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Dietary Modification and Supplement Use For Endometriosis Pain

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Introduction

Endometriosis is a neuroinflammatory reproductive disorder defined by the presence of endometrial-like tissue (lesions) outside the uterus that is difficult to diagnose and treat.[1] Chronic pain is a common symptom but patients also have infertility, fatigue, and gastrointestinal (GI) symptoms, including those similar to irritable bowel syndrome and abdominal bloating (colloquially referred to as endo belly). Current treatment options are largely limited to surgery or hormone-suppressive drugs.[1] The gut microbiome has been implicated as a regulator of pain in inflammatory conditions, including endometriosis, and its modification by diet has been explored to manage symptoms.[2] We conducted an online survey to gain insights into which dietary modifications and/or supplements were perceived as beneficial for pain management by individuals with endometriosis.

Methods

This survey study was developed with a local patient support group, was approved by the Edinburgh Medical School Research Ethics Committee, and followed the AAPOR reporting guideline. A 24-question survey was available in English on the online platform, Qualtrics (Qualtrics Ltd), between June 10 and September 2, 2022 (eMethods, eFigure, and eTable in Supplement 1). Data were analyzed using Python 3.0 (Python), and statistical comparisons of distributions were performed using the Mann-Whitney *U* test. Statistical significance was set at $P < .05$, and tests were 2-sided. Data were analyzed from September 2022 to January 2025.

Results

Among the 2858 individuals who started the survey, 2599 completed more than 80% of the questions, and 2388 of these respondents had a confirmed diagnosis of endometriosis (103 Asian respondents [4.3%]; 45 Black respondents [1.9%]; 2110 White respondents [88.4%]; mean [range] age, 35.4 [16-71] years) (**Table**). Most respondents reported pelvic pain (2313 [96.9%]) and frequent abdominal bloating (2177 [91.2%]). Notably, 2001 respondents (83.8%) had tried 1 or more diets to manage their symptoms and 1404 had used supplements (58.8%), with 1339 (66.9%) and 609 (43.4%) considering these self-help strategies had improved their pain, respectively.

When respondents' pain scores (0 to 10 scale) were represented on a histogram, there was a statistically significant difference between those who reported the modification had improved pain compared with those who did not, with the former having lower pain scores than the latter (median [IQR], 4.0 [3.0-6.0] for respondents reporting improvement from dietary modification vs 5.0 [4.0-7.0] for respondents reporting no improvement; $P < .001$; 4.0 [3.0-6.0] for respondents reporting improved pain from any supplements vs. 5.0 [4.0-7.0] for respondents reporting no improvement, $P < .001$) (**Figure** A and B). Responses to questions about access to information by survey respondents revealed that the most popular source(s) of advice that prompted a change of dietary

+ Supplemental content

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habits were from social media or a health care professional. Among the most popular dietary modifications attempted, pain improvement was reported by 666 of 1252 who reduced alcohol (53.2%), 523 of 1151 who reduced gluten (45.4%), 512 of 1132 who reduced dairy (45.2%), and 473 of 1091 who reduced caffeine (43.4%) (Figure C).

The low-Fermentable Oligosaccharides, Disaccharides, Monosaccharides, and Polyols diet (ie, FODMAP) was less popular (181 of 563 [32.1%]). Among the 812 respondents who used magnesium, 262 (32.3%) reported a benefit (Figure D).

Table. Characteristics of the 2388 Survey Respondents Who Completed More Than 80% of Questions and Had a Confirmed Diagnosis of Endometriosis

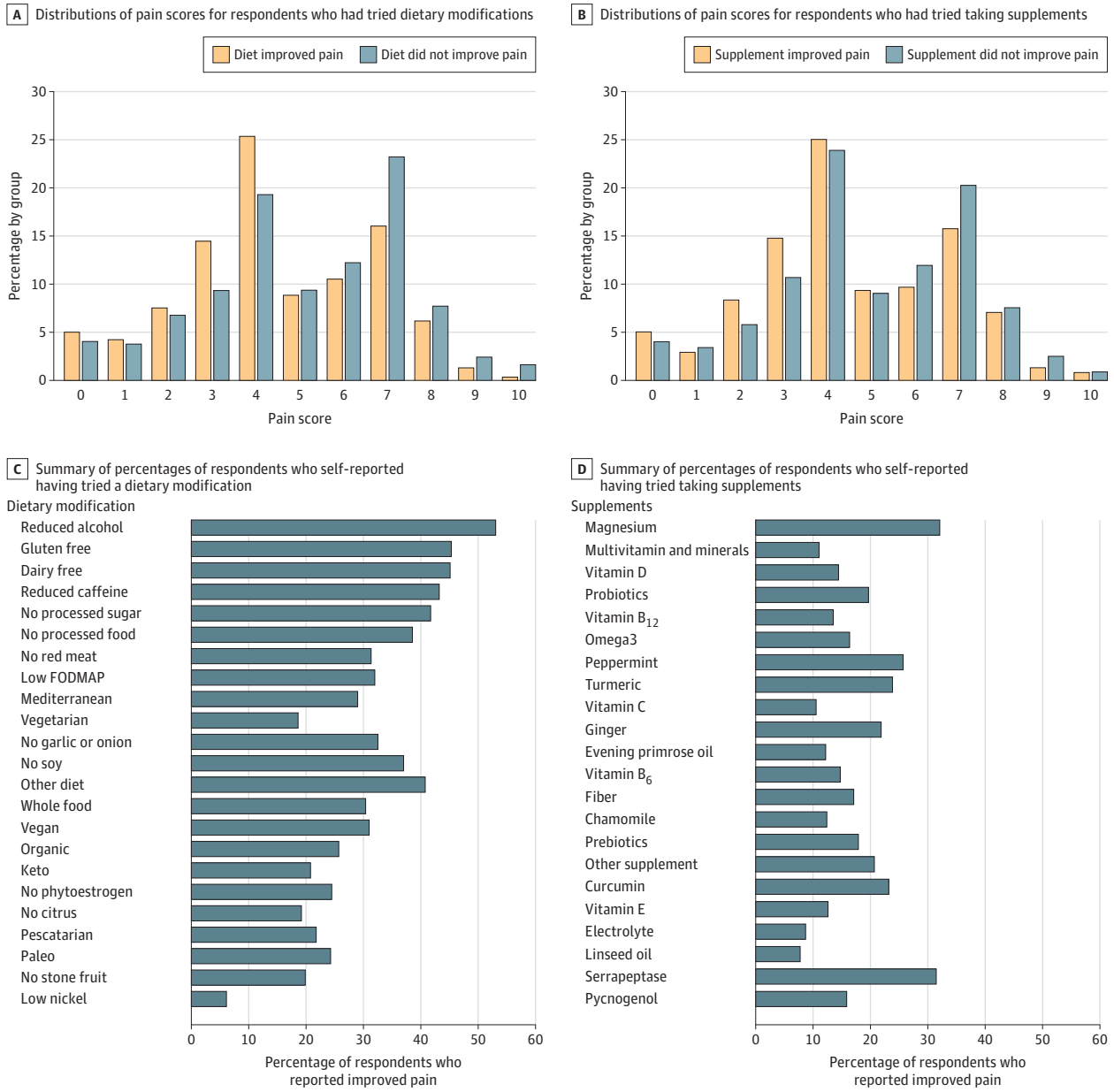
Characteristic	Participant, No. (%)
Gender	
Female	2364 (99.0)
Nonbinary	16 (0.7)
Prefer not to say or transgender	8 (0.3)
Ethnicity	
Arab	5 (0.2)
Asian	103 (4.3)
Black	45 (1.9)
Hispanic or Latin American	29 (1.2)
Mixed or multiple	93 (3.9)
White	2110 (88.4)
Continent	
Africa	30 (1.3)
Asia	57 (2.4)
Europe	1788 (74.9)
North America	93 (3.9)
Oceania	414 (17.3)
South America	6 (0.3)
Age, y	
16-24	232 (9.7)
25-34	895 (37.5)
35-44	928 (38.9)
45-59	329 (13.8)
≥60	4 (0.2)
Endometriosis subtype	
Deep (infiltrating)	635 (26.6)
Ovarian	217 (9.1)
Superficial peritoneal	164 (6.9)
Multiple or other	784 (32.8)
Do not know	588 (24.6)
Abdominal or pelvic pain	
Yes	2313 (96.9)
No	75 (3.1)
Frequent abdominal bloating (ie, endo belly)	
Yes	2177 (91.2)
No	211 (8.8)

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Discussion

To our knowledge, this is the largest international survey to date of individuals with endometriosis who have tried diets and/or supplements to manage pain symptoms. A large number of different diets or strategies were reported but it was noted that the most popular involved reduction or elimination of specific items (eg, alcohol, gluten, dairy, caffeine) rather than specific diets, such as the low-FODMAP diet, as previously reported.[3,4] These data supported the findings of previous surveys and clinical trials that suggested dietary modifications may help individuals manage pain associated

Figure. Number of Survey Respondents Who Reported Using Diets or Supplements



A, Distributions of pain scores for respondents who had tried dietary modifications to manage endometriosis-associated pain showed those who found that at least 1 modification improved pain (1339 [66.9%]) had lower pain scores than those who did not (662 [33.1%]). B, Distributions of pain scores for respondents who had tried taking supplements to manage endometriosis-associated pain showed those who found that at least one supplement improved pain (609 [43.4%]) had lower pain scores than those who did not (795 [56.6%]). C, 2001 patients responded to survey question; the survey allowed respondents to select more than 1 diet. D, 1404 respondents answered the question; respondents could select more than 1 supplement.

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with endometriosis. However, no single modification was uniquely perceived as beneficial, and none of the changes were helpful for some individuals.[5,6] Limitations of the study include the selection bias of individuals interested in dietary changes and lack of alternative language options and questions regarding the length of diet use and impact on abdominal bloating.

ARTICLE INFORMATION

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Author Contributions: Ms Hearn-Yeates had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: Hearn-Yeates, Horne, O'Mahony, Saunders.

Acquisition, analysis, or interpretation of data: Hearn-Yeates, Edgley, Horne, Saunders.

Drafting of the manuscript: Hearn-Yeates, Horne, Saunders.

Critical review of the manuscript for important intellectual content: Edgley, Horne, O'Mahony, Saunders.

Statistical analysis: Hearn-Yeates, Edgley.

Obtained funding: Horne.

Administrative, technical, or material support: Hearn-Yeates.

Supervision: Horne, O'Mahony, Saunders.

Conflict of Interest Disclosures: Dr Horne reported receiving grants from the National Institute for Health and Care Research Health Technology Assessment, Chief Scientist Office, Wellbeing of Women, Roche Diagnostics, and European Union, receiving personal fees from Theramex and Gedeon Richter, and having patents issued for a UK patent application No. 2217921.2 and international patent application No. PCT/GB2023/053076 outside the submitted work. Dr Saunders reported receiving personal fees from Gesynta Pharma and having a patent pending for UK Patent Application No. 2310300.5 outside the submitted work. No other disclosures were reported.

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Data Sharing Statement: See Supplement 2.

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SUPPLEMENT 1.

eMethods.
eFigure. Advertisement for Online Survey
eTable. Study Survey

SUPPLEMENT 2.

Data Sharing Statement

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