https://doi.org/10.1038/s44294-025-00096-6

Understanding endometriosis knowledge among diagnosed and symptomatically at-risk individuals in Australia

Anne Reinhardt[1] ✉, **Amelia K. Mardon**[2,3], **Sarah Eitze**[4,5], **Hannah Adler**[6], **Danielle Howe**[2], **Michelle O'Shea**[2] & **Mike Armour**[2]

Endometriosis affects 5–14% of women and those presumed female at birth (PFAB), yet public understanding remains limited. In an online survey of 427 Australians, diagnosed individuals had better knowledge about endometriosis than those at risk but undiagnosed. In detail, at-risk individuals underestimated prevalence, consequences, and diagnostic pathways. Targeted education may improve symptom recognition and healthcare engagement, supporting earlier diagnosis and better care.

Endometriosis is a chronic inflammatory condition characterized by endometrial-like tissue growing outside the uterus, often resulting in pain, infertility, and other symptoms. In Australia, around 1 in 7 women and individuals presumed female at birth (PFAB) are diagnosed with endometriosis by the age of 49 years (Australian Institute of Health and Welfare, 1 in 7 Australian women aged 44–49 have endometriosis, https://www.aihw.gov.au/news-media/media-releases/2023/2023-september/1-in-7-australian-women-aged-44-49-have-endometriosis, 2023), though owing to underdiagnosis the true prevalence is likely higher[1]. Structural and social barriers, including menstrual stigma and knowledge gaps[2], often contribute to extensive delays between symptom onset and diagnosis. These delays can be broken into time between symptom presentation and seeking medical attention, and time between seeking medical attention and receiving a diagnosis. In Australia, these are 2.9 years and 4.9 years respectively, with most people seeing five doctors before receiving a formal diagnosis[3].

In the context of endometriosis, increased knowledge can encourage positive help-seeking behaviors[4]. Knowledge is crucial for informed health decision-making because it empowers individuals to recognize symptoms, seek timely medical advice, and evaluate treatment options. Furthermore, informed people have agency to engage in shared decision-making with healthcare providers, advocate for themselves, and adhere to treatment plans, ultimately improving health and quality of life outcomes[5]. Accordingly, this study explored knowledge disparities between individuals with a confirmed endometriosis diagnosis and those at risk due to symptom presence but without diagnosis. We asked: *What do diagnosed and at-risk individuals know about endometriosis?*

Across the full sample ($N = 427$), overall endometriosis knowledge was rather good ($M = 7.20$ out of 9, $SD = 1.33$), with significantly higher scores among diagnosed individuals ($n = 143$; $M = 7.83$, $SD = 0.99$) than at-risk individuals ($n = 284$; $M = 6.88$, $SD = 1.36$; $t(373.0) = 8.19$, $p < .001$). Item-level analyses revealed important knowledge differences (Fig. 1; for detailed Chi^2 tests for each item, see Supplement 1 on OSF).

While the sample demonstrated solid understanding of core aspects—such as disease contributors (K1; diagnosis group: 100%, at-risk group: 99%), typical symptoms (K2; diagnosis group: 98%, at-risk group: 100%), consequences of the disease (K6; diagnosis group: 99%, at-risk group: 97%), and treatment options (K8; diagnosis group: 99%, at-risk group: 92%)—diagnosed individuals consistently outperformed at-risk participants on more nuanced items. For instance, 90% of the diagnosed group correctly identified "pain during sex" as a key symptom (K3), compared to only 73% in the at-risk group. Instead, notable shares of the at-risk group mistakenly chose "increased progesterone levels" (14%) or "mood changes" (11%). Diagnostic knowledge (K4) also differed sharply, with 97% of diagnosed individuals correctly identifying laparoscopy as a definitive diagnostic method, compared to 70% of at-risk individuals—26% of whom incorrectly believed ultrasound was sufficient. While the phrasing of K4 ("most widely *accepted* way") may have invited varied interpretations, this applied equally across groups. The significant difference nevertheless points to a meaningful knowledge gap. Knowledge about mental health impacts (e.g., depression; K7) was lower among the at-risk group (75%) compared to the diagnosed group (86%), and misconceptions including attributing weight gain to endometriosis were more prevalent among at-risk participants (22% vs.

---

[1]Department of Media and Communication, Ludwig-Maximilians-Universität München, Oettingenstr. 67, 80538 Munich, Germany. [2]NICM Health Research Institute, Western Sydney University, Westmead, NSW, Australia. [3]IIMPACT in Health, University of South Australia, Adelaide, SA, Australia. [4]Department of Media and Communication Sciences, University of Erfurt, Nordhaeuser Strasse 63, 99089 Erfurt, Germany. [5]Health Communication, Implementation Sciences, Bernhard Nocht Institute for Tropical Medicine, Hamburg, Germany. [6]Centre of Social and Cultural Research, Griffith University, 170 Kessels Road NathanQLD, 4111 Brisbane, Australia. ✉e-mail: anne.reinhardt@ifkw.lmu.de

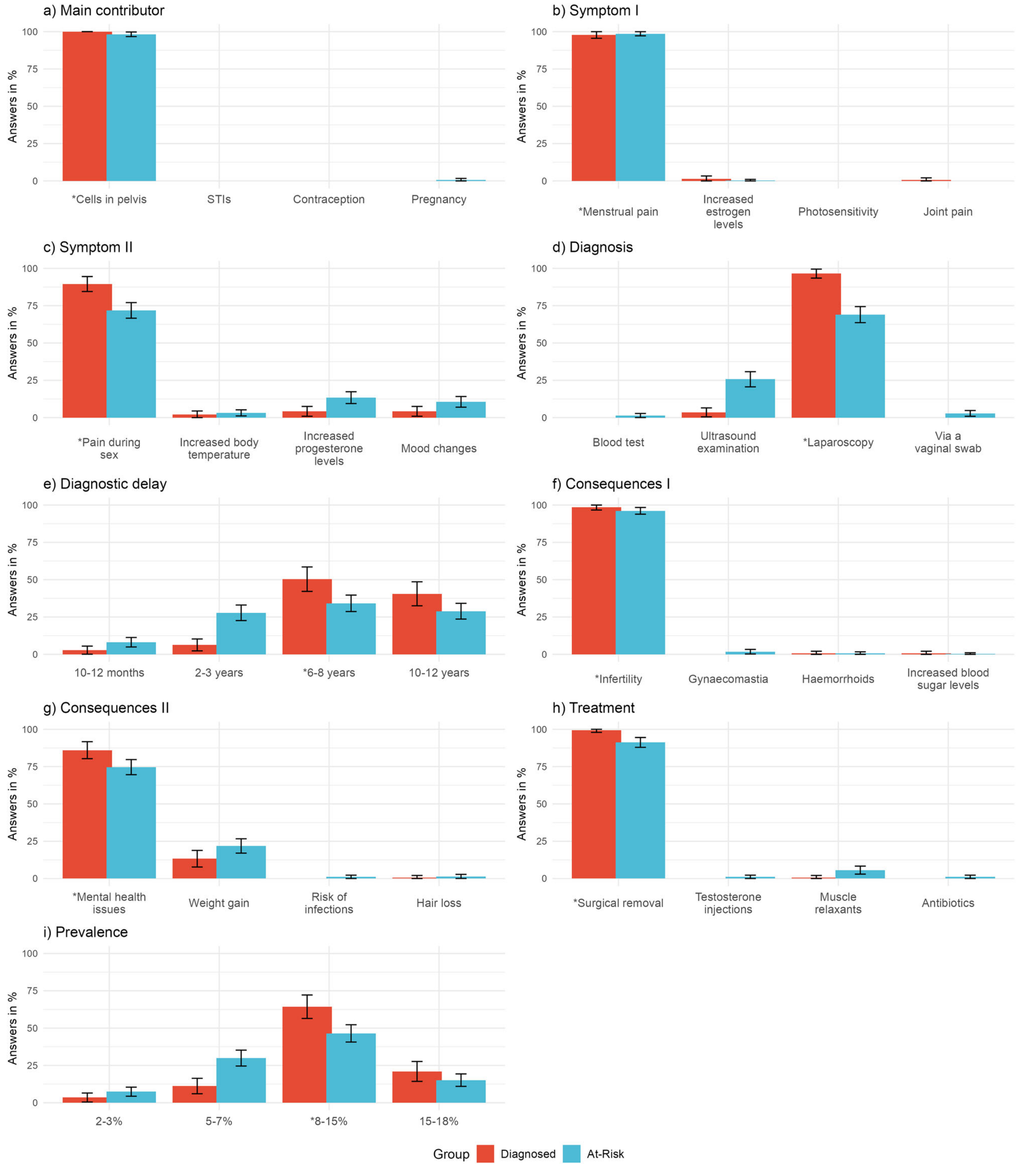

Fig. 1 | Knowledge assessment by group and item (with 95% confidence interval). Relative frequencies of response options for each of the nine knowledge items (panels **a** to **i**), stratified by group. Blue bars represent participants in the at-risk group, and red bars represent participants with a formal endometriosis diagnosis. Percentages refer to the proportion of participants selecting each response option. Error bars indicate 95% confidence intervals. Correct response options are indicated with an asterisk (*).

13%; however, the differences in K7 did not reach statistical significance after correction for multiple testing, see Supplement 1).

Notably, both groups exhibited limited knowledge of statistical information. Only half of the diagnosed group and 35% of the at-risk group correctly estimated the average time to diagnosis (K5). Diagnosed individuals tended to overestimate (41% answered 10–12 years), while at-risk participants tended to underestimate (28% answered 2–3 years). Similarly, endometriosis prevalence knowledge (K9) was limited, with 64% of the diagnosis group and 47% of the at-risk group answering correctly: 21% of the diagnosis group overestimated prevalence (believing that 15–18% of women/PFAB are affected), while 30% of the at-risk group underestimated it, assuming only 5–7% are affected.

The findings suggest that public knowledge about endometriosis in Australia among diagnosed and at-risk individuals is relatively high, particularly regarding basic symptomatology, disease causes, and treatment options. This encouraging baseline may reflect the impact of recent awareness campaigns and increased media coverage[3]. However, deeper analyses reveal persistent knowledge gaps—especially among individuals at risk who have not yet received a diagnosis—that have significant implications for both public health and clinical care.

One key issue is the widespread underestimation of diagnostic delays among at-risk individuals. While those with a confirmed diagnosis often overestimated the average time to diagnosis—likely reflecting their own experiences with symptom invalidation and extended diagnostic journeys[6]—at-risk individuals were more likely to underestimate how long the process can take. This gap points to structural and social barriers that contribute to delays, including trivialization of menstrual pain, limited clinical expertise, and importantly, menstrual shame and taboo[7,8]. Menstrual stigma reduces menstrual health literacies and silences the personal stories of people who have endured long diagnostic pathways[9]. Accordingly, at-risk individuals may be unaware that others have similarly struggled to receive a formal diagnosis, leading them to assume that delays are unusual and/or their own symptoms are not serious enough to warrant ongoing medical attention. This perception is often reinforced by a broader cultural ignorance toward menstrual-related pain, which is frequently dismissed or trivialized rather than recognized as a legitimate health concern[8,10]. A cycle of silence then ensues: those not yet diagnosed may fail to seek continued help, while those who have been diagnosed may hesitate to share their experiences. Targeted education must extend beyond factual knowledge of the disease. It should address how social norms contribute to diagnostic delay—normalizing open discussions of menstrual and pelvic pain, and by making personal diagnostic journeys more visible through public discourse. Breaking this cycle of silence is essential to helping people recognize their symptoms not as isolated experiences, but as part of a broader pattern that deserves medical attention.

A second critical misconception concerns endometriosis prevalence. Many at-risk individuals significantly underestimated how common endometriosis is—often assuming that only 5–7% of women/PFAB individuals are affected, when estimates range from 8–15%, with some studies suggesting even higher rates due to underdiagnosis[11]. This finding could indicate how those affected remain unable to adequately represent their interests in the public. If a condition is perceived as rare, individuals may be less likely to relate their own experiences to it, dismissing symptoms or attributing them to other causes. Public health communication must therefore work to normalize endometriosis as a widespread health concern and combat the perception that those affected are exceptions.

Third, symptom misconceptions—particularly that mood changes are a hallmark of endometriosis—warrant careful consideration. While endometriosis is associated with elevated risks for mental health conditions such as depression and anxiety, these are often secondary consequences of chronic pain, diagnostic delays, and the social and reproductive challenges posed by the disease[12]. Conversely, general mood changes are not considered a diagnostic criterion for endometriosis. In our study, 11% of at-risk individuals incorrectly selected "mood changes" as a key symptom, compared to 4% in the diagnosed group. This difference potentially reflects cultural narratives inaccurately conflating menstruation with volatility or irrationality[13]. These interpretations can legitimize endured stereotypes and may contribute to stigmatization of people with endometriosis and/or those experiencing mental health issues. Consequently, both conditions are taken less seriously than they should be. Public health messaging should therefore acknowledge the psychological burden that can accompany endometriosis without reinforcing stereotypical or dismissive language.

Fourth, even among diagnosed individuals, certain knowledge gaps remain. Despite their relatively high awareness overall, many were unaware of accurate prevalence data and tended to overestimate the time to diagnosis. These findings underscore the need for continuing patient education post-diagnosis, including resources on long-term management, mental health, and navigating healthcare systems[12,14]. Providing this information can support coping strategies and empower individuals to advocate for themselves in future medical encounters.

Efforts to address these gaps should focus on practical strategies. Public health initiatives could develop targeted awareness campaigns to address statistical misconceptions using infographics, video explainers, and testimonials that present relatable and norm-correcting information. Collaborating with schools, workplaces, and community organizations could help integrate endometriosis education into broader health literacy efforts, normalizing discussions about the condition from an early age[15]. Digital platforms and social media campaigns could expand outreach and importantly credentialed information[16], building on the success of past campaigns in Australia.

Finally, healthcare providers should be equipped with tools to emphasize key facts during clinical practice. Checklists or patient handouts could help debunk myths and provide clearer guidance. Additionally, training medical professionals to proactively address the mental health aspects of endometriosis would ensure comprehensive care that includes psychological support. The quality of medical care provided to those with endometriosis also needs to be assessed to ensure that medical professionals are adequately educated on endometriosis. It is important that the onus of endometriosis education is not solely placed on 'the patient,' and health campaigns should also be geared toward the medical community in improving their knowledge.

Methods

Sampling procedure

The study received ethical approval from the Western Sydney University Human Research Ethics Committee (ID H16020) confirming that this study complied with the Declaration of Helsinki. Participants were recruited between May 26 and July 31, 2024, through targeted social media advertisements (Meta) to people in Australia aged 18–45 years. Eligibility criteria included: (1) being between 18–45 years old, (2) born as female, (3) living in Australia, and (4) reporting at least one symptom related to endometriosis (see measures section for assessment criteria).

Design

We conducted an online survey targeting Australian citizens who met the screening criteria. After providing informed consent, participants completed a self-assessment for endometriosis and shared information regarding their awareness and personal diagnosis of the condition. Subsequently, we assessed participants' endometriosis knowledge and examined variables related to menstrual and endometriosis (the more specific findings related to stigma will be reported separately). Overall, the study design was adapted from a previous study of the authors[2].

Sample

The final study sample included 427 participants who either had a formal diagnosis of endometriosis ($n = 143$) or were classified as at-risk based on their reported symptoms ($n = 284$). At-risk status was defined as experiencing severe menstrual pelvic pain at least occasionally despite taking painkillers, in combination with at least one of the following symptoms occurring occasionally: diarrhea and/or bowel pain during menstruation, abdominal pain unrelated to menstruation, or pain during intercourse. To ensure data quality, participants with a mean survey completion time of less than 3 min were excluded.

Of the final sample, 87.8% ($n = 375$) identified as women, while 11.2% ($n = 48$) identified as other (i.e., male, genderqueer, transgender, or non-binary), and another 1% ($n = 4$) preferred not to say. Regarding education, 34.4% ($n = 147$) had lower to medium education levels (up to upper secondary and post-secondary vocational education), and 64.4% ($n = 275$) held a tertiary degree ($n = 5$ preferred not to disclose their educational status). A slightly higher proportion of participants in the at-risk group did not hold a university degree, which could have influenced response patterns in the knowledge measurement. However, it is worth noting that only one participant in the at-risk group had no formal school qualification, while all others had completed at least a secondary school degree (equivalent to Year 10), indicating an overall high educational baseline across the sample. All participants reported being familiar with the term endometriosis. A detailed description of the sample can be found in Table 1.

Table 1 | Sample characteristics

	Overall		Diagnosed		At-risk	
	n	%	*n*	%	*n*	%
Gender identity						
Female	375	87.8	135	94.4	240	84.5
Other	48	11.2	8	5.6	40	14.1
Prefer not to say	4	1.0	–	–	4	1.4
Education						
Lower/medium	147	34.4	34	23.8	113	39.8
Higher	275	64.4	98	68.5	167	58.8
Prefer not to say	5	1.2	10	7.0	4	1.4

Sociodemographic characteristics of the overall sample ($N = 427$), the diagnosed subsample ($N = 143$), and the at-risk subsample ($N = 284$). The table reports distributions of gender identity and educational attainment. The gender category “other” includes participants identifying as male, genderqueer, transgender, or non-binary.

Measures

The *self-test for endometriosis* symptoms[2] included the most common symptoms of the condition. Participants rated their experiences on a scale from 1 (never) to 5 (always). Items included pelvic pain during menstruation, the use of painkiller medication, and pelvic pain despite medication intake. Additional questions addressed diarrhea and/or bowel pain during menstruation, pain during sexual intercourse, and pelvic pain occurring several days a month, independent of menstruation.

Participants’ *endometriosis diagnosis* status was assessed with a dichotomous variable: “Have you yourself been diagnosed with endometriosis?” (0 = no, 1 = yes).

Lastly, *knowledge of endometriosis* was evaluated through nine single-choice questions covering the disease’s definition, incidence, symptoms, and treatment options[8]. Each question offered one correct answer and three distractors. Correct responses were summed to create a knowledge score ranging from 0 (“no correct answers”) to 9 (“all answers correct”). An overview of all knowledge items is provided in Table 2.

Table 2 | Knowledge questionnaire

Name	Question	Response options
K1	Which of these is the main contributor to endometriosis symptoms?	**1** = **“Cells similar to the lining of the uterus found in the pelvis”** 2 = “Sexually transmitted infections such as Herpes or Chlamydia” 3 = “Side effects of contraception pills” 4 = “Complications during pregnancy/birth”
K2	What is a typical symptom of endometriosis?	**1** = **“Severe menstrual pain”** 2 = “Increased estrogen levels” 3 = “Photosensitivity” 4 = “Joint pain”
K3	What is another common symptom of endometriosis?	**1** = **“Pain during sex”** 2 = “Increased body temperature during the period” 3 = “Increased progesterone levels” 4 = “Mood changes”
K4	What is the most widely accepted way to diagnose endometriosis?	1 = “Blood test” 2 = “Ultrasound examination” **3** = **“Laparoscopy”** 4 = “Via a vaginal swab”
K5	How long, on average, does it take to get an endometriosis diagnosis in Australia?	1 = “Approximately 10–12 months” 2 = “Approximately 2–3 years” **3** = **“Approximately 6–8 years”** 4 = “Approximately 10–12 years”
K6	What is a possible consequence of endometriosis?	**1** = **“Infertility”** 2 = “Gynecomastia (abnormal non-cancerous enlargement of one or both breasts)” 3 = “Hemorrhoids” 4 = “Increased blood sugar levels”
K7	What other condition is commonly experienced by people with endometriosis?	**1** = **“Mental health issues (e.g., depression)”** 2 = “Weight gain” 3 = “Increased risk for infections such as Herpes” 4 = “Hair loss”
K8	How can endometriosis be treated?	**1** = **“Surgical removal of the tissue”** 2 = “Testosterone injections” 3 = “Medication for muscle relaxation” 4 = “Antibiotics”
K9	What is the current estimate for how many women and people assigned female at birth are affected by endometriosis in Australia?	1 = “2–3% (2 to 3 out of 100)” 2 = “5–7% (5 to 7 out of 100)” **3** = **“8–15% (8 to 15 out of 100)”** 4 = “15–18% (15 to 18 out of 100)”

Overview of all knowledge items and corresponding response options (single choice format). Correct response options are indicated in **bold**.

Data availability

The datasets and R codes for this study are available in the Open Science Framework repository and can be accessed via this link: https://osf.io/spzej/?view_only=17961cfb1a664e6eb70be280a4b1d7c2.

Code availability

The underlying code for this study is available in the Open Science Framework repository and can be accessed via this link: https://osf.io/spzej/?view_only=17961cfb1a664e6eb70be280a4b1d7c2.

Received: 22 April 2025; Accepted: 23 July 2025;

References

1. Reid, R. et al. The prevalence of self-reported diagnosed endometriosis in the Australian population: results from a nationally-representative survey. *BMC Res. Notes* **12**, 88 (2019).
2. Eitze, S. & Reinhardt, A. Keep Period Pain a Secret? Expanding the Theory of Planned Behavior with Endometriosis Knowledge and Menstrual Stigma to Explain Women's Intentions to Talk About Menstrual Discomfort. *Health Psychol.* **44**, 437–447 (2025).
3. Armour, M. et al. Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: an Australian survey. *Sci. Rep.* **10**, 16253 (2020).
4. Armour, M. et al. Evaluation of a web-based resource to improve menstrual health literacy and self-management in young women. *J. Psychosom. Res.* **162**, 111038 (2022).
5. DiVasta, A. D., Vitonis, A. F., Laufer, M. R. & Missmer, S. A. Spectrum of symptoms in women diagnosed with endometriosis during adolescence vs adulthood. *Am. J. Obstet. Gynecol.* **218**, 324.e1–324.e11 (2018).
6. Bontempo, A. C. Conceptualizing symptom onvalidation as experienced by patients with endometriosis. *Qual. Health Res.* **35**, 248–263 (2025).
7. Zaman, R. T. & Mohiuddin, M.dF. Impact of menstruation-related stigma and behavior on female employee performance in Bangladesh: mediating role of non-work related stress. *South Asian J. Bus. Stud.* **12**, 169–185 (2023).
8. Reinhardt, A. & Eitze, S. Breaking the endometriosis silence: a social norm approach to reducing menstrual stigma and policy resistance among young adults. *Psychol. Health* **40**, 881–903 (2025).
9. Hawkey, A., Chalmers, K. J., Micheal, S., Diezel, H. & Armour, M. "A day-to-day struggle": A comparative qualitative study on experiences of women with endometriosis and chronic pelvic pain. *Fem. Psychol.* **32**, 482–500 (2022).
10. Armour, M., Dahlen, H. G. & Smith, C. A. More than needles: The importance of explanations and self-care advice in treating primary dysmenorrhea with acupuncture. *Evid. Based Compl. Alternat. Med.* **2**, 3467067 (2016).
11. Harder, C., Velho, R. V., Brandes, I., Sehouli, J. & Mechsner, S. Assessing the true prevalence of endometriosis: A narrative review of literature data. *Int. J. Gynecol. Obstet.* **167**, 883–900 (2024).
12. Sims, O. T., Gupta, J., Missmer, S. A. & Aninye, I. O. Stigma and endometriosis: A brief overview and recommendations to improve psychosocial well-being and diagnostic delay. *Int. J. Environ. Res. Public. Health* **18**, 8210 (2021).
13. Ussher, J. M. Managing the monstrous feminine in Regulating the reproductive body: Managing the monstrous feminine (ed. Ussher, J. M.) 1–18 (Routledge, 2006).
14. Kocas, H. D., Rubin, L. R. & Lobel, M. Stigma and mental health in endometriosis. *Eur. J. Obstet. Gynecol. Reprod. Biol. X* **19**, 100228 (2023).
15. Khan, K. N. et al. A targeted educational programme improves fundamental knowledge of menstrual pain and endometriosis in young women: The Endometriosis Awareness Promotion Project. *Reprod. Biomed. Online* **45**, 1216–1229 (2022).
16. Hirsch, M., Aggarwal, S., Barker, C., Davis, C. J. & Duffy, J. M. N. Googling endometriosis: a systematic review of information available on the Internet. *Am. J. Obstet. Gynecol.* **216**, 451–458.e1 (2017).

Acknowledgements

This study received no funding.

Author contributions

A.R.: Conceptualization, Methodology, Formal Analysis, Data Curation, Writing (Original Draft), Writing (Review & Editing), Visualization, Supervision, Project Administration M.M.: Methodology, Software, Investigation, Writing (Original Draft), Writing (Review & Editing), Project Administration SE: Conceptualization, Methodology, Writing (Original Draft), Writing (Review & Editing) H.A.: Writing (Original Draft), Writing (Review & Editing) D.H.: Writing (Original Draft), Writing (Review & Editing) M.O.: Writing (Original Draft), Writing (Review & Editing) M.A.: Conceptualization, Resources, Writing (Original Draft), Writing (Review & Editing), Supervision, Project Administration.

Funding

Open Access funding enabled and organized by Projekt DEAL.

Competing interests

The authors declare no competing interests.

Additional information

Supplementary information The online version contains supplementary material available at https://doi.org/10.1038/s44294-025-00096-6.

Correspondence and requests for materials should be addressed to Anne Reinhardt.