RESEARCH

‘A glimmer of hope’: perceptions, barriers, and drivers for medicinal cannabis use amongst Australian and New Zealand people with endometriosis – a qualitative study

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Abstract

Previous quantitative research has shown that cannabis use, mostly illicit, is used for symptom management amongst those with endometriosis living in Australia or New Zealand, but the drivers and barriers for use of legal, medicinal cannabis in this population are currently unclear. This study sought to investigate, *via* online focus groups, the perceptions, barriers, drivers, and experiences associated with cannabis use, whether legal or illicit, amongst 37 Australians and New Zealanders, aged 18–55, with a medical diagnosis of endometriosis. Previous cannabis usage was not required to participate. Discussion topics included strategies employed to manage symptoms, exploration of current medications, previous use of cannabis for pain management, and interest in using medicinal cannabis as a management strategy. Participants with moderate-to-severe symptoms of medically diagnosed endometriosis reported inadequacies with their current medical and self-management strategies and were inclined to try medicinal cannabis, both as part of their medical management and as part of a clinical trial. Barriers to medicinal cannabis adoption identified in this cohort included high costs of legal cannabis products, lack of clarity and fairness in current roadside drug testing laws and workplace drug testing policies, concern over the impact of stigma affecting familial, social and workplace life domains, and subsequent judgement and the lack of education/engagement from their medical providers regarding cannabis use. Given the interest in medicinal cannabis and the reported lack of effective symptom management, clinical trials are urgently required to determine the potential role that medicinal cannabis may play in reducing the symptoms of endometriosis.

Lay summary

Previous research has demonstrated that cannabis, either medically or illicitly obtained, is being used to manage the pain and associated symptoms of endometriosis in people across Australia and New Zealand. However, there are no clinical trials yet to determine how safe and effective medicinal cannabis might be for endometriosis symptoms. Before we design our clinical trial we wanted to get input from people in the community who have endometriosis to understand what kind of barriers there might be to both being in a clinical trial and using medicinal cannabis for their symptoms.

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Overall, the vast majority of participants were open to trying medicinal cannabis as a management option, driven mainly by inadequacies in their current medical and self-management strategies. Several barriers to adoption were identified, including the high costs of legal cannabis products, current drug driving laws or workplace drug testing policies, and the negative stigma around cannabis usage.

Keywords: ▶ endometriosis ▶ cannabis ▶ medicinal cannabis ▶ Australia ▶ New Zealand

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Introduction

Endometriosis is an oestrogen-dependent, chronic inflammatory condition characterised by the presence of endometrial-like tissue outside of the uterine cavity (Hickey *et al.* 2014, Johnson *et al.* 2017) and is fairly common, with prevalence rates ranging between 5 and 11% of women and those assigned female at birth (Zondervan *et al.* 2020, Rowlands *et al.* 2021). Common symptoms include chronic pelvic pain, fatigue, period pain, painful urination, back pain and painful sex (Ramin-Wright *et al.* 2018, Armour *et al.* 2021). The severe and unrelenting nature of symptoms can have a deleterious effect across numerous life domains, negatively affecting academic, social, work, and sexual/romantic relationships, which consequently impinge upon mental/emotional well-being (De Graaff *et al.* 2013, Armour *et al.* 2020). Moreover, the disease contributes to a significant cost of illness burden to both individuals and society (Nnoaham *et al.* 2011, Armour *et al.* 2019*a*, O'Hara *et al.* 2020, Malik *et al.* 2022), with lost productivity being the most significant modifiable factor (Nnoaham *et al.* 2011, Armour *et al.* 2019*a*).

The updated European Society of Human Reproduction and Embryology (ESHRE) guidelines released in 2022 (Becker *et al.* 2022) strongly recommend hormone treatments utilising combined hormonal contraceptives, progestogens, or gonadotrophin releasing hormone (GnRH) agonists or antagonists, and surgical removal of lesions, to address endometriosis-associated pain. Surgical studies report short- to medium-term reduction in pain (Leonardi *et al.* 2020), but these invasive procedures are associated with considerable cost and risk, and require access to skilled surgeons. Opioid, non-steroidal anti-inflammatory (NSAID) and anti-neuropathic medications have also been used for pain management, but variously, a lack of effectiveness, their side effects or the risk of addiction limit their long-term use (Australian Institute of Health and Welfare 2018, Roxburgh 2018, Bolshakova *et al.* 2019). Most endometriosis patients report ongoing challenges with pain and symptom management (Moradi *et al.* 2014, Hawkey *et al.* 2022). A modest reduction in pain of just 20% would save approximately AU$9,000 per person per year (Armour *et al.* 2019*a*), in addition to improvements in health-related quality of life. Therefore, effective pain management strategies are vital to reduce these burdens.

The chemical constituents of *Cannabis* spp. (mainly phytocannabinoids) such as delta-9-tetrahydrocannabinol (THC) and cannabidiol (CBD) have well-described analgesic, anti-inflammatory, anxiolytic, antidepressant, and anti-emetic actions (Rahn & Hohmann 2009, Bolognini *et al.* 2010, Zanelati *et al.* 2010, Aggarwal 2013, 2017, Burstein 2015). Previous research has demonstrated that both legal and illicit cannabis is being utilised by endometriosis patients to not only manage pain, but also ameliorate other challenging co-morbid symptoms such as nausea, fatigue, poor sleep, mood disorders, and gastrointestinal issues (Armour *et al.* 2019*b*, 2021, 2022, Sinclair *et al.* 2019, 2021). Australia legalised medicinal cannabis in 2016, with Special Access Scheme (Category B) prescription numbers reaching 375,466 as of 15 June 2023. New Zealand adopted the Medicinal Cannabis Scheme in July of 2020, with both countries opting for strict regulatory controls and high-quality standards for dispensing medicinal cannabis products. The majority of those with endometriosis report the use of illicit cannabis, even in countries with legal access (Sinclair *et al.* 2021, Armour *et al.* 2022). Therefore, whilst patient uptake of legal cannabis is growing across both countries, what is currently unclear is why those with endometriosis are still commonly choosing to use illicit sources of cannabis.

Despite its relative popularity as a self-management strategy (Armour *et al.* 2019*b*), the evidence base for use of medicinal cannabis to manage endometriosis is scarce, and randomised controlled trials or similar prospective designs are urgently needed to determine the

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effectiveness of medicinal cannabis on endometriosis. Co-design is a crucial aspect of clinical trials, and given that concerns around medicinal cannabis usage have been raised for primary dysmenorrhoea (i.e. period pain) (Sinclair *et al.* 2022*a*), it is crucial that the acceptability and feasibility of using medicinal cannabis is explored, with possible barriers considered, when designing future trials for those with endometriosis.

The aims for this study were first to explore the drivers and barriers for use of medicinal cannabis in endometriosis with both cannabis consumers and non-consumers and, second, to investigate concerns about acceptability and feasibility of medicinal cannabis as a potential treatment option for endometriosis pain and symptoms.

Materials and methods

Design

The present work incorporates both quantitative and qualitative aspects. Quantitative data were collected to determine demographics, previous cannabis use, health-related quality of life, and pain management strategies. However, qualitative data were the major study focus, using a descriptive approach to focus holistically on the 'who, what, when, where and why' of events and experiences, which assisted the gleaning of insight from participants regarding a poorly understood phenomenon (Kim *et al.* 2017, Clark 2019, Clark *et al.* 2019). These qualitative data were analysed using a critical realist lens which supposes the existence of an objective truth, but acknowledges that inquiry and observation are also inevitably ensnared within the subjective perceptions of the researcher (Hesse-Biber 2016).

Population and sampling

This study was approved in December 2020 (Approval #H14115) by the Western Sydney University Human Research Ethics Committee. Study participants who responded to expressions of interest *via* social media were invited to participate anonymously, with written informed consent obtained and participant screening conducted prior to formation of the focus groups. Candidates were deemed eligible to participate in the virtual focus groups if they were currently residing in Australia or New Zealand, were aged between 18 and 55 years, and had been told by their physician that they have endometriosis. It was disclosed within the social media recruitment that the study would be discussing (illicit or legal) cannabis usage, but previous usage of cannabis was not a requirement for participation in this research project, as a variety of opinions were valued, including the interests or concerns of the cannabis-naive. Recruitment was conducted *via* the social media platforms (i.e. Instagram and Facebook) of Endometriosis Australia and Endometriosis New Zealand, two of the largest (i.e. combined reach of over 45,000 followers) endometriosis support and advocacy groups in the region.

Due to the potential disclosure of illegal activity, anonymity was considered vital. Prior to focus-group formation, participants supplied a fictitious username in the pre-focus group survey (completed 1 week before the focus groups were conducted), and then used that username within the virtual focus groups. This allowed the collection of demographic and quantitative data anonymously whilst ensuring that only those who attended the focus groups had their demographic and other quantitative data included in the analysis. Focus groups were conducted virtually *via* Zoom® (MA conducted the first focus group for instruction purposes for JS1; JS1 conducted the remaining five focus groups solo) and were between 60 and 90 min in duration, and all participants were asked to keep their cameras turned off, in order to maintain anonymity. This was also important to ensure participants felt more comfortable discussing potentially illegal activity. Focus-group topics were derived from findings from an Australian Senate Inquiry investigating barriers to cannabis access as well as authors previous qualitative research on medicinal cannabis and primary dysmenorrhoea (Community Affairs References Committee 2020, Sinclair *et al.* 2022*b*). A total of six online focus groups were run between 18 June 2021 and 21 July 2021. These groups were stratified according to country (Australia or New Zealand) and by age, with group 1: 18–24 years, group 2: 25–35 years, and group 3: 36–55 years.

Data collection

Prior to instituting the focus groups, a quantitative survey link utilising the Qualtrics© platform was rovided and data collected on demographics, endometriosis-specific symptoms, and employment of pharmaceutical medications or possible self-management strategies. The Pelvic Pain Impact Questionnaire (PPIQ) and Endometriosis Health

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Profile-30 (EHP-30) instruments were used for omparative analysis. The PPIQ (8 Core and 2 supplemental questions using a 5-point Likert scale where 0 = Not at all, 1 = A little, 2 = Somewhat, 3 = Quite a bit, and 4 = A great deal) aims to assess the impact of pelvic pain, regardless of diagnosis, and has high reliability, easy scoring and sound psychometric performance (Chalmers *et al.* 2017). The EHP-30 (30 core questions using a 5-point Likert scale where 0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Often, and 4 = Always) is a reliable and validated instrument for assessing pain, control and powerlessness, social support, emotional well-being and self-image (Hansen *et al.* 2022). For both the PPIQ and EHP-30, higher scores indicate more negative impact and lower quality of life.

For contextual clarity, various self-management strategies were classified as non-pharmacological, physical, or psychological and could be conducted by oneself, without practitioner assistance. Topics covered in the focus groups explored possible barriers and drivers for cannabis usage. Potential barriers included challenges with current medical/self-management strategies, the potential impact of cannabis-associated stigma, medicinal cannabis product costs, drug testing at either work or at roadside mobile drug testing stations, and any substitution of pharmaceuticals by cannabis. Possible drivers for cannabis usage included asking about sub-optimal clinical results from current orthodox medical management and/or adverse events associated with current pharmaceutical management options. Supplementary File 1 (see section on supplementary materials given at the end of this article) provides the questions used in all focus groups.

Statistical analysis

Analyses and coding of the data used a qualitative descriptive approach (Sandelowski 2000). This methodological approach is both accessible and inclusive, is presented in colloquial language (Sullivan-Bolyai *et al.* 2005), and describes a participant summation of their everyday experience. The qualitative descriptive method seeks to capture the meaning attributed by the participant to that experience with as much clarity as possible (Caelli *et al.* 2003). Data analyses were focussed on a qualitative content analysis (Erlingsson & Brysiewicz 2017), with one researcher (JS1) breaking the data down into codes and then sorting into sub-categories, and grouping into overall categories. The entire data analysis process was overseen by the primary supervisor and senior author (MA). After a consensus was reached between JS1 and MA relating to code classification and categorisation, quotations in each domain were summarised and presented in a qualitatively descriptive manner. Due to the potentially illegal activities being discussed, anonymity was considered essential, as was attributing accurately the quotes to participants. A code was devised which captured the focus group (AUS = Australia/NZ = New Zealand), the participant age group (18–24/25–35/36+), and the particular participant (P) in that group being quoted (e.g. participant 5 from New Zealand in the 36+ group would be represented as NZ-36+; P5).

Descriptive statistics, including frequencies and percentages, means and standard deviations, or median and interquartile range, were used to report demographic information, symptoms, management strategies, and the PPIQ and EHP-30 scores.

Results

In total, 39 subjects participated in the online focus groups. No data on gender identity were collected. Two of the participants did not use the same username in the focus group as they had provided in the survey, so their quantitative data sets were eliminated, leaving a balance of 37 total participants (Australia $n = 24$/New Zealand $n = 13$). Table 1 outlines the demographics of participants.

Table 2 outlines the endometriosis related demographics, symptoms and self-management options. The majority of participants had been diagnosed by laparoscopy (91%), and were less than 5 years from diagnosis. Both opioids and non-opioids were commonly used pharmaceuticals, whilst heat and dietary choices were the most popular self-management options.

PPIQ and EHP-30 scores are provided in Tables 3 and 4, respectively. Both tools demonstrated a noticeable impact, with the EHP-30 demonstrating a substantive impact to participants in both countries across domains such as self-image, control and powerlessness, and social support.

Focus group content analysis

Category 1: 'It's completely changed my life'

In this study, 73% ($n = 27$) of participants across both countries had previously used cannabis, with many noticing substantial symptomatic benefits from

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Table 1 Participant demographics. Data are presented as *n* (%).

Characteristics	Combined	Australia	New Zealand
Average household income			
Australian (AU$)		$81,636.36	
New Zealand (NZ$)			$142,214.28
n	37	24	13
Participant age, median (range)	29 (18–47)	30.5 (20–47)	28 (18–38)
Location[a]			
Urban area (e.g. city)	32 (86.5)	20 (83.3)	12 (92.3)
Rural area	4 (10.8)	3 (12.5)	1 (7.7)
Remote area	1 (2.7)	1 (4.2)	0 (0)
Education			
Did not finish high school	2 (5.4)	1 (4.2)	1 (7.7)
Completed high school	6 (16.2)	4 (16.7)	2 (15.4)
Diploma/certificate	11 (29.7)	7 (29.2)	4 (30.8)
Bachelor's degree	13 (35.1)	8 (33.3)	5 (38.5)
Master's degree	5 (13.5)	4 (16.7)	1 (7.7)
Doctoral degree (e.g. PhD)	0 (0)	0 (0)	0 (0)
Previous cannabis use			
Yes	27 (73.0)	17 (70.8)	10 (76.9)
No	10 (27.0)	7 (29.2)	3 (23.1)
Reason for cannabis use			
Recreational (Rec)	4 (14.8)	2 (11.8)	2 (20.0)
Symptom management (SM)	7 (25.9)	4 (23.5)	3 (30.0)
Both Rec and SM	16 (59.3)	11 (64.7)	5 (50.0)

[a]Self-reported by participants.

recreational/social use of illicitly sourced material. Most respondents that medicated with cannabis felt significant reductions in their endometriosis symptoms. However, some noted that they did have previous experiences that were sub-optimal. Some participants also noted that the experience when utilising cannabis changed between social and therapeutic use cases.

> *Like, I tried it a few times recreationally and really didn't like it. And then in 2016, I was diagnosed with endometriosis, and gradually my symptoms have gotten worse and worse. And it wasn't until around this time last year that I tried cannabis again. And it's completely changed my life. Like, I found it the best kind of tool to managing the symptoms mentally, the pain. I feel more like myself. It helps with sleep, more energy, all of that. (AUS-25–35; P11)*

> *I was using illicit cannabis to treat my pain and psychological symptoms for three years before I was prescribed medical cannabis. And the difference in the treatment that it gives me has been huge. I've been able to not use any other pain relief and just rely on the medicinal cannabis in oil and flower form (AUS-25–35; P5)*

> *What I have noticed is that when I do smoke recreationally and I'm feeling good, I get high, let's say. But when I'm in a lot of pain, I smoke weed and I don't get that high. It's just like, it doesn't get to my brain, it relaxes me and I feel like it just goes to my body. It's very strange. It's completely different experience when I'm in pain. (NZ-36+; P2)*

Category 2: 'A glimmer of hope'

The majority of focus-group participants reported struggling with feelings of helplessness and frustration due to their failure to find adequate pain and symptom relief from orthodox medical treatments, whether surgical or pharmaceutical. The constant pain impacting their ability to lead a normal life was strongly acknowledged; so too was the hope that another alternative, such as medicinal cannabis, might be a therapeutic option for them.

> *... I've had quite a number of bad experiences with my endometriosis. I've only been diagnosed for four years, but it has been like the hardest four years. Like, I'm facing a fourth surgery now. I've had so many different types of pills and all the different kind of contraceptives there are. Nothing has worked for me. So it's like, to even just have a glimmer of hope that something else may work .... (AU-18–24; P7)*

> *I'm sure everyone else here can get that this is something that doesn't allow you to have a normal life. And for the amount of time that I have had endometriosis, I don't know what living a normal life with no pain is even like,*

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Table 2 Endometriosis demographics and symptoms. Data are presented as *n* (%).

	Combined	Australia	New Zealand
How were you diagnosed?			
Told by doctor/specialist	2 (5.4)	2 (8.3)	0 (0)
Surgery (e.g. laparoscopy)	34 (91.9)	22 (91.7)	12 (92.3)
Ultrasound	1 (2.7)	0 (0)	1 (7.7)
How long since diagnosed?			
Years	4.2	4.5	3.8
Number of doctors seen before diagnosis?			
1	1 (2.7)	1 (4.2)	0 (0)
2–3	12 (32.4)	7 (29.2)	5 (38.5)
3–5	9 (24.3)	5 (20.8)	4 (30.8)
>5	15 (40.5)	11 (45.8)	4 (30.8)
Endometriosis stage at last surgery?			
Unsure/do not know	5 (14.7)	3 (13.6)	2 (16.7)
Stage 1 (minimal)	1 (2.9)	1 (4.5)	0 (0)
Stage 2 (mild)	7 (20.6)	4 (18.2)	3 (25.0)
Stage 3 (moderate)	11 (32.4)	7 (31.8)	4 (33.3)
Stage 4 (severe)	10 (29.4)	7 (31.8)	3 (25.0)
Endometriosis symptoms experienced			
Period pain	36 (97.3)	24 (100.0)	12 (92.3)
Heavy menstrual bleeding	30 (81.1)	20 (83.3)	10 (76.9)
Chronic pelvic pain (not associated with menses)	34 (91.9)	22 (91.7)	12 (92.3)
Anxiety	27 (73.0)	17 (70.8)	10 (76.9)
Depression	23 (62.2)	15 (62.5)	8 (61.5)
Painful sex	28 (75.7)	16 (66.7)	12 (92.3)
Difficulties sleeping	22 (59.5)	13 (54.2)	9 (69.2)
Fatigue	34 (91.9)	22 (91.7)	12 (92.3)
Nausea	28 (75.7)	18 (75.0)	10 (76.9)
Back pain	34 (91.9)	21 (87.5)	13 (100.0)
Bowel symptoms	28 (75.7)	18 (75.0)	10 (76.9)
Bladder symptoms	20 (54.1)	13 (54.2)	7 (53.8)
Gastrointestinal symptoms	22 (59.5)	15 (62.5)	7 (53.8)
Headache or migraine	25 (67.6)	17 (70.8)	8 (61.5)
Other symptoms			
Mood swings[a]	1 (2.7)	1 (4.2)	0 (0)
Abdominal and chest pain[a]	1 (2.7)	1 (4.2)	0 (0)
Nerve pain/sciatica[a]	1 (2.7)	1 (4.2)	0 (0)
Get sick easily[a]	1 (2.7)	0 (0)	1 (7.7)
Shaking before onset of flare[a]	1 (2.7)	0 (0)	1 (7.7)
Bloating[a]	1 (2.7)	0 (0)	1 (7.7)
Pharmaceutical medication usage			
Non-opioid pain medication (ibuprofen, etc.)	29 (78.4)	18 (75.0)	11 (84.6)
Opioid-based pain medication (codeine, oxycodone, etc.)	20 (54.0)	14 (58.3)	6 (46.1)
Hormonal Rx (OCP, Visanne, Mirena, etc.)	25 (67.6)	18 (75.0)	7 (53.8)
Anti-anxiety medication (Xanax, Valium, etc.)	5 (13.5)	4 (16.7)	1 (7.7)
Antidepressant medication (Prozac, etc.)	8 (21.6)	3 (12.5)	5 (38.5)
Anti-nausea medication (Maxalon, etc.)	3 (8.1)	2 (8.3)	1 (7.7)
Sleeping medications	2 (5.4)	1 (4.2)	1 (7.7)
Neuroleptic medication	3 (8.1)	0 (0)	3 (23.1)
Self-management strategies used[b]			
Acupressure (self-applied)	6 (16.2)	3 (12.5)	3 (23.1)
Breathing exercises	18 (48.6)	11 (45.8)	7 (53.8)
Dietary choices (gluten free, dairy free, etc.)	23 (62.2)	13 (54.2)	10 (76.9)
Dietary supplements (vitamin D, melatonin, etc.)	17 (45.9)	11 (45.8)	6 (46.1)
Heat (heat packs, hot water bottles)	36 (97.3)	23 (95.8)	13 (100.0)
Herbal medicines (purchased OTC)	5 (13.5)	3 (12.5)	2 (15.4)
Low intensity aerobic exercise (walking)	18 (48.6)	9 (37.5)	9 (69.2)
Massage	11 (29.7)	7 (29.2)	4 (30.8)
Meditation	11 (29.7)	7 (29.2)	4 (30.8)
Moderate- to high-intensity aerobic exercise	8 (21.6)	5 (20.8)	3 (23.1)

(Continued)

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Table 2 Continued.

	Combined	Australia	New Zealand
Pilates	4 (10.8)	4 (16.7)	0 (0)
Tai Chi	1 (2.7)	1 (4.2)	0 (0)
Yoga	9 (24.3)	7 (29.2)	2 (15.4)
Swimming in ocean[a]	1 (2.7)	1 (4.2)	0 (0)
Stretching[a]	1 (2.7)	1 (4.2)	0 (0)
Dance and gym[a]	1 (2.7)	0 (0)	1 (7.7)
Cupping[a]	1 (2.7)	0 (0)	1 (7.7)
Other medications/treatment used			
Amitriptyline[a]	2 (5.4)	1 (4.2)	1 (7.7)
Acupuncture/TCM herbal medicine[c]	5 (13.5)	5 (20.8)	0 (0)
Herbal medicine (herbalist, naturopath)[c]	4 (10.8)	4 (16.7)	0 (0)
Physiotherapy – pelvic exercises[c]	9 (24.3)	5 (20.8)	4 (30.8)
Zinc, fish oil, magnesium, vitamin D[a]	1 (2.7)	0 (0)	1 (7.7)
CBD oil[a]	2 (5.4)	0 (0)	2 (15.4)
Cannabis cream applied topically[a]	1 (2.7)	1 (4.2)	0 (0)
Medicinal cannabis[a]	1 (2.7)	1 (4.2)	0 (0)

[a]Derived from free text box attached to 'other' response option; [b]Strategies that can be done by oneself without practitioner assistance for endometriosis symptom management; [c]Service provided or prescribed by qualified physiotherapist, acupuncturist/TCM practitioner, herbalist, or naturopath.

at all, because I was diagnosed when I was really, really young at the age of 16-17. I'm 37 now, and never really lived a life. I just want to live a life, you know .... (NZ-36+; P4)

Category 3: 'I would ... but you'd fine me'

Participants reported their experiences, perceptions and general lack of knowledge relating to driving after cannabis use within the context of safety, current roadside drug-testing, and the potential for consequent criminal charges, particularly in Australia where the mere presence of THC in oral fluid constitutes a strict liability offence. Participants were advised on current drug-driving laws, as well as the pharmacokinetics of THC staying detectable for hours to days after infrequent use, or weeks to months with frequent, chronic use, due mainly to phytocannabinoid lipophilicity and distribution characteristics (Grotenhermen 2003, Huestis 2007). Most participants suggested that they would not feel comfortable using medicinal cannabis until such 'unfair laws' were changed, and that advice from medical practitioners was not clear, or was inaccurate, around cannabis use and driving. Some participants still drove despite the risks, and those in regional and remote locations felt particularly distressed when considering that a vehicle is the only method of transport available to them.

Just wanted to say I live regionally in Victoria. So for me, not driving is almost impossible. We don't really have much infrastructure and public transport, so I have to drive. And I guess I just have to take it upon myself to monitor how I'm feeling the next morning after smoking, like a lot of other people have said on here, codeine does not agree with me. I feel ten times worse after a night of taking two codeine than I do of having a joint before I go to bed. (AUS-25–35; P6)

Table 3 Pelvic Pain Impact Questionnaire (PPIQ) scores.

PPIQ descriptor	Combined (*n* = 37)	Australia (*n* = 24)	New Zealand (*n* = 13)
Energy levels	3.08	2.96	3.31
Mood	2.89	2.79	3.08
Sleep	2.41	2.21	2.77
Stomach and intestinal function	2.54	2.38	2.85
Ability to sit longer than 20 min	1.68	1.50	2.00
Ability to perform and function normally at home/work/school/university	2.78	2.63	3.08
Ability to take part in physical activity	2.78	2.54	3.23
Ability to wear certain clothes	3.00	2.92	3.15
Pelvic pain affect ability to use tampons	2.26	2.25	2.29
Pelvic pain affect levels of intimacy/sexual relationships	2.85	2.77	3.00

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Table 4 Endometriosis Health Profile-30 (EHP-30) scores. Data are presented as mean (s.d.).

EHP-30 domain	Combined (*n* = 37)	Australia (*n* = 24)	New Zealand (*n* = 13)
Pain	57.13 (12.47)	55.78 (6.28)	59.62 (2.72)
Control and powerlessness	71.13 (15.49)	70.49 (3.01)	74.04 (2.95)
Emotional wellbeing	55.18 (15.09)	53.99 (12.21)	57.37 (7.83)
Social support	67.23 (14.36)	64.84 (6.24)	71.63 (5.06)
Self-image	73.65 (14.95)	70.49 (4.04)	79.49 (4.73)

I have a confession to make. I do drive. I take that risk every day. I try not to drive long distances for whatever that's worth. I am lucky in that I don't, I live inner city, so things are fairly close by for me. I don't have a family. So any risks that I take, really, it's me that has to deal with the consequences. The way I treat it is the same way as if I'd had a couple of drinks and felt too impaired to drive. If I felt impaired by the THC, I wouldn't get in the car. (AUS-36+; P3)

I'm ready to go and try and get some for me to try. But since you've mentioned the laws not changing and the length of time that it stays in your system, I'm more hesitant to try until the laws have changed. (AUS-36+; P8)

Driving is a huge concern for me. I only started taking THC because the doctor that prescribed it assured me that it wouldn't register in any drug driving kit if it was more than 8 hours since I'd taken it. So he said to me, never take it after midnight because I need to be driving to work at 08:00 a.m. Now, however, hearing you say that it could still stay in the system for up to three days or even longer, it really makes me not want to take it at all until the laws have been changed. (AUS-36+; P4)

I've also been pulled over by a cop and he says, 'oh, hun you look at bit, you know, worse for wear' as such. I'm like, 'well, yeah, that does it when you haven't had any sleep for like 24 hours and got chronic pain'. And he's like, 'oh, just go home and have a joint'. Yeah, well, I would but you'd fine me. (NZ-36+; P3)

Category 4: 'Grappling with stigma'

Focus-group participants reported on the impact that stigma associated with cannabis has across social, religious, cultural, and professional relationships, despite its legality in both countries. The potential for damage to their professional or social standing, if their use of cannabis became known, was of poignant concern. Participants described how they grappled with the judgment of their cannabis use, with many stating they had to use this now-legal medicine in a clandestine manner, in contrast to having worse side effects from prescribed medicines which impact their ability to conduct their duties.

I don't really have any personal, religious or cultural concerns, so I feel fortunate that that wasn't something I had to grapple with. But I do have concerns. I work in government. And I, you know, therefore, I have to keep it very quiet that I use CBD oil to treat my symptoms. And I guess I also get frustrated because I find it ironic that I can turn up to my job, kind of high as a kite on prescribed medication, but feel completely fine and have managed symptoms on CBD oil, but it'd be a risk to my professional opportunities. (NZ-25–35: P5)

I'm a teacher, so if I take CBD oil at school, I have to hide it and take it in private. Whereas if I took an Ibuprofen or anything else, I can just sit there and take one in the middle of a lesson, but I have to be quite secretive about it at work, and then with some people in my private life as well. I also, being a teacher, I couldn't post anything online about using it because that could mess with my job. If a parent was like, you know, she's a drug addict, why are you letting her teach our children? (NZ-25–35; P7)

But then to chuck in you're taking cannabis oil, they'll make jokes about 'oh, do you want to bring some to movie night?' And it's ... I think it's just that stigma around it and it's hard to deal with, like with family and even close friends for me, and even my partner to a degree. So it's definitely there, and it's hard to deal with. (AUS-36+; P5)

Category 5: 'Substitution effect'

Participants described their experiences using legal and non-legal cannabis for their endometriosis symptoms and how this decreased their regular pharmaceutical medication usage. Decreases in opioid, antidepressant, non-steroidal anti-inflammatory, anti-neuropathic, hormonal, and anxiolytic medication has been previously described in the literature (Armour *et al.* 2019*b*, 2021, 2022, Sinclair *et al.* 2019, 2021) for those using cannabis for endometriosis, but there has been a paucity of qualitative data on this topic. Conversely, some participants expressed concern that using cannabis may change the way their other medications work, which was an important consideration for many. Comments around replacing certain pharmaceuticals

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'cold turkey' with cannabis is also of significant clinical concern for certain medications, and has been highlighted in previous research in the endometriosis cohort (Sinclair *et al.* 2021).

I've been using well, it's sort of homemade CBD oil, so it probably has THC in it as well. A friend's dad made it for me about maybe four or five months ago now, but I got an endometriosis diagnosis a couple of years ago, and I find it a really effective replacement for codeine. (NZ-25–35; P5)

I know when I was on the CBD capsules for the ten days that I tried it, I managed to go cold turkey off my oxycodone daily and was only taking one dose of OxyNorm, whereas I'm normally four doses of OxyNorm a day and then two doses of oxycodone a day on top of everything else ... like that in itself just probably made me feel more human. (NZ-36+; P4)

Yeah. I mean, the alternative is, you know, dosing up to my eyeballs on codeine, but then that puts me out not only for that day, but I pretty much am out for the whole next day with what I call like a codeine hangover. This is where I just feel ill, and I haven't got that with the cannabis. (AUS-25–35; P10)

The only thing I bear in mind is obviously all the other medication that you're taking, that it's not going to interfere with it, because I'm taking medication for anxiety and stuff. (NZ-36+; P4)

Category 6: 'The cost is prohibitive'

Focus-group participants reported varied viewpoints on the cost acceptability of quality-assured medicinal cannabis products *versus* products obtained from the non-legal 'green market'. Taking into account the many medications that patients are already taking to manage their endometriosis, and other co-morbid symptoms and conditions, the majority expressed during focus-group discussions that the cost of legal products was prohibitive, particularly given a lack of government subsidy, such as the Pharmaceutical Benefits Scheme (PBS), or the ability to utilise private health funds to claim money back. Comments reflecting the expense of normal medical and gynaecological care were common, which deleteriously affected their decisions on being able to afford an alternative such as medicinal cannabis.

The cost is prohibitive and I have been able to make changes with the medical cannabis where I'm not needing to spend money in other medical areas. But it's really, really a huge decision again, that I have to make almost every month about whether, okay, yes, I do need this, it helps so much when I reflect on, you know, the pain relief and the mental support. So I make other sacrifices I guess. (AUS-25–35; P5)

I would look at other options, like getting medicinal cannabis, but at the moment, until I finish my studies, I can't really afford specialist care, even just for gynaecology. So it's not really an option. (AUS-25–35; P9)

No, not prescribed. I do have a script for CBD, but refused to pay the amount they want for it. So it just sits in my drawer somewhere. (NZ-36+; P3)

For me is not prohibitive, but I find it ridiculous. I would be willing to pay what it takes, what it costs, if it works. (NZ-36+; P2)

Well, I'm lucky enough to be able to afford it at the moment. I can see how it would be really prohibitive for anyone that was on a lower income or needed a health care card because these medications aren't on the PBS. And it's sort of very similar to the fact that excision surgery isn't widely available to people, or finding a gynaecologist that is an excision specialist and actually knows about endometriosis. All of this stuff is really for people who are privileged. And that's the unfortunate thing, because really the majority of women, aren't, you know, in the position necessarily to afford medical cannabis or to receive good care from a gynaecologist that actually knows about endometriosis. (AUS-36+; P3)

Category 7: 'Lack of choice ... and consistency'

Focus-group participants commented on the disparity between Australia and New Zealand when it comes to access to a variety of different medicinal cannabis products and dosage forms. Whilst Australia has had a legal medicinal cannabis program since 2016, New Zealand did not rollout their Medicinal Cannabis Scheme until 2020 (Ministry of Health 2020), which may explain this discrepancy for lack of choice due to the latter nascent industry still becoming established. Participants described a lack of availability of different dosage forms and higher potency THC-based products, with some citing this inequity when compared to the international jurisdictions they had experienced, where both medicinal and recreational/adult-use products are legally available.

I think it's great that we can get a prescription for it, but if we can't afford to actually hand in the prescription, or we can't get a wide range of products, because it can't just treat everybody with one or two products. (NZ-25–35; P7)

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So every time I go to the United States, is like, I feel like it's my dream come true... Yeah, that's very limiting here, because what you get here is basically, is the idea that one thing fits everybody, and that's not how it is. (NZ-36+; P2)

So I guess the availability of it, and the cost, and there are products available in New Zealand, but there's not that wide of a range. It's also, I guess, the kinds of products that I could take aren't as good as I think they should be. (NZ-25–35; P6)

Furthermore, participants did highlight the lack of quality or consistency in products sourced from the illicit market, which raises concern over the lack of quality-assurance in these products as a public safety issue. This could be circumvented by a wider variety of legal dosage forms and a reduction in cost for these products.

I've used several different black-market brands over the last probably four years, all having, I suppose, varied effects as well. I've used balms and I've vaped as well. I'm now on prescription CBD as well as the THC oil because I found what I was using off the black market was ... sometimes works, sometimes didn't, and there was absolutely no consistency'. (AUS-36+; P7)

Discussion

Focus-group participants in this study frequently highlighted that their current medical management of endometriosis-associated pain and related symptoms was sub-optimal. This was their main driver for cannabis use, with the majority using illicitly procured cannabis despite barriers associated with criminal risks, lack of quality assurance and the experience of inconsistent clinical outcomes. Apparently greater barriers associated with prescribed cannabis included the high cost of the quality-assured product; the stigma still surrounding even legal medicinal cannabis; an inability for participants to obtain a legal prescription from their doctor due to what their doctor described as a paucity of evidence; and a lack of medical practitioner knowledge for the prescription of cannabis. Incorrect information conveyed to patients by doctors about current drug-driving laws was also a concern for some who had been told that a THC dose 8 h before driving would not appear in a roadside (oral swab) drug test. On the contrary, whilst patients would possibly be unimpaired 8 h post administration, the highly lipophilic nature of phytocannabinoids (Huestis 2007) means positive oral swab results for THC would be highly probable (Anizan *et al.* 2013, Swortwood *et al.* 2017) (dependent on dose and frequency) and could result in criminal charges. Additional barriers to medicinal cannabis utilisation included concern over current workplace drug testing policies and roadside drug driving laws, and that even though cannabis was now legally available as a management option, participant real-world experience deemed that others in their life, whether personal or professional, viewed it through a lens of being less legitimate than classically prescribed pharmaceuticals. This weighed heavily on participant considerations for initiating or continuing cannabis use.

The cost of legally prescribed medicinal cannabis products was raised as a barrier to access. This has been reported in previous qualitative research on primary dysmenorrhoea (Sinclair *et al.* 2022*b*), and in an Australian Senate inquiry report by the Community Affairs References Committee (2020). Media articles have also identified cost as a major barrier to patient access across New Zealand (NZ Herald 2020, 1 News NZ 2022). Product costs, depending on dosage form and phytocannabinoid concentration, can vary widely. The Victorian Government reports that medicinal cannabis products may cost between AU$200 and $4000 per month (Department of Health 2022) depending on the clinical indication. Cannabis industry reports suggest the average monthly cost is declining over time, with 2020 (Fresh Leaf Analytics 2020) and 2021 (Fresh Leaf Analytics 2021) reports placing the average monthly cost to patients at AU$384 and AU$278, respectively. Whilst the exact mechanisms for these declining prices are unknown, they are likely the result of growing competition and increased product availability, as the Australian medicinal cannabis cultivation/manufacturing industry matures. However, even these declining costs still represent a significant barrier to more widespread utilisation when compared to products available *via* prescription (e.g. codeine) or over-the-counter (e.g. ibuprofen) access. Medicinal cannabis products are not currently subsidised by Medicare or *via* the Pharmaceutical Benefits Scheme for endometriosis. Additional out-of-pocket costs for prescribed cannabis products include consultation and prescription costs, with initial medical consultations costing between AU$300-500 (2020*c*) which may exceed the cost of a specialist gynaecological consultation.

Current driving regulations across all states and territories in Australia do not exempt medicinal cannabis use (i.e. provide a medical defence (Perkins *et al.* 2021).

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The presence of THC constitutes a strict liability offence (i.e. criminal record, fines, and driving licence disqualification) if detected *via* a mobile drug testing (MDT) event, despite that test not being able to prove impairment. Participants complained (particularly those in Australia) that it is unfair that the bodily presence of medications such as opioids and benzodiazepines, which have been shown to cause impairment (Lader 2011, Strand *et al.* 2017), were not of concern for roadside drug testing, and that current laws negatively impacted their decision to explore or continue medicinal cannabis as a potential management option. Patients face the risk of losing their driving licence, which represents a threat often too difficult to ignore, considering familial, social and career responsibilities. In addition, for participants living in rural and remote locations, the problem is compounded because of distance, and they struggle to even locate a cannabis prescribing doctor/clinic. In contrast, current New Zealand regulations require both evidence of impairment (i.e. field impairment assessment at roadside by police) and THC presence in blood to constitute an offence. A recently introduced bill pending in the New Zealand parliament proposed changes to their drug-driving laws, with the inclusion of offences for the presence of THC in oral fluid. However, a medical defence will be available to those prescribed medicinal cannabis (Perkins *et al.* 2021, Ministry of Transport 2020*d*). Similarly, workplace drug testing policies in both countries were also mentioned as a significant barrier, being described as lagging behind the laws regulating cannabis use as a medicine. Employees in government roles, including teaching, defense, transport, police, maritime, and mining activities, all potentially face the prospect of random drug testing, which is deemed as mandatory within their employment contracts, constituting a further barrier to patient utilisation.

Although legal access policies for medicinal cannabis have been adopted across many international jurisdictions over the previous 20 years, it is not yet normalised as a treatment, with a stigma often associated with its use (Reid 2020). Disapproval, marginalisation, discrimination, or loss of social status from the wider population are commonly described by users of medicinal cannabis products (Bottorff *et al.* 2013). They are also highly vulnerable to the effects of stigma, with individuals' fear of discrimination leading to self-perceptions of guilt and shame (Bottorff *et al.* 2013). Given the low levels of understanding, funding, education, and support for female reproductive conditions, including endometriosis, the additional stigma associated with cannabis use may exacerbate the self-imposed protective isolation that such patients already experience. Participants in this study highlighted substantial concerns around reputational damage, or others perceiving them as irresponsible regarding their legal medicinal cannabis use, particularly in the workplace. This worry demonstrates that despite medicinal cannabis being a legal medicine, much more needs to be done to educate the general public, law enforcement personnel and healthcare providers.

Access to medicinal cannabis was raised as a substantive barrier, with many of the participants' doctors refusing to prescribe it, often citing a lack of evidence as their predominant rationale. Clinical trial results are not currently available to directly support the use of medicinal cannabis for endometriosis, *per se*. However, indirect evidence resides within data from the Australian Therapeutic Goods Administration (2022). They report that as of the 15 June 2023, over 199,000 approvals have been granted for chronic pain conditions (of which endometriosis qualifies) through the Special Access Scheme Category B pathway (Therapeutic Goods Administration 2022*a*). Moreover, co-morbid clinical indications commonly experienced by endometriosis patients have also seen consistent approvals, including for anxiety ($n = 90{,}000$ approvals), insomnia ($n = 7600$), sleep disorders ($n = 17{,}450$), migraines ($n = 2180$), and depression ($n = 5040$) (Therapeutic Goods Administration 2022*b*). In New Zealand, cannabidiol based medicines that meet minimum quality standards are prescription medicines, whereas all other cannabinoid-type medicines (with the exception of Sativex™) are classified as unapproved medicines or controlled drugs, with prescription pathways being more onerous. Official figures for medicinal cannabis approval numbers in New Zealand do not appear to exist in the public domain, although a media source reported that approximately 17,000 New Zealanders had accessed cannabis legally in 2020 (NZ Drug Foundation 2022). Whilst more significant clinical trial evidence for medicinal cannabis efficacy in endometriosis is required, medical practitioners need to be aware of the role that their behaviours or actions may have in contributing to the stigma of cannabis use as a medicine when communicating with patients. Clearly, as has been demonstrated by this small sample of participants, cannabis use may be a useful management option when all else has failed.

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Strengths and limitations

A strength of this study was the diversity of voices that were interviewed, allowing for a richness in content and a variety of participant opinions and experiences to be expressed across two countries. Conversely, lower levels of recruitment were experienced in the New Zealand cohort, particularly across the 18–24 ($n=4$) and 36+ age ($n=2$) groups. Most (73%) of the Australian and New Zealand cohort reported having previously used cannabis, either socially or medically, or both. This is much higher than the usage rate (11.6%) of the general Australian population (2019). Therefore, it is probable that our participants have a different view on cannabis use than the wider population as there was a significant proportion of participants who previously or currently utilised cannabis, and so may not be reflective of the broader population. Whilst generalisability is not the intended goal within this analysis (Roberts *et al.* 2020) scores for the Pelvic Pain Impact Questionnaire were comparable to previous endometriosis studies (Armour *et al.* 2019*b*, Sinclair *et al.* 2019). Similarly, the Endometriosis Health Profile-30 scores of study participants were analogous to a recent international survey (Armour *et al.* 2022) of over 1600 responses from 46 countries, suggesting the present participants experienced levels of impact similar to those in the wider endometriosis population.

Conclusion

People with moderate-to-severe symptoms of medically diagnosed endometriosis reported inadequacies with their current medical and self-management strategies, and were optimistically disposed to try medicinal cannabis. A substantial proportion of this cohort already utilise cannabis for this reason and report significant symptomatic relief and substitution of cannabis with current pharmaceuticals, mainly due to reduced side effects and self-perceived effectiveness. Barriers against the adoption of cannabis use in this cohort included high costs of legal medicinal cannabis products, lack of clarity and fairness in current roadside drug testing laws and workplace drug testing policies, concern over the impact of stigma affecting familial, social, and workplace life domains, and subsequent judgement and lack of education/engagement from their medical providers. Given the common nature of endometriosis, and its significant burden on quality of life, with consequent economic hardships, formal trials of cannabis therapies and other types of evidence-based alternatives for symptom management are urgently needed.

Supplementary materials

This is linked to the online version of the paper at https://doi.org/10.1530/RAF-23-0049.

Declaration of interest

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 united and tied funding for work to advance the vision and mission of the institute. JS1 formerly sat on the scientific advisory board for BioCeuticals and is a current member of the scientific advisory board for United in Compassion (*pro bono*) and a board member of the Australian Medicinal Cannabis Association (*pro bono*). JA reports funding in the form of grants and honoraria from MRFF for multiple endometriosis-related research; is a member on advisory boards with Hologic Australia and CSL Vifor (formerly Vifor Pharma Pty. Ltd.); is a member of the Endometriosis Advisory Group to the Australian Government; chairs the Expert Endometriosis Working Group for the Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG); was the chair for the publication of the Diagnosis and Management of Endometriosis Clinical Guideline in 2021. CN manages research grant funding from the MRFF and was a previous employee with CSL Vifor (formerly Vifor Pharma Pty. Ltd.). MA is an advisory board member for Evolv Health. All other authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

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Author contribution statement

JS1 and MA wrote the manuscript. JS1 performed focus-group content analysis and data analysis from the quantitative survey, which was supervised by MA. JA, AM-W, SE, CN, and JS2 provided feedback on the manuscript and tables. All authors reviewed the manuscript prior to submission.

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