Self-management strategies amongst Australian women with endometriosis: a national online survey

Sinclair, J. Smith, C. Abbott, J. Chalmers, J. Pate, D. Armour, M.1

Introduction

Endometriosis is a chronic inflammatory condition that affects 1 in 10 women worldwide.² Its symptoms include chronic pain, dysmenorrhea, dyspareunia and fatigue.

Physical, mental, and emotional health are all significantly impacted by endometriosis. These affect all aspects of patients' well-being and the impact on the physical quality of life has been demonstrated to be similar to that of cancer.

Conventional treatments often provide only limited relief, leading women to seek alternative therapies to manage their symptoms. Cannabis has shown efficacy in alleviating symptoms of various pain conditions and some women with endometriosis report its utility in their self-management strategies.

Preliminary research suggests that the endocannabinoid system may play an important role in managing endometriosis pain and in turn reduce dependence on opioid-based pain relief. Little is known about the prevalence of cannabis use in this population or its perceived benefits and risks in endometriosis symptom management.

Aim of the study

To determine the prevalence of use, safety and self-rated effectiveness of self-management techniques in endometriosis patients.

Methods and materials

An online survey of 484 women aged 18-45 years with laparoscopy-diagnosed endometriosis recruited through patient advocacy organisations on social media platforms.

The survey collected:

- Demographics
- Disease characteristics
- Medical history
- Self-management techniques in the previous 6 months
- Frequency and duration of self-management
- Adverse events
- Self-rated effectiveness
- Reductions in endometriosis-related medication use

The Pelvic Pain Impact Questionnaire (PPIQ) was included to assess pain severity.

Primary and secondary outcomes

The primary outcome was to record the self-management techniques used by women with endometriosis.

The secondary outcomes were to assess the effectiveness of these interventions and record adverse events.

Results

The results showed that self-management of endometriosis symptoms was high in women who completed the study, and their choice of technique may correlate with the symptom they experience.

Of the 484 respondents, the most commonly used forms of self-management were heat (70%), rest (68%) and meditation/breathing exercises (47%). 13% reported using cannabis to manage their endometriosis symptoms (fig 1).

The self-rated efficacy of the self-management technique was measured on a 10-point scale, with 0 representing ineffective and 10 extremely effective. Women reported cannabis as the most effective self-management intervention (7.6 \pm 2.0) (fig 1), with 56% of cannabis users able to reduce their endometriosis-related medications to manage their symptoms by more than 50%.

Similarly, one-third of CBD users reported reducing their endometriosis-related medication by 50% or more.

Adverse events varied considerably depending on the self-management intervention. Women using alcohol and exercise for symptom management reported the highest percentage of adverse events (52.8% and 34.2%), including hangovers, increased pain and fatigue (fig 1).

Of the cannabis users, 10.2% recorded adverse events including drowsiness, increased anxiety and tachycardia and 8.3% adverse events were reported for CBD oil (fig 1).

Self-management technique	Proportion of women using the technique	Proportion of users experiencing adverse events	Effectiveness of pain relief mean (10-point scale)
Cannabis	13%	10.2%	7.6
Heat	70%	15.9%	6.5
Dietary choices	44%	5.9%	6.4
Hemp/CBD oil	3%	8.3%	6.3
Acupressure	8%	7.1%	6.3
Cold	5%	5.6%	5.5
Massage	32%	6.8%	5.5
Rest	68%	7.3%	5.3
Exercise	42%	34.2%	4.9
Herbal medicines	16%	3.2%	4.8
Alcohol	14%	52.8%	4.7
Stretching	40%	14.8%	4.6
Meditation/breathing	47%	3.4%	4.6
Yoga/Pilates	35%	15.9%	4.5
Taichi/Qigong	2%	0%	4.0

Figure 1: Self-management techniques and percentage of usage, percentage of adverse events and mean efficacy on a 10-point scale, listed in order of efficacy

Discussion

This study provides insights into self-management interventions and the effectiveness of these strategies in managing endometriosis-related symptoms.

As there are a lack of effective medications to treat endometriosis and its symptoms, women are seeking alternative self-management techniques and changes in lifestyle.

Although cannabis was only used by 13% of women in the survey, it scored the highest in reported pain relief and users had the greatest reduction in use of endometriosis-related medication compared to other interventions. The findings suggest that cannabis may be a promising intervention for endometriosis and warrants further study.

Future clinical trials are required to determine the use of legal, quality-assured medical cannabis in endometriosis management and treatment of pelvic pain.

References

- Armour, M., Sinclair, J., Smith, C. A., Abbott, J., Chalmers, K., & Pate, D. 2019. Self-management Strategies Amongst Australian Women with Endometriosis: A National Online Survey. BMC Complementary and Alternative Medicine, 19, 17. https://doi.org/10.1186/s12906-019-2431-x
- 2. National Institute for Health and Care Excellence. 2020. Endometriosis: how common is it? Accessed 28.04.2023. Available: https://cks.nice.org.uk/topics/endometriosis/background-information/prevalence



Rokshaw Ltd Unit 5a & Unit 7 Rivergreen Industrial Estate Sunderland SR4 6AD **Tel:** 0191 5106500 **Web:** rokshaw.co.uk Partnership Enquiries: medicalcannabis@rokshaw.co.uk MHRA No: MS 41467 Vat No: 139418693C Company No: 08154114