Reproduction & Fertility

Reproduction & Fertility (2025) **6** e240098
https://doi.org/10.1530/RAF-24-0098

Received 23 September 2024
Accepted 30 May 2025
Available online 30 May 2025
Version of Record published 12 June 2025

RESEARCH

‘In the weeds’: navigating the complex concerns, challenges and choices associated with medicinal cannabis consumption for endometriosis

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Abstract

People with endometriosis report consuming cannabis to manage their symptoms. Given the range of differing legalities and access pathways across the world, this study aimed to investigate the drivers and barriers to cannabis use worldwide. An online, anonymous, cross-sectional survey was distributed internationally by endometriosis organisations and was open to anyone consuming cannabis for endometriosis symptoms. Survey questions included motivations for both starting and ongoing cannabis consumption, concerns over cannabis use, reasons for stopping cannabis, and communication of cannabis consumption with healthcare providers. Eight hundred and eighty-nine responses were collected across >10 countries. Illicit cannabis (56.7%) was the most common access pathway. 99% of respondents stated they would continue to use cannabis to manage their endometriosis-based symptoms, with 90% reporting they would recommend its use to a friend or relative with the disease. The most common motivation(s) for cannabis consumption were inadequate pain control (68.6%) and bothersome side effects of medications (56.3%). Similar motivations were reported for ongoing cannabis consumption, with concerns over dependence/addiction on pharmaceutical medications (43.9%) being another common motivation. Those using illicit cannabis were significantly less likely ($P < 0.0001$) to disclose their cannabis consumption to medical professionals. Cannabis was viewed as superior to pharmaceuticals both in terms of effectiveness and side-effect profile. Despite this, concerns around cost, breaking the law, judgement due to stigma, and current drug-driving laws were reported. Illicit usage and lack of medical oversight raise concerns over potential drug interactions or withdrawal effects due to reduction in pharmaceutical medications because of cannabis.

Lay summary

Survey participants reported that it is most common internationally for people using cannabis to manage endometriosis pain and associated symptoms to access this illegally, despite medical access being available in many countries. Many respondents also reported that cannabis was more effective and had a more tolerable side-effect

Published by Bioscientifica Ltd.
https://raf.bioscientifica.com

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profile than pharmaceutical medications they had used previously. However, over half of respondents were concerned about the negative impact of stigma associated with cannabis and how this might affect their day-to-day lives. Other concerns were potentially breaking the law where they live, possibly losing their driving licence due to drug-driving laws, or losing their job due to workplace drug-testing policies. Such concerns may be why more than 30% of participants reported not disclosing their cannabis consumption to their doctor. This is concerning because medical supervision is important to monitor for side effects and potential drug interactions, which people using cannabis may not know exist.

Keywords: cannabis; endometriosis; stigma; concerns; non-disclosure

Introduction

Endometriosis is a common gynaecological condition characterised by the presence of endometrial-like tissue found outside the uterus (Bulun 2009, Johnson *et al.* 2017). While current pharmaceutical management options are symptomatically helpful for many, a portion of women and people presumed female at birth (PFAB) cease standard pharmaceutical treatments due to ineffectiveness (15.6–26.1%) or side effects (10–43.5%) (Sinaii *et al.* 2007). Consequently, many people with endometriosis report a lack of satisfaction with current treatments (Evans *et al.* 2022) and commonly adopt self-care and self-management strategies (Armour *et al.* 2019*a*, O'Hara *et al.* 2021, 2022, Mardon *et al.* 2023). Illicit cannabis consumption is a relatively common self-management strategy across Australia and New Zealand for many people with endometriosis, with a slow shift towards legal prescribing as part of medical management occurring over time (Armour *et al.* 2019*a*, Sinclair *et al.* 2019, Carrubba *et al.* 2020, Armour *et al.* 2021, Sinclair *et al.* 2021*a*, 2023*a*).

Numerous barriers have been identified for medicinal cannabis (MC) uptake by people with endometriosis (Sinclair *et al.* 2021*b*, 2023*a*), and for other chronic conditions more broadly (Bottorff *et al.* 2013, Belle-Isle *et al.* 2014, Sinclair *et al.* 2022, Troup *et al.* 2022, Fehr *et al.* 2023), and include cost and access (Lintzeris *et al.* 2018, Siewert *et al.* 2020, Armour *et al.* 2022). The cost of MC products, inclusive of additional medical consultation fees, appears to be driving the rationale for increased illicit cannabis consumption for therapeutic purposes, particularly in countries with newly implemented MC programmes (Sinclair *et al.* 2023*a*).

Endometriosis already exacts a heavy financial burden, both in terms of direct healthcare costs and loss of income (Armour *et al.* 2019*b*), being a further potential catalyst for self-management *via* illicit cannabis consumption. Such financial barriers also play a substantive role in patient access, which is not just limited to geographical isolation (e.g. living in rural or remote locations). Familial, social, cultural, workplace, medical and even religious domains exert a profound influence on how people who use MC may be perceived or treated (Bottorff *et al.* 2013, Sinclair *et al.* 2021*b*, 2023*a*, Troup *et al.* 2022, Fehr *et al.* 2023). Stigma is attached to and created within society and often exists for MC due to the blurred boundary between medicinal and recreational cannabis (Lancaster *et al.* 2017), and the broader stigma attached to drug use. Furthermore, stigma associated with MC can come from external sources or be perceived by oneself (Bottorff *et al.* 2013).

Previous research has identified that MC consumption by those with endometriosis across Australia and New Zealand, whether medically prescribed or illicitly sourced, is consistently associated with substitution effects. Current pharmaceutical treatments are reduced or completely replaced by cannabis (Armour *et al.* 2019*a*, 2021, Sinclair *et al.* 2021*b*), with reductions in opioids being commonly reported (Armour *et al.* 2021, Sinclair *et al.* 2021*b*). While such substitutions can have positive clinical outcomes, reducing or ceasing such medications under medical supervision is critically important given the potential for dependency and withdrawal effects (Benyamin *et al.* 2008). Furthermore, premature self-initiated weaning off medications can lead to a potential worsening of both symptoms and disease progression. Previous research indicates that many people are not reporting their cannabis usage to their doctors (Sinclair *et al.* 2021*b*), especially in areas where cannabis is illegal (Azcarate *et al.* 2020), or where they believe their doctor will not approve of its usage (King *et al.* 2024).

While we know that people with endometriosis are consuming cannabis to help manage their symptoms, what is currently unclear is the extent to which stigma affects people's choice to start and continue using medicinal cannabis for their endometriosis symptoms. It is also unclear if different access pathways (legal recreational, legal medical, and illicit) that are present in various states, territories, and countries influence this stigma and any disclosure to medical professionals about cannabis consumption.

The aim of this study was to explore why people with endometriosis consume cannabis and identify barriers to adoption across various geographical contexts. Of particular importance was to determine if any of these barriers, such as stigma, may influence disclosure to medical professionals about cannabis consumption.

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Materials and methods

Sample and recruitment

This international, cross-sectional survey was approved in December 2020 by the Western Sydney University Human Research Ethics Committee (Approval # H14115). The survey was a convenience sample, voluntary, and was hosted on the Qualtrics platform (Qualtrics Ltd), open to people worldwide, and required approximately 15–30 min to complete. The survey was developed by the research team and comprised seven sections and a total of 78 questions covering demographics, endometriosis symptoms, and cannabis consumption. A copy of the survey tool is provided in Supplementary File 1 (see section on Supplementary materials given at the end of the article). Features were enabled within the Qualtrics platform (no IP addresses recorded; no cookies used) to ensure anonymity due to potential disclosure of illegal activities, as well as features to prevent the usage of 'bots' and duplicate responses. The survey was open for 12 weeks between mid-January and mid-April 2021, and no incentives to complete the survey were provided to respondents.

People were eligible to participate if they had a medical diagnosis of endometriosis, were aged between 18–55 years, and had used cannabis or phytocannabinoid-based products (e.g. cannabidiol (CBD) oil, whole cannabis oils, legal dried flowers ('buds') with known levels of delta-9-tetrahydrocannabinol (THC) and/or CBD, or non-legal forms of cannabis) in the past 3 months specifically for the purpose of managing their endometriosis pain and/or related symptoms. Recruitment was conducted *via* the social media platforms of Endometriosis New Zealand, Endometriosis Australia, Nancy's Nook, EndoIreland, Endometriosis UK, the World Endometriosis Society and Endometriosis Network (Canada), and was open to people with endometriosis globally.

Demographic information including age, location, education level, and classification of cannabis consumption has been reported. Data were also collected on respondent rationale for the use of cannabis as a therapeutic management strategy, classification of cannabis consumption, likelihood of continuing cannabis use, likelihood of recommendation to friends and family with endometriosis, concerns over ongoing cannabis use, and reasons for stopping cannabis. Disclosure of cannabis consumption to medical professionals was also captured.

Statistical analysis

Data analyses were conducted using SAS software (Version 9.4). Summary statistics were produced for continuous (means and standard deviations for parametric data; medians and interquartile ranges for non-parametric data) and categorical (numbers and percentages) variables. The association between cannabis category (legal medical/legal self-medication/illicit/non-legal) and i) informing medical professionals of cannabis consumption, ii) motivation for choosing cannabis, iii) reasons for continuing cannabis consumption, and iv) concerns over continuing cannabis consumption were all assessed by Chi-square test. Free-text responses were categorised using a qualitative descriptive approach (Sandelowski 2000). Of the free-text responses relating to motivations and concerns of cannabis consumption, and why respondents did not intend to tell their doctor about cannabis usage, initial meaning units were condensed into codes by the first author (JS). Codes with similar patterns were grouped into categories, with the entire process and categorisation overseen by the senior author (MA). Some inductive content categories were also created, meaning an abductive approach to content categorisation was used. Missing data were not replaced. Values were considered statistically significant if $P < 0.05$.

Results

Eligible responses were received from 889 respondents spanning 28 countries. The mean age of respondents was 30.3 years (median 29 years). Table 1 outlines the demographics of survey respondents.

Type of cannabis utilisation (medical, legal or non-legal/illicit)

Participants were asked to identify how they would categorise their cannabis utilisation, with legal pertaining to legal social/adult use (i.e. recreational) for therapeutic purposes (e.g. Canada or certain states in the USA), medical meaning under medical prescription and supervision, and non-legal indicative of illicit/legacy therapeutic self-administration. Results of this are reported in Fig. 1. Categorisation of cannabis utilisation by country is also reported in Table 2.

Motivation for cannabis utilisation

Respondents were also asked to report what their initial motivation was for starting to utilise cannabis as part of a management strategy for their endometriosis-associated symptoms and pain (see Table 3).

Ninety (10.1%) respondents indicated 'other' reasons for cannabis consumption. The most common were self-education on cannabis (19 people, 21.1%), recommendation by a family member (11 people, 12.2%), or feelings of desperation/helplessness (6 people, 6.6%). A statistically significant association

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Table 1 Survey demographic data. Data are presented as mean ± SD or as *n* (%).

Demographics	Values
Endometriosis diagnosis*, *n*	889
How were you diagnosed with endometriosis?	
Surgery (e.g. Laparoscopy)	740 (83.2)
Ultrasound	226 (25.4)
Magnetic resonance imaging	108 (12.1)
Told by a medical doctor/specialist based on my symptoms	327 (36.8)
How long in years since you have been diagnosed with endometriosis?	6.3 ± 6.7
Age at diagnosis? (*n* = 850)	24.8 (6.5)
Country	
USA	247 (27.8)
UK	234 (26.3)
Australia	200 (22.5)
Canada	93 (10.5)
New Zealand	51 (5.7)
Ireland	19 (2.1)
Netherlands	11 (1.2)
Other (combined – 21 countries)†	34 (3.8)
Reside	
Remote area	21 (2.4)
Rural area	248 (27.9)
Urban area	620 (69.7)
Highest level of education (*n* = 888)	
Did not finish high school/secondary education	32 (3.6)
Completed high school/secondary education	185 (20.8)
Diploma/certificate	234 (26.3)
Bachelor's degree	315 (35.5)
Master's degree	101 (11.4)
Doctorate/PhD	21 (2.3)
Classification of cannabis consumption	
Yes – I've used it both recreationally‡ and for endometriosis symptom management	484 (54.4)
Yes – I've used it recreationally	15 (1.7)
Yes – I've used it to manage my endometriosis symptoms	390 (43.9)
How long (in years) have you been using cannabis (whether legal or illegal) to manage the pain and associated symptoms of endometriosis?	4.4 ± 5.0

*Multiple choices allowed if applicable. †See Appendix 1 for detailed breakdown. ‡Goal of use was non-therapeutic.

between medical professionals recommending cannabis use was reported.

Reasons for continuing to utilise cannabis

Table 4 outlines respondent reasoning for continuing to utilise cannabis for endometriosis symptom management. When asked whether respondents would continue to utilise cannabis into the future, 99% (*n* = 880) answered 'yes'. Respondents were also asked whether they would recommend cannabis as a treatment option to friends or family members with endometriosis, with 90.2% (*n* = 802) reporting 'yes', 9.4% (*n* = 84) reporting 'maybe', and 0.3% (*n* = 3) reporting 'no' responses.

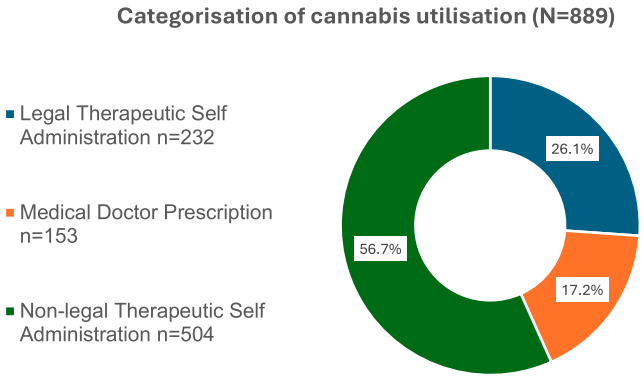

Figure 1

Categorisation of cannabis utilisation.

Concerns over cannabis utilisation

Respondents were asked to report any concerns they had over utilising cannabis as a management strategy for their endometriosis pain and symptoms, which are presented in Table 5. There was a statistically significant association between medical cannabis use and cost. Additional statistically significant associations between non-legal therapeutic cannabis consumption and concerns about breaking the law, being drug tested in the workplace, losing their driving licence, being judged due to stigma associated with cannabis, and concerns over poor product quality or adulteration of illicitly sourced cannabis were noted.

Other free-text responses regarding participants' concerns over continuing cannabis consumption included potential long-term damage of smoking/vaping to their lungs (*n* = 7), long-term effects on mental health and cognition (*n* = 6), and as yet unknown long-term impacts to health (*n* = 3). Other concerns were the legal implications of travelling with their medication between states or jurisdictions that do not have legal or medical cannabis programmes (*n* = 4), and judgement from healthcare providers and the quality of healthcare they might receive after disclosure of cannabis consumption (*n* = 6). Furthermore, these worries were also related to the possibility of disappointing family members if they found out (*n* = 2), and concerns over government agencies finding out about cannabis consumption (*n* = 2), particularly child or family-centric government departments. Not being able to compete in certain athletic events was also raised as a concern (*n* = 1), due to drug testing programmes across different sporting disciplines.

Reasons for discontinuation of cannabis consumption

Despite only nine (1%) respondents discontinuing cannabis, similar concerns were highlighted by those

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Table 2 Cannabis categorisation by country.

Country	*n*	Medical doctor prescription	Legal therapeutic self-administration	Non-legal therapeutic self-administration
USA	247	65 (26.3)	108 (43.7)	74 (30.0)
UK	234	6 (2.6)	33 (14.1)	195 (83.3)
Australia	200	45 (22.5)	9 (4.5)	146 (73.0)
Canada	93	32 (34.4)	56 (60.2)	5 (5.4)
New Zealand	51	3 (5.9)	3 (5.9)	45 (88.2)
Ireland	19	0 (0.0)	1 (5.3)	18 (94.7)
Netherlands	11	0 (0.0)	8 (72.7)	3 (27.3)
Other*	34	2 (5.9)	14 (41.2)	18 (52.9)

*See Appendix 1 for detailed breakdown.

who decided to continue cannabis, including side effects (*n* = 4, 44%), stigma (*n* = 4, 44%), cultural/religious judgement (*n* = 4, 44%), and potential illicit cannabis adulteration (*n* = 4, 44%). Other reasons for discontinuation included breaking the law (*n* = 3, 33%), concern over police roadside drug testing and possible loss of licence (*n* = 3, 33%), finding cannabis ineffective (*n* = 2, 22%), poor product access (*n* = 2, 22%), employment drug testing (*n* = 2, 22%), cost (*n* = 1, 11%), and cannabis not managing their pain completely (*n* = 1, 11%).

Communication of cannabis utilisation with medical professionals

Participants were asked about their disclosure of cannabis consumption for therapeutic purposes to medical professionals (see Table 6). Responses ranged from *no – I do not intend to tell them* (*n* = 210, 23.6%), *not yet – but I intend to tell them* (*n* = 170, 19.1%), *yes – cannabis usage was my idea, but I informed them* (*n* = 436, 49%), and *yes – cannabis usage was their suggestion* (*n* = 73, 8.2%). More than half of those utilising non-legal cannabis for therapeutic purposes are not disclosing this information to medical professionals. There was a statistically significant association in terms of informing medical professionals by cannabis category, with a larger proportion of medical/legal cannabis being discussed with medical professionals compared to non-legal.

Free-text responses as to why respondents did not intend to tell their doctor about cannabis consumption were wide ranging. Where responses bridged multiple thematic categories, all were included in data analysis. Concerns over legal repercussions (*n* = 98, 46%) and concerns over the doctor's reaction or their doctor being unhelpful (*n* = 49, 23%) were the most common reasons for non-disclosure, with concerns over societal judgement (*n* = 21, 10%) and a presumed unwillingness of their doctor to prescribe medicinal cannabis (*n* = 8, 3.8%) also being reported. There were 41 (19%) responses that were deemed non-relevant/erratum or were blank. Other notable findings from free-text responses include not wanting cannabis consumption on their medical records (*n* = 7, 3.3%), fear of being reprimanded due to having a child and potentially being reported to social services (*n* = 4, 1.9%), and concerns over how disclosure may impact their career (*n* = 9, 4.2%) if such information came to light.

Table 3 Motivation for cannabis utilisation* (*n* = 889). Data are presented as *n* (%).

Motivation for cannabis utilisation	Total	Medical doctor (*n* = 153)	Legal therapeutic (*n* = 232)	Non-legal therapeutic (*n* = 504)	X^2	*P*
Inadequate pain control from pharmaceutical medications	610 (68.6)	112 (73.2)	144 (62.1)	354 (70.2)	6.7	0.03
Side effects of pharmaceutical medications were intolerable	501 (56.3)	91 (59.5)	134 (57.8)	276 (54.8)	1.3	0.52
Was utilising cannabis recreationally and noticed pain and / or symptom reduction	416 (46.8)	68 (44.4)	85 (36.6)	263 (52.2)	15.8	0.0004
Recommended by an endometriosis support group	313 (35.2)	49 (32)	96 (41.4)	168 (33.3)	5.3	0.07
Difficulty in finding access to medical expertise on endometriosis in your region	282 (31.7)	42 (27.5)	88 (37.9)	152 (30.2)	6.0	0.05
Recommended by a friend or work colleague with endometriosis	226 (25.4)	26 (17)	60 (25.9)	140 (27.8)	7.2	0.03
Recommended by a medical professional	110 (12.4)	53 (34.6)	29 (12.5)	28 (5.6)	91.6	<0.0001
Delayed or cancelled surgery due to COVID-19	94 (10.5)	7 (4.6)	28 (12.1)	59 (11.7)	7.1	0.03
Lack of finances / insurance to afford surgery	90 (10.1)	13 (8.5)	24 (10.3)	53 (10.5)	0.5	0.76
Lack of finances / insurance to afford pharmaceutical medications	73 (8.2)	11 (7.2)	13 (5.6)	49 (9.7)	3.8	0.15
Recommended by an employee at a legal recreational cannabis dispensary	21 (2.4)	5 (3.3)	11 (4.7)	5 (1)	10.3	0.006
Other	90 (10.1)	14 (9.2)	29 (12.5)	47 (9.3)	2.0	0.38

*Multiple choices allowed if applicable.

Table 4 Reasons for continuing to utilise cannabis for endometriosis-based symptoms*. Data are presented as *n* (%).

Reasons for continuing to utilise cannabis (*n* = 880)	Total	Medical doctor (*n* = 153)	Legal therapeutic (*n* = 232)	Non-legal therapeutic (*n* = 504)	X^2	*P*
I find the side effects to be less severe than my current or previous pharmaceutical medication	688 (78.2)	126 (82.4)	175 (75.4)	387 (76.8)	2.8	0.25
I find it to be more effective in managing my symptoms than my current or previous pharmaceutical medication	684 (77.7)	122 (79.7)	169 (72.8)	393 (78)	3.2	0.20
I prefer what I consider to be a more natural product	592 (67.3)	95 (62.1)	149 (64.2)	348 (69)	3.3	0.19
I am concerned about dependence or addiction with my current or previous pharmaceutical medications	387 (43.9)	75 (49)	85 (36.6)	227 (45)	6.8	0.03
I find it more cost-effective than my current or previous pharmaceutical medication	162 (18.4)	20 (13.1)	49 (21.1)	93 (18.5)	4.0	0.13

*Multiple choices allowed if applicable.

Discussion

This study found that motivations for cannabis consumption by people with endometriosis internationally are comparable to those previously reported in Australia and New Zealand (Armour *et al.* 2019*b*, Sinclair *et al.* 2021*b*, 2023*a*). In addition, significant associations were observed for the non-legal therapeutic cohort relating to the negative impact of cannabis-associated stigma, breaking the law, and potentially losing employment or driving licences due to prevailing laws or workplace drug policies, which mirror concerns from previous research in Australia and New Zealand (Sinclair *et al.* 2023*a*). Similarly, those seeing medical professionals to obtain their cannabis reported a significant impact relating to cost concerns *versus* non-legal therapeutic and legal therapeutic access pathways. The impact of the cost of medicinal cannabis products has been previously reported (Lintzeris *et al.* 2018, Lintzeris *et al.* 2020, Proudfoot *et al.* 2024), and may be driving people to utilise cannabis from non-legal sources. Such trends raise concerns about equity, particularly as those utilising non-legal cannabis are also concerned about the potential poor quality and adulteration (e.g. heavy metals, pesticide residues, microbial contamination, non-standardised cannabinoid profile) of the cannabis they are accessing, described in this study and others (Lintzeris *et al.* 2018, Sinclair *et al.* 2021*b*, 2023*a*). As such, barriers to cannabis usage by people with endometriosis appear relatively universal across various geographical locations and cultural backgrounds, as represented by our diverse sample of respondents.

Respondents' motivations to try cannabis are interlinked with their subsequent decisions behind continuing to consume cannabis for symptomatic management. Similar to the motivations reported in this study, previous research, both qualitative and quantitative (Mercurio *et al.* 2019, Sinclair *et al.* 2021*b*, 2023*a*), has highlighted that participants with endometriosis deemed cannabis to be superior to prescription medications, while also having fewer side-effects and improving quality of life. Another common reason for ongoing cannabis consumption included concerns over addiction and dependence on pharmaceutical medications. These concerns are valid given people with endometriosis have higher probabilities of prolonged use of opioids and concomitant use with benzodiazepines (Lamvu *et al.* 2019), as well as a four-times greater risk of chronic opioid use compared to those without endometriosis (Chiuve *et al.* 2021).

Table 5 Concerns over continuing consumption of cannabis as a management option. Data are presented as *n* (%).

Concerns over continuing cannabis consumption (*n* = 880)	Total	Medical doctor (*n* = 153)	Legal therapeutic (*n* = 232)	Non-legal therapeutic (*n* = 504)	X^2	*P*
I am worried I will be judged due to the stigma associated with cannabis use	503 (57.2)	77 (50.3)	102 (44)	324 (64.3)	29.6	<0.0001
I am concerned about the cost of using cannabis	416 (47.3)	98 (64.1)	101(43.5)	217 (43.1)	22.2	<0.0001
I am concerned that by using cannabis I am breaking the law where I live	397 (45.1)	13 (8.5)	19 (8.2)	365 (72.4)	363.0	<0.0001
I am concerned that I might be detected by police via mobile drug testing, and potentially lose my licence	326 (37.0)	52 (34)	36 (15.5)	238 (47.2)	69.3	<0.0001
I am concerned about being tested as part of my employment	317 (36.0)	45 (29.4)	63 (27.2)	209 (41.5)	17.3	0.0002
I am concerned about potential adulterants and lack of quality in illicitly sourced cannabis	284 (32.3)	15 (9.8)	24 (10.3)	245 (48.6)	148.7	<0.0001
I am concerned about dependence on cannabis	140 (15.9)	16 (10.5)	37 (15.9)	87 (17.3)	4.1	0.13
I am worried about judgement (or punishment) from people within my religion or culture	116 (13.2)	11 (7.2)	31 (13.4)	74 (14.7)	5.8	0.054

*Multiple choices allowed if applicable.

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Table 6 Participant informing medical professional of cannabis consumption and comparative analysis by cannabis category.

Participant response	Medical doctor (*n* = 153)	Legal therapeutic (*n* = 232)	Non-legal therapeutic (*n* = 504)	*P*
No – I do not intend to tell them	10 (6.5)	31 (13.4)	169 (33.5)	<0.0001
Not yet – but I intend to tell them	9 (5.9)	43 (18.5)	118 (23.4)	<0.0001
Yes – cannabis was my idea, but I informed them	87 (56.9)	143 (61.6)	206 (40.9)	<0.0001
Yes – cannabis usage was their suggestion	47 (30.7)	15 (6.5)	11 (2.2)	<0.0001

Conversely, cannabis itself (mainly the THC component, as CBD is non-addictive) also has addiction and abuse potential (Panlilio *et al.* 2015, Zehra *et al.* 2018, Millar *et al.* 2021), with cannabis use disorder (CUD) being an underappreciated risk that impacts up to 10% of the population utilising cannabis (Connor *et al.* 2021). Such risks highlight the importance of open communication with medical professionals, and their ongoing supervision and monitoring. Unfortunately, non-disclosure of cannabis consumption for endometriosis symptom management to health professionals, that our team has previously reported in Australia and New Zealand (Sinclair *et al.* 2021*b*), appears to be occurring worldwide. Concerns include potentially clinically important pharmacokinetic and pharmacodynamic interactions between cannabis and pharmaceutical medications, which, while rare (Maccallum & Russo 2018), are an important consideration, particularly with warfarin, clobazam, and drugs that affect the central nervous system (CNS) (Devinsky *et al.* 2017, Maccallum & Russo 2018, Damkier *et al.* 2019, Lopera *et al.* 2022).

There are potential consequences from this lack of discussion or disclosure: i) possible interactions between cannabis and pharmaceutical drugs that patients are taking concurrently (Alsherbiny & Li 2019, Lopera *et al.* 2022), ii) potentially significant adverse outcomes such as CUD and cannabis hyperemesis syndrome (Sinclair *et al.* 2023*b*) that consumers may not be aware of, and iii) patient-initiated reductions in medications such as opioids and benzodiazepines, both commonly prescribed in endometriosis (Lamvu *et al.* 2019, Chiuve *et al.* 2021), being undertaken without medical supervision, which is potentially dangerous, especially in the case of benzodiazepines, due to potentially fatal withdrawals (Schweizer & Rickels 1998). In addition, patients undergoing surgery who do not disclose cannabis utilisation to their medical team are risking possibly dangerous interactions with anaesthesia.

Another significant driver for cannabis consumption was that consumers considered it a natural product. The emphasis on 'naturalness' may be an indication that people with endometriosis perceive cannabis as a safer option compared to other pharmaceutical treatments. While it cannot be known if the concern towards current or previous pharmaceutical medications is derived from prior experience, respondents were less worried about possible dependence on cannabis, with only 15.9% concerned about this, compared to the 43.9% who were concerned about dependence or addiction with their current or previous pharmaceutical medications. This is similar to trends observed in the wider reproductive health field; women have reported dissatisfaction with hormonal contraceptives because they are deemed 'unnatural', thus less safe, than natural options (Le Guen *et al.* 2021). However, perceived naturalness being inherently healthier and safer is not necessarily the case. While cannabis usage has been linked with decreased side-effects compared to other commonly prescribed analgesics (e.g. opioids) (Boehnke *et al.* 2016), it is not without its risks (as noted above), and there is little evidence on long-term safety for regular consumers. As such, healthcare professionals need to be aware that some people consuming cannabis may not be aware of potential adverse events and believe this option to be 'risk free', and thus need to spend time educating those who consume cannabis on possible risks and side-effects. Another factor in the emphasis on the naturalness of cannabis may also be an effort to de-stigmatise its usage (Morris 2020). Naturalism is often used to downplay stigma associated with cannabis, as framing cannabis as a medicine of 'nature' and 'natural' works to separate cannabis from chemical substances; with the latter viewed as carrying more side-effects (Morris 2020).

Regarding concerns related to cannabis consumption, stigma is still the greatest concern expressed by respondents continuing to consume cannabis. This finding is a consistent concern across various jurisdictions and clinical indications (Bottorff *et al.* 2013, Reid 2020, Sinclair *et al.* 2022, 2023*a*, Troup *et al.* 2022, Fehr *et al.* 2023, Nayak *et al.* 2023), and in this study, is greater for the population relying on non-legal cannabis for therapeutic purposes. The pervasiveness of stigma represents a critical challenge to overcome if cannabis is to be taken seriously as a medical management option in the wider community, aside from the need for more robust clinical evidence. Stigma is a complex barrier, interwoven into various levels of society, including macro, meso, and micro stigmas, attached to the fact that cannabis as both a medicinal object and recreational object are difficult to separate (Lancaster *et al.* 2017). A recent UK study highlighted there is a high prevalence of perceived stigma facing patients treated with MC from

Reproduction & Fertility (2025) **6** e240098
https://doi.org/10.1530/RAF-24-0098

government officials, medical professionals, the criminal justice system, and society more broadly (Troup *et al.* 2022). Similar evidence has been reported in the USA (Satterlund *et al.* 2015, Valencia *et al.* 2017, Howell *et al.* 2019), Canada (Ko *et al.* 2016), and Australia and New Zealand (Siewert *et al.* 2020, Sinclair *et al.* 2022, 2023*a*). While factors such as prevalence, availability, and social tolerance are often cited as reasons for cannabis undergoing a normalisation process in certain countries (Hathaway *et al.* 2011), other factors such as geographical location, gender, race, culture, religion, socioeconomic status, and social privilege suggest that cannabis-related stigma and discrimination is still largely extant, and that ideas of normalisation may be somewhat premature (Reid 2020, 2021). Certainly, some participants in this study noted extra worries or fears attached to cannabis consumption for certain patient populations, such as people worried about fear of being reprimanded due to having a child; parents who consume cannabis may be further stigmatised and judged more than those without children (Reid 2020). This stigma also seemed to persist across geographical boundaries, even in places such as Canada, where cannabis is federally legal both as a medicine and a recreational substance. To assist in mitigating the impact of stigma, future government health policies, and public health education more broadly, should take a balanced and proactive stance to assist in reducing stigma associated with MC (Clobes *et al.* 2022).

Respondents reported consuming both legal (medical or social/recreational) and illicit cannabis products. An interesting finding was that in Canada, a country that has federally legalised both social/adult use and medicinal cannabis programmes, the predominant cannabis access pathway for managing their endometriosis symptoms was *via* legal social/adult use dispensaries, ostensibly *without* direct medical supervision. The prevalence of obtaining cannabis from social/adult use dispensaries for therapeutic purposes may be due to avoidance of additional incurred medical costs of seeing their doctor, and the convenience of using a local dispensary. This raises an important point for discussion, which is what 'medicinal cannabis' is and what it is not. In North America, a doctor typically provides legal authorisation (e.g. a medical cannabis card) for a patient to access and utilise cannabis, but does not specify the specific products to be utilised, with this information typically coming from dispensary staff; conversely, in countries such as New Zealand and Australia, the access to and prescription of specific medicinal cannabis products is entirely overseen by doctors, with pharmacist dispensation of product. As such, it does raise concerns as to whether cannabis dispensary staff are adequately equipped to address the complex symptomatology of endometriosis, and whether this pathway may reduce disclosure to, and oversight by, medical doctors. Lack of communication about cannabis consumption for therapeutic reasons should not be considered as solely the responsibility of the patient. Doctors and other healthcare providers have reported a lack of knowledge and a dearth of clinical evidence associated with cannabis being responsible, in part, for hindering the discussion, and subsequent prescription, of MC (Karanges *et al.* 2018, Gardiner *et al.* 2019, Oldfield *et al.* 2020, Dobson *et al.* 2024). Similarly, King *et al.* (2024) also found this to be the case in the US, with this present study adding to the evidence that people anticipate stigma from healthcare providers, thus leading to non-disclosure of cannabis consumption. The issue of stigma in the doctor-patient interaction may be even more relevant for those with endometriosis, given that people with endometriosis often report inadequate treatment by healthcare professionals (Evans *et al.* 2022, Sirohi *et al.* 2023). As standard endometriosis care is often perceived as inadequate, this may be exacerbated by treating doctors who know little about MC, leading to further stigmatisation and inadequate care. As more people with endometriosis are seeking and using cannabis as a viable symptom management option, healthcare professionals should educate themselves on MC and its potential role in endometriosis treatment. Despite our data being collected in 2021, stigma still unfortunately seems to remain a significant barrier for cannabis consumption in a variety of age groups (Dahlke *et al.* 2024, King *et al.* 2024), noting that there is often a lag between societal change and the published literature.

There are several limitations to this study which are important to outline. Recall bias (Pannucci & Wilkins 2010) and non-response bias (Berg 2005) can influence responses and skew the sample towards those that are either more severe in their symptom expression or more favourable towards cannabis, are respective limitations. So too is sampling bias (Benedict *et al.* 2019) due to the survey being advertised through the use of social media to endometriosis advocacy and support groups, potentially skewing results to include people more negatively impacted by their endometriosis compared to the general population. It also stands to reason that those having strong positive or negative responses to MC consumption may be more likely to spend time completing the survey, and therefore it is likely that the responses may be skewed. Notwithstanding, data from this paper is consistent with previous studies of similar scope and design (Armour *et al.* 2019*a*, 2021, Sinclair *et al.* 2019). While international in scope, limited participation was noted compared to our team's previous study (Armour *et al.* 2022), with lower than projected responses. This in part could be due to the survey running in the midst of the global COVID-19 pandemic; however, it may also be a result of survey (response) fatigue (De Koning *et al.* 2021, Brown *et al.* 2024), as this method of inquiry (i.e. surveys) was all that was available to many research teams during this time, and results may therefore not be generalisable to the wider endometriosis population. The sample was also

Western-centric, which may influence the barriers described by respondents compared with other geographic locations. This data was collected in 2021, and cannabis regulations may have changed for certain countries since this time (e.g. Germany legalised medicinal cannabis in 2017, but legalised recreational cannabis in 2024). Given the majority of our respondents were from Western-centric countries that had state-specific or federally legal medicinal cannabis programmes before 2021 (i.e. USA, Canada, Australia, UK, Ireland, New Zealand), these changes are unlikely to materially impact our findings.

Conclusion

This international, cross-sectional study identified that people with endometriosis who consume cannabis predominantly access it *via* non-legal self-therapeutic pathways and self-report both positive and negative experiences of cannabis usage. Comparatively, cannabis was viewed as superior to previously used pharmaceuticals in both effectiveness and side-effect profile. Despite these results, and high continuation use rates and acceptability, statistically significant associations were reported relating to concerns around cost, breaking the law, judgement due to stigma, and loss of licence due to current drug driving laws, consistent with previous research. Furthermore, trepidations about non-legal therapeutic consumption included significant concern over potential adulterants and lack of quality assurance. Significant non-disclosure of respondents' illicit cannabis consumption to medical professionals was also reported, identifying an urgent need to encourage joint communication between patient and doctor, and preserve the doctor-patient relationship, while also improving clinical outcomes and patient safety. This is especially important for endometriosis, given that care is often both challenging and inadequate before the complexity of MC is added. More research is urgently needed, including clinical trials and real-world data to evaluate the safety, tolerability, and effectiveness of quality-assured medicinal cannabis products in the endometriosis population.

Supplementary materials

This is linked to the online version of the paper at https://doi.org/10.1530/RAF-24-0098.

Declaration of interest

As a medical research institute, NICM Health Research Institute receives research grants and donations from foundations, universities, government agencies, individuals, and industry. Sponsors and donors also provide untied funding for work to advance the vision and mission of the Institute. JS is the recipient of a Western Sydney University Postgraduate Research Scholarship. JS is employed by Australian Natural Therapeutics Group 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*). J.Sarris (JS1) is Co-CEO of Psychae Therapeutics, a commercial entity undertaking research with psychedelic compounds (holding equity), and a Co-Director of the connected NFP Psychae Institute. He has also received either presentation honoraria, travel support, clinical trial grants, book royalties, or independent consultancy payments from: Australian Natural Therapeutics Group (being a former scientific advisor to Australian Natural Therapeutics Group: a cannabis grower and manufacturer), Integria Healthcare & MediHerb, Pfizer, HedoniaUSA, Scius Health, Key Pharmaceuticals, Taki Mai, Fiji Kava, FIT-BioCeuticals, Blackmores, Soho-Flordis, Healthworld, HealthEd, HealthMasters, Kantar Consulting, Angelini Pharmaceuticals, Grunbiotics, Polistudium, Research Reviews, Elsevier, Chaminade University, International Society for Affective Disorders, Complementary Medicines Australia, SPRIM, Terry White Chemists, ANS, Society for Medicinal Plant and Natural Product Research, Sanofi-Aventis, Omega-3 Centre, and the National Health and Medical Research Council, CR Roper Fellowship. MA receives honoraria or independent consultancy payments from NECTR brands, Metagenics, and OzMedicann Group, all outside the submitted work. He is the PI on several ongoing trials for medicinal cannabis and pelvic pain. All other authors declare no conflicts of interest.

Funding

This research did not receive any specific grant from any funding agency in the public, commercial, or not-for-profit sector, and forms part of a PhD research project for JS.

Author contribution statement

JS and MA conceived the study. JS and AE analysed survey data. JS, MA, HA, and AE wrote the paper. JA, AM, JS1, OH, and MA provided critical subject matter expertise and revisions.

Acknowledgements

The authors wish to thank Endometriosis New Zealand, Endometriosis Australia, Nancy's Nook, EndoIreland, Endometriosis UK, the World Endometriosis Society, Endometriosis Network (Canada), and the participants of this survey for their support.

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