a dietitian through the NHS. Importantly, the difficulty in recruiting dietitians who worked with IWE ($n = 21$) to complete the survey, compared with the large number of responses received to the IWE survey ($n = 1385$), clearly suggests the disparity between the need and provision of nutritional care.

The potential overlap between IBS and endometriosis and consequential misdiagnosis of endometriosis as IBS, has been highlighted by previous research.^{10,29} As a result of the diagnosis of endometriosis requiring

invasive laparoscopic surgery, patients often receive multiple etiologies and diagnoses for their symptoms, with IBS being the most common.¹⁰ The association between the two conditions has been investigated by three recent systematic reviews, all of which found evidence of two- to three-fold risk of IBS in IWE compared to those without endometriosis.^{11,12,30} Nabi et al.³⁰ who analysed 17 studies ($n = 96,974$), reported a pooled prevalence of IBS in women with endometriosis of 23.4%. Saidi et al.¹² identified a gap in adjusting for factors that may have affected gastrointestinal symptoms (e.g., phases of the menstrual cycle and psychological aspects). Chiaffarino et al.¹¹ noted that information on the temporal sequence of IBS and endometriosis is often lacking and therefore the direction of association between the two conditions cannot be confirmed as causal. Other studies suggest that the location of endometriosis and the different definitions/methods used to diagnose IBS may also affect the variation in prevalence rates reported.^{10,29,31}

In our sample, 38.5% ($n = 533$) of respondents reported to have been diagnosed with IBS, with most (80%, $n = 427$) having been diagnosed prior to endometriosis. These values are slightly higher than those reported in the three aforementioned systematic reviews^{11,12,30}; however, our sample may have been biased because those with gut symptoms were more likely to participate and diagnoses of both conditions were self-reported. Nevertheless, although global symptom relief, pain when opening bowels and stool type were all significantly worse in respondents with IBS, more than half of IWE without IBS also had abnormal findings for these parameters. Similarly, all of the functional gut symptoms, with the exception of heartburn, were significantly more likely to be experienced frequently/continuously in those with IBS. However, the most common symptoms of tiredness, bloating and abdominal pain were still experienced frequently/continuously by 82.8% ($n = 696$), 70.4% ($n = 592$) and 37.9% ($n = 319$) of respondents without IBS respectively, demonstrating a considerable health burden.

Looking at dietary practices of our respondents, 52.2% ($n = 723$) had tried dietary modifications to relieve their gut symptoms. Overall, the composite gut symptom score did not differ between those who had and had not changed their diet; however, as a result of the cross-sectional design of the survey, we are unable to establish the temporality of dietary modification and any symptom relief. Currently, 11.8% ($n = 164$) consume a gluten free diet, with small numbers consuming a dairy free, anti-inflammatory or a low FODMAP diet. This trend is similar to an Australian cross-sectional survey study ($n = 488$),³² who found that 44% of respondents used dietary strategies for symptom management, with restricted gluten, dairy and low FODMAP being the most common approaches used. Respondents reported a 6.4/10 effectiveness score for reduction in pelvic pain

with dietary changes, with no difference in pain reduction between the various diets used. Moore et al.¹⁸ undertook a retrospective study to determine the response to a low FODMAP diet in women with IBS and endometriosis compared with those with IBS only. The proposed mechanism of action of FODMAPs in triggering symptoms is a result of fermentation in the large bowel, leading to gas production, water retention and luminal distension. The low FODMAP diet was beneficial in a substantially higher proportion of patients with endometriosis than in those in whom such a diagnosis had not been made. Indeed, a known diagnosis of endometriosis conferred a threefold greater chance of responding to the diet.¹⁸ Very high adherence to the diet was noted (91%–93%); however, the study was performed within private practice and patient selection was biased toward higher socio-economic groups.

Evidence on the effect of nutrients and dietary patterns in endometriosis has been summarised in three recent systematic reviews. Huijs and Nap¹⁴ identified 12 studies which assessed the effect of a range of nutrients and foods including vitamin D, fatty acids, antioxidants, gluten and soy. Nine studies added nutrients, with seven finding a positive effect, whereas three studies were restrictive. They concluded that nutrients with direct or indirect anti-inflammatory properties might be effective against endometriosis symptoms, but the quality of evidence is very low. Similarly Nirgianakis et al.¹³ identified nine human studies, of which only two were randomised controlled trials. Overall, they could not identify specific dietary interventions with proven benefit on symptoms, but they made the pragmatic recommendation that the Mediterranean diet could be recommended as a long-term beneficial dietary change for IWE. However, for those with gastrointestinal symptoms, they suggested a gluten-free, low-nickel or low-FODMAP diet could be beneficial; albeit noting the difficulties adhering to these diet. Finally Sverrisdottir et al.¹⁵ summarised that five of six identified studies reported a significant reduction in pain perception in IWE, indicating that a high intake of polyunsaturated fatty acids, a gluten-free diet and a low nickel diet may improve painful endometriosis. The majority of available evidence was derived from non-randomised controlled trials, with high risk of bias and meta-analysis not possible as a result of considerable heterogeneity. Of note, both the studies by Borghini et al.³³ (low nickel) and Marziali et al.³⁴ (gluten free) had poor study completion, with 34% and 63% unable to comply with the dietary restrictions, respectively, suggesting further support and guidance from a healthcare professional is required.

In the present study, we note the small percentage of respondents who had seen a dietitian despite a considerable proportion (21.2%) also having another diet-related medical condition. Additionally, a high percentage of respondents (50%) reported taking nutritional supplements and seeking nutritional advice from a variety of

sources, some of which may not be evidence-based. Similar trends have been reported elsewhere. Huijs and Nap¹⁴ expressed concerns around the numerous internet sources promoting dietary restrictions for the treatment of endometriosis, the risk of nutritional deficiencies and difficulties in adhering to such diets. Armour et al.³⁵ highlighted the potential difficulties of those who self-manage with dietary modifications, including increased stress, food preparation time and financial costs, which is also confirmed by qualitative research. Although the focus of the present study was gut symptoms, we noted that more than half of respondents had unintentionally lost (13.5%, $n = 184$) or gained weight (50.4%, $n = 688$) in the past 3–6 months, with 29.8% ($n = 407$) reporting a reduced appetite. This demonstrates that the nutritional implications of endometriosis are broad and many may be self-managing and over-restricting their dietary intake without adequate help and guidance. Qualitative research on dietary self-management of endometriosis from Sweden echoes this.³⁵ Although IWE found dietary changes had a beneficial effect on their wellbeing, symptoms and energy levels, there was a distinct lack of HCP interest and support, which made implementing dietary changes challenging.³⁵ Given that it is not yet known which dietary intervention has which effect on women with specific types of endometriosis or specific characteristics,¹⁹ individualised, patient-centred care is required.

Although the prevalence of endometriosis in the UK is comparable to the number of women affected by Crohn's, rheumatoid arthritis and diabetes, it is relatively underfunded, with high cost implications for the healthcare system.^{1,6} The economic burden of treatment, healthcare costs and loss of work in the UK is estimated to account for £8.2bn a year.³ Supporting self-management has been given importance in the NICE guidance for endometriosis,⁷ with international panels of experts^{20,36} raising the need for a multidisciplinary approach for effective management of IWE. There is good evidence that from the IBS literature that symptomatic relief can be achieved when dietary changes are facilitated by a suitably trained dietitian.^{37–39} This has also been shown to be effective in the long term when delivered from primary care.⁴⁰ Applying this model to endometriosis care, it is plausible that dietetic intervention could therefore help with long-term gastrointestinal symptom management and prevent restrictive dietary practices, at the same time as also advising on appropriate nutritional supplementation, taking into account weight, appetite changes and other diet-related medical conditions. Additionally, by being part of the primary care network and facilitating as a first contact practitioner,⁴¹ there is potential for dietetic intervention to improve symptoms and management early in the path to diagnosis, particularly for those patients where misdiagnosis of IBS and endometriosis is likely.

Strengths and limitations

The present study has a number of limitations, namely self-reporting of symptoms and diagnoses, with lack of adjustment to confounders, such as the location of endometriosis lesions and treatment aspects. As is the case with many health surveys, the respondents were highly educated and not necessarily representative of the population. The nature of recruitment of participants meant that it would only have been accessible to those with internet access and active social media accounts. The strengths of the study are the use of validated gastrointestinal symptom scales, the involvement of representatives from a national patient charity group in the development of the IWE survey and the large number of respondents to the IWE survey.

CONCLUSIONS

The present study has demonstrated the complex nature of functional gut symptoms in endometriosis. Gut symptoms are common and painful in IWE, regardless of whether they have co-existing IBS or not. Self-management via dietary restriction is also very common, despite the lack of evidence for the effectiveness of dietary approaches. The high number of responses received in the IWE survey compared to the low number of respondents to the dietitian survey highlights the disparity between the need and provision of care. Greater access to dietitians, either in primary care or as part of the endometriosis multidisciplinary team, could help reduce morbidity and improve the quality of life of IWE. An urgent need for nutrition and dietetic research, training and guideline development to standardise nutritional care in endometriosis is required to help bridge the gap between need and provision.

AUTHOR CONTRIBUTIONS

Komal Deepak Kumar was responsible for data collection, data analysis, interpretation and drafting of the manuscript. Bridie Appleby-Gunnill contributed to interpreting results and drafting of manuscript. Kate Maslin was responsible for study design and supervising data collection and analysis. All authors contributed reviewing and approving the final version of the manuscript submitted for publication.

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CONFLICTS OF INTEREST STATEMENT

The authors declare that there are no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data availability from authors will be reviewed on request.

TRANSPARENCY DECLARATION

The authors affirm that this manuscript is an honest, accurate and transparent account of the data being reported. No important aspects of the study have been omitted and any discrepancies have been explained.

PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jhn.13158>.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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