

# Self-managed dietary changes and gut symptoms in endometriosis: a qualitative interview study

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Endometriosis is a chronic gynaecological condition characterised by the growth of endometrial lining outside the uterus leading to symptoms such as pain and functional gut symptoms. This can have a profound impact on their quality of life. The prevalence can range from 2–10% of the general population, however, is seen as up to 50% amongst those with infertility; it can be said that the exact prevalence is unknown<sup>(1)</sup>. Currently, there is no cure for endometriosis. It is primarily managed with surgery, analgesia and hormonal medication; research suggests dietary changes may effectively reduce pain and recurrence of gut symptoms, especially in those with coexisting irritable bowel syndrome<sup>(2,3)</sup>. However, endometriosis guidelines do not formally endorse dietary changes, and little is known about how they are self-managed. Thereby, the objective of this study is to undertake semi-structured interviews to understand nutritional practices and management of gut symptoms in people with endometriosis in the UK.

Participants were recruited as part of a larger survey study<sup>(4)</sup> via endometriosis support groups on social media in August 2021. Eligibility criteria were: a self-reported physician-led diagnosis of endometriosis, over 18 years old and residing in the UK. Semi-structured interviews were undertaken virtually via Zoom. A predefined interview guide was developed based on previous literature and the results of our group's survey<sup>(4)</sup>. All interviews were transcribed and analysed using thematic analysis. Ethical approval was obtained from the University of Plymouth (ref. 2809).

10 participants 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, vegetables, fruits, and animal products. These changes impacted participants' weight, nutritional status and relationship with food. Four strong themes emerged from the analysis:

- 1) their life shaped by pain and symptoms
- 2) lack of being taken seriously
- 3) their attempts to self-manage dietary symptoms
- 4) lack of dietetic intervention

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.

Overall, participants demonstrated some patterns of restrictive eating behaviour and wanted more professional support to help manage their endometriosis-related gut symptoms. This concurs with our previous research<sup>(4)</sup>, highlighting the need for dietitians to be involved in endometriosis care to help alleviate gut symptoms whilst ensuring nutritional adequacy and weight management for women with endometriosis in different life stages ranging from puberty onwards, with symptoms extending beyond menopause in some cases.

## References

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