

# Dietary practices of women with Endometriosis: a cross-sectional survey

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## Research Article

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# Abstract

**Background:** Endometriosis causes deleterious effects on the lives of sufferers across multiple domains impacting quality of life. Commonly utilised pharmaceutical interventions offer sub-optimal efficacy in addition to potentially intolerable side effects for many women. There is some evidence for dietary therapies reducing endometriosis symptoms but little data on dietary preferences / strategies used, and their impact, in a community setting.

**Methods:** A cross-sectional online survey was conducted between October and December 2017 to investigate the self-management strategies employed by women with endometriosis. Participants were aged 18-45 years, living in Australia and had a surgically confirmed diagnosis of endometriosis.

**Results:** Four hundred and eighty-four responses were included for analysis, with 76% of women reporting the use of general self-management strategies within the last six months. Of these, 44% of respondents reported using dietary strategies for symptom management. Reducing or eliminating gluten, reducing or eliminating dairy and the low FODMAP diet were the most commonly reported dietary strategies utilised. 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. Further, women self-reported significant improvements in co-morbidities such as gastrointestinal disturbance (39%), nausea and vomiting (15%) and fatigue (15%).

## Conclusions:

Dietary modifications are a very common self-management strategy employed by people with endometriosis, with the greatest benefit reported on gastrointestinal symptoms. Reducing or eliminating gluten, dairy or FODMAPs, or a combination of these, were the most common strategies. No single diet appeared to provide greater self-reported benefits than others.

# Introduction

Endometriosis is an oestrogen dependent, chronic, inflammatory disease characterised by the presence of lesions containing endometrial-like tissue outside the uterine cavity.<sup>1,2</sup> Estimates of worldwide prevalence rates range between 5 to 10% of women of reproductive age.<sup>3,4</sup> Endometriosis has a diverse symptom profile, with the most common symptoms including dysmenorrhea (period pain), non-cyclic pelvic pain<sup>5</sup> and fatigue.<sup>6</sup> In addition to pain and fatigue many women have gastrointestinal (GI) symptoms that present in a similar manner to irritable bowel syndrome.<sup>7</sup>

While there are a number of medications, of varying effectiveness, used to treat the pain related symptoms of endometriosis,<sup>8</sup> there is a paucity of medical interventions used for other key symptoms such as fatigue and GI issues. The lack of medical options may be a driving factor in using non-

pharmacological self-care to manage these symptoms, with 75% of women with endometriosis in Australia reporting the use of self-care in the last 6 months.<sup>9</sup> In recent years, academic interest has grown in the role of diet in endometriosis due to the influence it can have on the physiological and pathological processes linked to endometriosis such as inflammation, oestrogen activity and menstrual cycles.<sup>10</sup> There is also increasing discussion on the internet regarding the use of diet to manage endometriosis<sup>11</sup>, many of which are not evidence-based.<sup>12, 13</sup> Despite the widespread use of self-prescribed management strategies and the increased research interest in diet as a treatment for managing endometriosis,<sup>14</sup> especially during COVID-19,<sup>15</sup> the dietary practices of women with endometriosis have not been previously well characterised.

Current evidence suggests that the risk of endometriosis is reduced in women who regularly consume fish oils, green vegetables, fruits (especially citrus fruits), and dairy products,<sup>10, 16, 17</sup> whereas the risk of endometriosis may be higher for women who regularly consume red meat.<sup>18</sup> In terms of preventing the progression of endometriosis in diagnosed cases, increased consumption of foods with anti-inflammatory properties (e.g. green tea, resveratrol, fish oil, soy isoflavones) has been shown to reduce lesion size in mouse models of endometriosis, positing that anti-inflammatory diets may be able to prevent the disease from progressing into the advanced stages, whilst possibly reducing the severity of pain symptoms.<sup>19</sup> However, it's unclear if modifying dietary factors (such as reducing red meat) after the onset of endometriosis symptoms influences progression of the disease or symptom severity in humans.

The aim is to describe the dietary practices of women with surgically diagnosed endometriosis and the self-reported effectiveness on the symptoms of endometriosis, financial costs and any adverse events related to these dietary practices.

## Materials And Methods

This survey was approved by the Western Sydney University Human Research Ethics Committee, approval number H12394 (approved 23<sup>rd</sup> October 2017). This paper reports on dietary practices from a larger survey exploring self-management strategies employed by Australian women with endometriosis.<sup>9</sup> The online questionnaire was developed by the research team in conjunction with 19 women with endometriosis. This survey was hosted on the Qualtrics platform (Qualtrics Ltd). Self-management was defined as physical (such as exercise or stretching) or psychological techniques (e.g., meditation or breathing techniques) that women could administer or perform themselves, or lifestyle interventions (e.g., dietary changes, alcohol consumption or cannabis usage) that were undertaken specifically for the management of endometriosis symptoms. The development process, methods and results for this survey have been previously reported in detail.<sup>9</sup> The present work reports only on those women who indicated they used dietary modifications to manage their symptoms.

A brief summary of the methods is described as follows. Women were eligible to participate in the survey if they were aged 18-45 years, currently living in Australia, and had a surgical diagnosis of endometriosis

within the last five years. Recruitment was conducted via the social media platforms of Endometriosis Australia and EndoActive, the two endometriosis advocacy and support groups in Australia with the most followers on social media, and via an invitation to participate on the Pelvic Pain Foundation of Australia's web site. Given the geographical distribution of the Australian population, social media was the most effective means of reaching potential participants.

All measures were self-reported and required recall over the past six months. The questionnaire collected demographic data utilising specific measurement tools, i.e., the Pelvic Pain Impact Questionnaire (PPIQ),<sup>20</sup> in addition to information on self-management techniques in the previous six months; reasons for non-usage of self-management; type and frequency of self-management; adverse events; self-rated effectiveness; and any subsequent reduction in endometriosis-related medication usage.

Data were analysed using SPSS v24 (IBM Corporation). Descriptive statistics were presented as means and standard deviations (for normally distributed data), medians and interquartile ranges (for non-normally distributed data), or number and percentages (for categorical data). Inferential statistics for between-group comparisons were performed using a one-way ANOVA or students t-test, depending on the number of groups. Statistical significance was set at  $p < 0.05$ . Missing data were not replaced.

## Results

The survey was completed by 590 women currently living in Australia who had a diagnosis of endometriosis confirmed by laparoscopy within the last 5 years. A total of 96 women were removed from data analysis due to incomplete responses (i.e. less than 25% of the survey complete) with a further 10 responses excluded due to methodological ineligibility. A total of 484 responses were included in the original analysis with 371 participants (76%) of respondents reporting the use of a self-management strategy in the past 6 months; 163 (44%) self-reported utilising dietary strategies for endometriosis symptom management.

Survey respondents had a mean age of 31 years and were predominantly located in urban areas (81.65% urban vs 18.35% rural), with all states and territories in Australia being represented. The three most popular dietary strategies reported were a gluten free diet (used by 22 respondents), a low FODMAP diet (used by 14 respondents) and removing dairy from the diet (used by 14 respondents) (See Table 1).

The Pelvic Pain Impact Questionnaire (PPIQ) scores of the women who implemented dietary strategies versus those that did not are reported in Table 2. There was no significant differences between cohorts except for greater pain when wearing tight or restrictive clothes in the dietary change group.

Self-rated effectiveness on pelvic pain for dietary modification was  $6.4 \pm 2.4$  on a 0-10 numeric rating scale, with 10 being most effective, as reported in our primary analysis.<sup>9</sup> There was no difference in self-rated effectiveness on pelvic pain between the various dietary strategies used ( $p = 0.067$ ). Dietary strategies were associated with a significant reduction in pharmaceutical medication usage (defined as a 50% or more reduction) by 18.7% of respondents, a moderate reduction (25-50% reduction) by 22.6%, a

minimal reduction (<25% reduction) by 27.7% and 29% reporting no change in medication use at all. Data on which specific medications were reduced was not collected.

Adverse event rates were infrequent, with nine women (5.9%) reporting an adverse event, the most common of which was gastrointestinal upset. Adverse events, diet types, reduction in pharmaceutical medication, free text descriptive data and associated costs are reported in Table 3. The majority of women (41%) spent less than AUD \$50 per month on dietary strategies, however 15% reported spending over \$250 per month, although whether this included nutritional supplements is unclear.

Supplementary Table 1 details the self-reported effects of diet on individual symptoms that are commonly reported by women with endometriosis in addition to pelvic pain. Gastrointestinal disturbance, nausea / vomiting, fatigue, depression and sleep were the five areas where women reported the most significant improvement of those assessed, with no significant differences between dietary strategies in terms of symptom improvement (p=0.081).

## Discussion

Our study demonstrates that dietary modification is a frequently utilised self-management strategy employed by women with endometriosis in Australia, with gluten free, FODMAP and dairy free diets being the most popular amongst our respondents. Results suggest that dietary modifications are associated with perceived improvements in endometriosis-related symptoms, with women self-reporting an overall reduction in GI disturbance, nausea/ vomiting, fatigue, depression and sleep, however there did not appear to be one dietary strategy that was associated with greater perceived improvements. Through adopting various dietary strategies, over a third of respondents reported significant improvements in gastrointestinal disturbances such as abdominal discomfort, bloating, flatulence and diarrhoea. These are common symptoms of irritable bowel syndrome (IBS), a prevalent comorbidity of endometriosis, with women having a diagnosis of endometriosis being two to three times more likely to display IBS symptoms than those without a diagnosis.<sup>21, 22</sup>

There is some preliminary evidence that gluten-free diets can significantly reduce the severity of endometriosis pain in women, whilst also improving physical function resulting in improved quality of life.<sup>21</sup> Gluten may have an impact on gut function via increased zonulin-mediated gut permeability that drives inflammation<sup>23</sup> (in the presence of a weakened intestinal barrier), this stimulation of proinflammatory cytokines could go on to exacerbate endometriosis symptoms. Thus using a gluten-free diet to mediate IBS symptoms could in turn reduce the pelvic and gastro-intestinal symptoms of those with endometriosis. This is especially true for those with coeliac disease<sup>24</sup> and with non-coeliac gluten sensitivity (NCGS).<sup>25, 26</sup>

The use of a FODMAP diet was also commonly reported. Common FODMAP fructans have been found to induce symptoms of IBS in those with NCGS<sup>27</sup> and FODMAP foods<sup>28</sup> are thought to increase gastrointestinal symptoms due to their indigestibility, which creates excess water and gas in the small

bowel and proximal colon.<sup>28</sup> A low FODMAP diet has previously been shown to be beneficial in reducing the symptoms of IBS in women with endometriosis in a cohort study.<sup>7</sup> A low FODMAP diet has also been shown to show changes in inflammatory cytokines, microbiota profile and short chain fatty acids (SCFAs),<sup>29</sup> which all have an impact on gut health in people with IBS. Another potential mechanism is that FODMAPs have been shown to cause visceral pain by increasing inflammation and bacterial endotoxins (such as lipopolysaccharides [LPS]) in the gut.<sup>30</sup> This is interesting in light of the newly emerging “Bacterial Contamination Hypothesis” for endometriosis, which proposes bacterial endotoxins such as LPS may contribute to pelvic inflammation and the growth and progression of endometriosis itself.<sup>31</sup>

Whilst a low FODMAP diet may improve symptoms of endometriosis, it carries limitations as a long-term symptom management strategy. This diet was originally designed to be used over a restricted period of 2-6 weeks, depending on the severity of symptoms. Relaxation after this period is imperative as carbohydrate restriction may negatively impact gut microbiota, with a reduced number of overall luminal bifidobacterial found after four weeks of FODMAP restriction.<sup>32</sup> This is likely due to the prebiotic effects of FODMAPs on gut bacteria that in turn may exert other benefits. A low FODMAP diets also risk altered nutrient intakes and potential deficiencies,<sup>33</sup> with some evidence suggesting low FODMAP diets may alter the intake of fibre, calcium and B vitamins.<sup>34</sup>

A dairy-free diet may also be useful in reducing endometriosis-related gastrointestinal symptoms as lactose (a milk sugar) is a known FODMAP that may cause symptoms of IBS in those intolerant to it. Furthermore, A1 casein (a milk protein) found in cow-based dairy products may also promote gastrointestinal inflammation<sup>35</sup> and IBS symptoms in those with self-reported lactose intolerance.<sup>36</sup> This effect is likely mediated due to the pain inducing effects of histamine, an inflammatory compound released by mast cells upon the digestion of A1 casein-derived betacasomorphin-7 [BCM-7], a powerful *histamine liberator*.<sup>37</sup> Histamine also stimulates ovarian oestrogen release, which may induce mast cell degranulation in the reproductive tissues.<sup>38</sup> Oestrogen in turn stimulates mast cell histamine release,<sup>39</sup> while also reducing the diamine oxidase (DAO) enzyme needed to break down excess histamine levels.<sup>40</sup> As mast cells are highly localised around blood vessels and nerve fibers,<sup>41</sup> they may play a role in the neuroinflammatory processes that underlie endometriosis pain pathophysiology.<sup>42</sup> In one study, it was postulated mast cells could be targeted to minimise these recurring inflammatory processes underlying endometriosis.<sup>43</sup> Mast cell activation is also associated with other endometriosis co-morbidities such as dyspareunia,<sup>44</sup> dysfunctional uterine bleeding,<sup>45</sup> an increased risk of pelvic pain<sup>46</sup> and has an increased effect on women.<sup>39</sup> As endometrial tissue and lesions are rich in mast cells, a diet free from A1 casein may therefore mitigate endometriosis pain by reducing mast cell activation and subsequent histamine release in endometrial tissues. It may be that restricting dairy confers some of the benefits of a full low FODMAP diet, however future studies are needed in women with endometriosis. It is plausible that these positive effects reported by those implementing these diets are likely mediated by the impact that removing or restricting these foods may have on inflammation and/or oestrogen metabolism. There is

increasing evidence that visceral pain comorbidities (e.g. bowel or bladder conditions) can exacerbate chronic pain conditions and vice-versa<sup>47</sup> and any reduction in GI disturbance may in turn reduce pelvic pain, via a reduction in intestinal distention and subsequent reduction in visceral nerve activation.<sup>7</sup> Mental health improvement was also a noted outcome of dietary modification in the endometriosis cohort. Possible mechanisms of how this is achieved may extend to the well-established link between the gut/brain connection, inflammation and depression,<sup>48</sup> with some research showing an association between pro-inflammatory diets and depression risk.<sup>49</sup> It is thought brain inflammation results from a flood of inflammatory cytokines, a pathophysiological process also underpinning endometriosis-related inflammation. The improvements in mental health symptoms reported by our respondents may be explained in context of the impact that gut inflammation has on mood.<sup>50</sup> Dairy-free diets in particular may help to alleviate symptoms of depression, as A1 casein (from dairy foods) in particular may exert a greater inflammatory, neurochemical impact on the body via its inflammatory opiate casomorphin (or BCM7)<sup>51</sup>. This has a cytokine stimulating, morphine-like influence that may drive mood and irritability disturbances, impact the immune system and hormonal function.<sup>52</sup> Research also suggests a low FODMAP diet could relieve symptoms of depression,<sup>53</sup> with one observational study linking low FODMAP diet to improved, long term symptoms of depression and increased levels of happiness.<sup>54</sup>

Despite the overall positive outcomes in symptoms reported by respondents adverse events were reported. Apart from gastrointestinal distress, which was relatively uncommon, other potential barriers to dietary modifications were reported including increased stress due to food restrictions, difficulty socialising, increased food preparation time and increased financial costs. Given the significant cost of illness burden already placed on women with endometriosis<sup>55</sup> and the impact endometriosis already has on family and social relationships<sup>56</sup> these may be significant barriers to long term dietary changes.

## Strengths And Limitations

This study has several strengths. First, women must have had endometriosis diagnosed via laparoscopy within the previous 5 years which should exclude women with a variety of other causes of chronic pelvic pain that may not respond in the same manner to dietary changes. Second, the sample size obtained was large in comparison to other survey methodologies on similar populations. However there the results must be considered in light of several important limitations. Firstly, all dietary changes, symptoms and changes in pharmaceutical medication was self-reported thus vulnerable to recall bias and could not be checked against any objective changes such as respondents medical records. Secondly, the classification of dietary changes was categorical and therefore unable to distinguish between degrees of adoption (such as between a reduction of gluten and being gluten free) and compliance.

## Conclusions

Dietary strategies are a common self-management strategy employed by people with endometriosis, with no single dietary strategy showing greater self-reported improvements than others. There is preliminary evidence to support the physiological change in pelvic pain and other symptoms reported by those reducing or eliminating gluten, dairy, FODMAPs or a combination thereof. Moderate or greater reduction in usage of endometriosis related medications was reported by just under half of respondents. Adverse events were rare but non-physiological barriers such as difficulty with adherence were reported and may impact long term effectiveness. Future prospective research needs to be undertaken to determine any relationship between adoption of, and adherence to, dietary strategies and changes in medication and symptoms.

## Declarations

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### *Availability of data and materials*

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

### *Authors' contributions*

MA and JS conceptualised the survey, MA, JS and CS designed the survey questions, MA, DV and JS performed the data analysis, while SL and MA interpreted the data. AM, JS and MA drafted the manuscript, with DV, SL and CS providing critical feedback and edits to the draft. All authors approved the final manuscript.

### *Ethics approval and consent to participate*

This survey was approved by the Western Sydney University Human Research Ethics Committee, approval number H12394. Participants were advised in the participant information sheet and survey introduction (prior to starting the survey) that consent was implied by completing the survey.

**Competing interests:** The authors declare the following competing interests: MA, DV, JS and CS: As a medical research institute, NICM Health Research Institute receives research grants and donations from foundations, universities, government agencies and industry. Sponsors and donors provide untied and tied funding for work to advance the vision and mission of the Institute. This survey was not specifically

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## Tables

### Table 1 - Demographics and dietary choices

**n=158**

**Age**

**Mean**

30.50

**Australian State**

**N (%)**

Australian Capital Territory

7 (4.43)

New South Wales

61 (38.61)

Queensland

30 (18.99)

South Australia

10 (6.33)

Tasmania

4 (2.53)

Victoria

37 (23.42)

Western Australia

9 (5.70)

**Regional Distribution**

**N (%)**

Urban

129 (81.65)

Rural

29 (18.35)

**Diet types (n=72)<sup>a</sup>**

**N (%)**

Removal of Gluten / Gluten free

22 (31%)

FODMAP Diet

14 (19%)

Removal of Dairy / Dairy free

14 (19%)

Reduction in processed foods

11 (15%)

Removal of red meat

9 (12.5%)

Removing / Limiting alcohol

6 (8%)

Eating anti-inflammatory foods

6 (8%)

Removing / Limiting caffeine

5 (7%)

Removal of soy

3 (4%)

Vegan/Vegetarian

2 (3%)

Removing Nightshade family plants (Solanaceae)

1 (1%)

Removing citrus foods

1 (1%)

Increased consumption of fish oils and fish

1 (1%)

Happy hormone diet

1 (1%)

<sup>a</sup> Multiple responses allowed – percentages sum to greater than 100.

**Table 2 – Pelvic Pain Impact Questionnaire (PPIQ) Scores**

PPIQ Scores (0-4)	Diet users (n=155)	Non-users (n=328)	p-value <sup>†</sup>
	Mean (SD)	Mean (SD)	
Energy levels	2.61 (1.00)	2.59 (1.0)	0.816
Mood	2.42 (1.02)	2.41 (1.00)	0.849
Sleep	2.14 (1.14)	2.03 (1.11)	0.332
Stomach / GI Function	2.68 (1.07)	2.56 (1.07)	0.224
Sitting	1.59 (1.31)	1.49 (1.19)	0.397
Work / School	2.27 (1.19)	2.11 (1.16)	0.148
Physical activity	2.40 (1.22)	2.20 (1.20)	0.079
Clothing	2.45 (1.24)	2.20 (1.31)	0.042 *

<sup>†</sup> two-tailed t-test \* p < 0.05

**Table 3 – Self-prescribed diets and its effect relating to financial cost, pharmaceutical use and adverse reactions in women with endometriosis**

<b>Financial expenditure per month (n=140)</b>	<b>N (%)</b>
\$0 - 50	58 (41)
\$51 - \$100	28 (20)
\$101 - \$150	14 (10)
\$151 - \$200	17 (12)
\$201 - \$250	2 (1)
> \$250	21 (15)
<b>Reduction in pharmaceutical medication (n=155)</b>	<b>N (%)</b>
Yes significant reduction (50% or more)	29 (18.71)
Yes moderate reduction (25-50%)	35 (22.58)
Yes minimal reduction (<25%)	43 (27.74)
No	45 (29.03)
Other	3 (1.94)
<b>Would you recommend dietary strategies to a friend or family member with endometriosis (n=155)</b>	<b>N (%)</b>
No	9 (5.81)
Yes	146 (94.19)
<b>Adverse / negative findings from implemented dietary strategies (free text responses)</b>	
Financial burden due to increased food costs	
Increased stress due to food restrictions (e.g. social exclusions and food restrictions)	
Developed new health issues (e.g. anaemia, GIT symptoms when removing gluten etc.)	
Time - time invested to prepare specific foods (e.g. make different food to other family members, food preparation time)	
Emotional - Using diets with high expectations and not seeing anticipated results	
Inconsistent results (e.g. due to lack of knowledge and appropriate dietary prescriptions)	

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementaryTable.docx](#)