

Use of Medicinal Cannabis for Epilepsy in the Australian Community 2023-2024: A Cross-Sectional Survey

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Original Article

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Background and Purpose: Epilepsy is a common indication for medicinal cannabis (MC) prescription in Australia. Despite legal MC products being available for 8 years, some individuals continue to rely on illicit cannabis. Here, we conducted a survey of Australian persons/people with epilepsy (PWE) and caregivers of a PWE to assess whether the current legal framework supports PWE and/or their caregivers to access prescribed MC.

Methods: The cross-sectional survey consisted of five sections examining sociodemographics, medical history, history of MC use, attitudes towards MC, and barriers to accessing MC.

Results: Of the 126 respondents included in these analyses, 102 were PWE (mean age, 40.9±12.3 years) and 24 were caregivers of a PWE (mean age of PWE, 14.1±8.9 years). Among PWE, 27.5% (28/102) had only used illicit MC products, 27.5% (28/102) had transitioned to prescribed MC products, and 16.7% (17/102) used both. Most caregivers 70.8% (17/24) had only accessed prescribed MC products. Most respondents 77.0% (97/126) reported using MC as an adjunct to conventional anti-seizure medications. Caregivers were more likely to administer prescribed high-cannabidiol products to children using oral routes of administration ($p<0.001$). In contrast, PWE often used inhaled cannabis ($p<0.001$). Overall, 67.0% (83/124) of respondents reported that MC “improved” or “greatly improved” their epilepsy, irrespective of MC type. The main barrier to accessing prescribed MC was “cost” (69.0%, 87/126), while tetrahydrocannabinol (THC)-related driving restrictions were also a significant concern for PWE.

Conclusions: The current regulatory framework in Australia supports MC access for PWE and their caregivers, primarily through cannabis clinics. However, cost remains a significant concern. The prevalent use of Δ^9 -THC-containing and inhaled MC products, either illicit or prescribed, highlights the urgent need to further investigate their safety and efficacy in epilepsy. (2025;15:56-69)

Key words: Cannabis, Epilepsy, Anticonvulsant, Cannabidiol, Public health, Regulation

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Introduction

Epilepsy is a common neurological condition characterised by recurrent seizures resulting from abnormal neuronal activity.¹ It affects up to 4% of people in the general population^{2,3} and is commonly diagnosed in childhood or older adulthood (>65 years).^{2,4} People with epilepsy (PWE) often experience co-morbid cognitive, behavioural, and psychiatric disorders.⁵ Treatment of epilepsy typically involves the prescription of one or more anti-seizure medications (ASMs), which aim to reduce the number, severity, and/or duration of

seizures.⁶ Although ASMs are effective for many patients, approximately one in three people with epilepsy are drug-resistant and/or experience intolerable side effects, placing them at risk of bodily injury, psychosocial disability, and/or premature mortality.^{3,7} It is, therefore, not surprising that some individuals turn to alternative, less conventional treatments to manage their seizures.⁸

Medicinal cannabis (MC) is an increasingly popular alternative treatment for PWE. The cannabis plant contains a large family of bioactive compounds known as phytocannabinoids, with Δ^9 -tetrahydrocannabinol (THC) and cannabidiol (CBD) the most well-studied. Purified CBD, in

the form of orally administered Epidyolex (Jazz Pharmaceuticals, Dublin, Ireland; known as Epidiolex in the USA), is now an approved medicine in the UK, USA, and Australia,⁹⁻¹¹ with robust clinical trial data supporting its safety and efficacy in various forms of paediatric epilepsy, including Dravet syndrome, Lennox-Gastaut syndrome, and tuberous sclerosis complex.^{12,13} CBD is non-intoxicating, and generally well-tolerated, even at high doses of up to 6,000 mg in single doses or 1,500 mg in multiple doses.^{14,15} The use of THC-containing preparations for treating epilepsy is more controversial and requires caution by the prescribing physician, given THC's potential to cause intoxication, cognitive impairment, and mood alterations, which may pose risks to individuals with epilepsy.^{16,17} While it has shown benefits in other conditions, such as multiple sclerosis spasticity and chemotherapy-induced nausea,¹⁸⁻²⁰ THC is generally used at much lower doses (5-20 mg) compared to the higher doses typical of CBD (300-1,500 mg).^{21,22} Preclinical evidence suggests that low doses of THC may have anticonvulsant properties.²³ Several open-label trials in paediatric epilepsy suggest that THC, when used as an adjunct in a 1:20 or 1:50 THC-to-CBD ratio, is both safe and effective.^{24,25} Nonetheless, the use of THC alone for epilepsy treatment lacks definitive clinical trial evidence and, in preclinical models, may even exhibit pro-convulsant effects at higher doses,²⁶ potentially contributing to its inconsistent efficacy in seizure management. Overall, the use of MC for epilepsy treatment needs to be considered carefully, as the effects of cannabinoids are not always favourable, and their use should be guided by robust clinical evidence and tailored to individual patient needs.

Observational studies in the UK,²⁷ USA,²⁸ Europe,²⁹ and Australia^{30,31} highlight the widespread community use of often illicit MC products, with unknown composition, by both paediatric and adult PWE populations. We previously examined the chemical composition of illicit cannabis extracts used to treat children with epilepsy in the Australian community.³¹ Contrary to parents' expectations, the majority of samples contained significant concentrations of THC and negligible amounts of CBD.³¹ Despite this, most parents rated these cannabis extracts as effective, which indicates either a strong placebo effect³² or the potential therapeutic utility of THC and/or minor phytocannabinoids in reducing seizures. Recently, preclinical research has shown that THC and minor phytocannabinoids, such as tetrahydrocannabinolic acid, cannabivarinic acid, and cannabigerolic acid, can reduce seizure frequency in animal models of epilepsy.^{33,34} However, the efficacy of these phytocannabinoids has yet to be convincingly demonstrated in randomised placebo-controlled clinical trials (RCT).^{33,35}

The use of MC products is now legal for medicinal and/or recrea-

tional purposes in over 64 countries.³⁶ In 2016, the Australian federal government passed legislation enabling a wide range of unregistered MC products to be prescribed to patients by healthcare professionals under the Special Access Scheme (SAS) and Authorised Prescriber schemes.³⁷ Since then, prescribing rates for MC have grown exponentially, with current estimates indicating that over 1 million patients now use MC.³⁸ Additionally, in 2020, Epidyolex (Jazz Pharmaceuticals) was approved and listed on the Australian Pharmaceutical Benefits Scheme (PBS), subsidising access for patients with severe paediatric epilepsy.^{39,40} While epilepsy and seizure management are relatively common indications for an MC prescription, they are less common than chronic pain, anxiety, and sleep disturbances—the primary conditions for which MC is prescribed.⁴¹

Despite these advancements—such as the increasing availability of legal MC, robust RCT evidence supporting CBD for epilepsy treatment, and the registration and PBS listing of Epidyolex (Jazz Pharmaceuticals)—surveys indicate that some Australian patients continue to rely on illicit cannabis products.⁴²⁻⁴⁶ This may be due to perceived complexities in accessing legal MC, the high cost of prescribed products when they are not eligible for the subsidised Epidyolex (Jazz Pharmaceuticals), and a preference among some patients for artisanal MC products (i.e., those produced outside of regulated commercial frameworks).^{41,44}

The aim of the present study was to evaluate the use of both illicit and prescribed MC for epilepsy in Australia, 8 years after significant legislative changes. We assessed 1) the respondents' patterns of MC use over time, including transitions between prescribed and illicit MC products; 2) the perceived composition, routes of administration, and efficacy of MC products for epilepsy; and 3) consumer attitudes towards MC. Using an anonymous, cross-sectional online survey, "Cannabinoids for Adult and Paediatric Epilepsy (CAPE)" survey, this study also aimed to enhance understanding of barriers to accessing prescribed MC. This will help determine whether the current legal framework supports patient needs.

The term 'MC', as used in this article, refers to any cannabis or hemp-derived product used for the treatment of epilepsy, whether legal (prescribed) or illicit (non-prescribed). In the Australian context, prescribed MC products are strictly regulated, federally approved, quality-assured, and only available on prescription from a medical doctor. All other MC products, which are unregulated and have an unknown composition, are referred to as illicit MC products.

Methods

Survey design

We conducted a cross-sectional online survey with PWE (aged 18 years and older) and parents or guardians ('caregivers') of a PWE (any age), who self-reported administering MC products for the treatment of epilepsy. The survey was anonymous, with survey questions examining: 1) Demographic characteristics (section 1); 2) medical history in relation to epilepsy (section 2); 3) current and lifetime patterns of illicit and/or prescribed MC use, including self-reported route of administration and cannabinoid profile of the product used (section 3); 4) perceived efficacy of MC using the patient global impression of change,⁴⁷ a seven-item scale assessing a patient's global impression of change in their health condition since commencing the cannabis product, ranging from 'very much worse' to 'very much better' (section 4); and 5) consumer perspectives on accessing MC in Australia, including perceived barriers (section 5). A visual overview of the study design and participant flow is illustrated in Supplementary Fig. 1.

Study data were collected and managed using Research Electronic and Data Capture (REDCap), a secure, web-based data collection platform.^{48,49} Responses were anonymous and the automatic internet protocol address capture feature was disabled to maintain confidentiality. The survey link was available online for 5 months between September 2023 and January 2024 and was promoted via Epilepsy Action Australia's website and mailing list; the Lambert initiative's 'expression of interest' mailing list; social media (Facebook and Reddit); and word of mouth. No cannabis-related imagery was used in any of the study's promotional material to comply with ethical and social media advertising guidelines. The study was approved by the University of Sydney Human Research Ethics Committee (#2023/313).

Eligibility criteria were: 1) ability to provide informed consent; 2) resident in Australia; 3) an adult aged 18 years or older with epilepsy or a caregiver of a PWE (any age); and 4) self-identified as having previously tried or currently using MC products, illicit and/or prescribed, to treat epilepsy. Participant responses were grouped and analysed according to several categories. 1) Type of respondent: 'PWE' versus 'caregiver of a PWE'; 2) status of MC use: 'currently using' versus 'previously used'; and 3) source of first and last/current MC product: participants were categorised into the following groups based on their use of prescribed or illicit MC products: 'prescribed' group refers to participants who only used prescribed MC; 'illicit' group refers to participants who only used illicit MC products; 'dual'

group refers to participants who used both prescribed and illicit MC products.

This categorisation allowed us to track the respondent's journey of MC over time (i.e., respondent type), which formed the basis for the statistical analyses. For example: 1) if both the first and last MC products used were prescribed, their respondent type was categorised as 'always prescribed'; 2) if the first MC product ever tried was prescribed, while the last or currently used MC product was illicit, their respondent type was categorised as 'prescribed to illicit'.

Data analysis

Data were analysed using SPSS ver. 19.0 (SPSS Inc., Chicago, IL, USA). Only valid responses were included, with no imputation of missing data. Where categorical variables had more than two levels (e.g., household income), these levels were collapsed into fewer levels to aid interpretation of the chi-squared tests. Independent samples *t*-tests were used to compare normally distributed data between PWE and caregivers of a PWE. Chi-square tests were used for categorical variables, with *post-hoc* analysis using adjusted standardised residuals and Bonferroni correction for categorical variables with more than two categories.⁵⁰ As the number of valid responses varied across different items in the survey, categorical variable frequencies were reported alongside the number of valid responses.

As a *post-hoc* analysis, we aimed to explore the influence of socioeconomic factors on cost as a barrier to accessing prescribed MC. The dependent variable-cost as a self-reported barrier to accessing prescribed MC products-was dichotomous, and the independent (predictor) variables included both dichotomous and continuous variables. Each independent variable was first entered into a univariate binary logistic regression analysis. To explore the influence of employment, we collapsed the full-time and part-time work groups into a single category labelled 'currently employed', while home duties, retired, student, unemployed, disability pension, and other groups were combined and labelled 'not currently employed'. Variables that predicted cost as a barrier with a significance level of $p < 0.1$ were subsequently included in a multivariate binary logistic regression analysis, with the final significance level set at $p = 0.05$.

Results

Demographics

Of the 267 participants who commenced the survey, four did not

provide informed consent, and a further 141 respondents were excluded for failing to provide any further information beyond section 3 ('accessing medicinal cannabis') (53% overall response rate).

Data are presented for 126 respondents, comprising 102 (80.9%) PWE and 24 (19.1%) caregivers of a PWE. Among the latter group, 18/24 (75.0%) caregivers were responding to the survey on behalf of

a child with epilepsy (<18 years), while 6/24 (25.0%) were responding on behalf of an adult with epilepsy (≥ 18 years). Demographic characteristics and between-group comparisons are presented in Table 1. A significant association was found between PWE and having an annual combined income of <\$50,000 ($p < 0.001$), as well as between being a caregiver of a PWE and having an annual combined

Table 1. Demographic characteristics of respondents

	N	PWE	N	Caregiver of a PWE	N	Total
Age (years)	102	40.9 $\pm$ 12.3	24	14.1 $\pm$ 8.9*	126	35.7 $\pm$ 15.7
Gender	102		24		126	
Male		55 (53.9)		14 (58.3)*		69 (54.8)
Female		43 (42.2)		10 (41.7)*		53 (42.1)
Non-binary/gender fluid		1 (1.0)		0 (0.0)*		1 (0.7)
Unspecified		3 (2.9)		0 (0.0)*		3 (2.4)
Relationship status	102		24		126	
Partnered (currently in relationship)		42 (41.2)		16 (66.7)		58 (46.0)
Single (not currently in relationship)		60 (58.8)		8 (33.3)		68 (54.0)
Indigenous status	102		24		126	
Aboriginal and/or torres strait Islander		14 (13.7)		3 (12.5)		17 (13.5)
State/territory	102		24		126	
New South Wales		42 (41.2)		10 (41.6)		52 (41.3)
Queensland		29 (28.4)		4 (16.7)		33 (26.2)
Victoria		14 (13.7)		4 (16.7)		18 (14.3)
Western Australia		8 (7.8)		3 (12.5)		11 (8.7)
South Australia		7 (6.9)		3 (12.5)		10 (7.9)
Tasmania		2 (2.0)		0 (0.0)		2 (1.6)
Australian Capital Territory		0 (0.0)		0 (0.0)		0 (0.0)
Northern Territory		0 (0.0)		0 (0.0)		0 (0.0)
Remote offshore territories		0 (0.0)		0 (0.0)		0 (0.0)
Employment status	102		24		126	
Full-time work		31 (30.4)		8 (33.3)		39 (30.8)
Part-time work		13 (12.7)		7 (29.2)		20 (15.9)
Home duties		2 (2.0)		2 (8.3)		4 (3.2)
Student		5 (4.9)		1 (4.2)		6 (4.8)
Unemployed		17 (16.7)		0 (0.0)		17 (13.5)
Retired		3 (2.9)		3 (12.5)		6 (4.8)
Disability pension		27 (26.5)		1 (4.2)		28 (22.2)
Other		4 (3.9)		2 (8.3)		6 (4.8)
Total household's income per year	102		24		126	
\$0 to \$50,000		62 (60.9)		5 (20.8)		67 (53.2)
\$50,001 to \$100,000		14 (13.7)		2 (8.4)		16 (12.6)
\$100,001 to \$150,000		18 (17.6)		5 (20.8)		23 (18.3)
>\$150,000		8 (7.8)		12 (50.0)		20 (15.9)

Values are presented as mean $\pm$ standard deviation or number (%).

PWE, persons with epilepsy.

*This demographic data pertains to the person with epilepsy under the care of the caregiver (i.e., parent or guardian), whilst the remaining demographic data pertains to the parent/guardian themselves.

income of >\$150,000 ($p<0.001$).

Medical history

Individuals with epilepsy self-reported being diagnosed significantly later in life (24.5 ± 13.9) compared to those under the care of a caregiver, all of whom were diagnosed before 18 years of age

(4.5 ± 4.6) ($p<0.01$) (Table 2). Tonic-clonic seizures were the most commonly reported seizure type by both PWE (61.8% [63/102]) and caregivers of PWE (62.5% [15/24]) (Table 3). There was a statistically significant association between being a caregiver of a PWE and identifying tonic-clonic seizures as the most impactful seizure type (50.0% [12/24]) ($p<0.001$).

Table 2. Epilepsy diagnosis and clinical history of respondents

	N	PWE	N	Caregiver of a PWE	N	Total
Age at diagnosis	102	24.5±13.9	24	4.5±4.6*	126	126.0±100.0
Health provider who made epilepsy diagnosis	102		24		126	
General practitioner		9 (8.8)		2 (8.3)		11 (8.7)
Adult neurologist		41 (40.2)		2 (8.3)		43 (34.1)
Child neurologist		16 (15.7)		10 (41.8)		26 (20.6)
Paediatrician		4 (3.9)		5 (20.8)		9 (7.1)
Doctor in the hospital		31 (30.4)		5 (20.8)		36 (28.7)
Other		1 (1.0)		0 (0.0)		1 (0.8)
Episodes of status epilepticus	102		24		126	
Yes		39 (38.2)		14 (58.3)		53 (42.1)
No		63 (61.8)		10 (41.7)		73 (57.9)
Number of ASMs currently taking	102	2.0±1.5	24	2.5±1.5	126	2.1±1.5
Number of ASMs tried and stopped	102	3.5±4.0	24	7.6±8.2	126	4.5±5.5
Using cannabis as an adjunct to ASMs	102		24		126	
Yes		81 (79.4)		21 (87.5) [†]		102 (81.0)
No		21 (20.6)		3 (12.5)		24 (19.0)
Drug-resistant epilepsy	102	42 (41.2)	24	20 (83.3) [†]	126	62 (49.2)
Number of hospitalisations due to epilepsy	102		24		126	
0 time		12 (11.9)		3 (12.5)		15 (11.9)
1-3 times		34 (33.3)		3 (12.5)		37 (29.4)
4-6 times		24 (23.5)		3 (12.5)		27 (21.4)
6-10 times		9 (8.8)		6 (25.0)		15 (11.9)
>10 times		23 (22.5)		9 (37.5)		32 (25.4)
Medical conditions other than epilepsy	102		24		126	
Developmental		15 (14.7)		16 (66.7)		31 (24.6)
Mental health		46 (45.1)		6 (25.0)		52 (40.5)
Pain		46 (45.1)		6 (25.0)		52 (41.3)
Sleep		58 (56.9)		9 (37.5)		67 (53.2)
Gastrointestinal		24 (23.5)		3 (12.5)		27 (21.4)
Cardiovascular		6 (5.9)		2 (8.3)		8 (6.3)
Endocrine/metabolic		8 (7.8)		1 (4.2)		9 (7.1)
Neurological		23 (22.5)		8 (33.3)		31 (24.6)
Cancer		5 (4.9)		0 (0.0)		5 (4.0)
Other		17 (16.7)		2 (8.3)		19 (15.1)
No other medical conditions		10 (9.8)		3 (12.5)		13 (10.3)

Values are presented as mean±standard deviation or number (%).

PWE, people with epilepsy; ASM, antiseizure medication.

* $p<0.01$.

[†] $p<0.001$.

MC use

Of the 126 respondents who completed this section, 26 (20.6%) reported previously using MC products but had since stopped (22 PWE and four caregivers of PWE), while 100 (79.4%) were currently

using MC products to treat their epilepsy (80 PWE and 20 caregivers of a PWE). Most participants (60.3% [76/126]) reported accessing 'prescribed' MC products, while 26.2% (33/126) accessed 'illicit' MC, and 13.5% (17/126) reported using both 'illicit' and 'prescribed'

Table 3. Overview of seizure types

	Presence of seizure types*			Most frequent seizure type			Most impactful seizure type		
	PWE (n=102)	Caregiver of a PWE (n=24)	Total (n=126)	PWE (n=102)	Caregiver of a PWE (n=24)	Total (n=126)	PWE (n=102)	Caregiver of a PWE (n=24)	Total (n=126)
Focal aware	41 (40.2)	7 (29.2)	48 (38.1)	22 (21.6)	2 (8.3)	24 (19.0)	7 (6.9)	1 (4.2)	8 (6.3)
Focal unaware	37 (36.3)	10 (41.7)	47 (37.3)	13 (12.7)	3 (12.5)	16 (12.7)	21 (20.6)	5 (20.8)	26 (20.6)
Tonic clonic	63 (61.8)	15 (62.5)	78 (61.9)	27 (26.5)	8 (33.3)	35 (27.8)	47 (46.1)	12 (50.0)	59 (46.8)
Absence	36 (35.3)	12 (50.0)	48 (38.1)	11 (10.8)	5 (13.9)	16 (12.7)	6 (5.9)	1 (4.2)	7 (5.6)
Atonic	11 (10.8)	5 (20.8)	16 (12.7)	2 (2.0)	0 (0.0)	2 (1.6)	1 (1.0)	0 (0.0)	1 (0.8)
Tonic	11 (10.8)	8 (33.3)	19 (15.1)	4 (3.9)	3 (12.5)	7 (5.6)	2 (2.0)	1 (4.2)	3 (2.4)
Myoclonic	19 (18.6)	8 (33.3)	27 (21.4)	11 (10.8)	3 (12.5)	14 (11.1)	4 (3.9)	2 (8.3)	6 (4.8)
I do not know	10 (9.8)	3 (12.5)	13 (10.3)	8 (7.8)	2 (8.3)	10 (7.9)	8 (7.8)	2 (8.3)	10 (7.9)
Other	4 (3.9)	1 (4.2)	5 (4.0)	4 (3.9)	0 (0.0)	4 (3.2)	6 (5.9)	0 (0.0)	6 (4.8)

Values are presented as number (%).

PWE, persons with epilepsy.

*Respondent could provide more than one answer.

Table 4. First and most recent (last) type of medicinal cannabis use among respondents

	PWE (n=102)	Caregiver of a PWE (n=24)
Currently using MC (first use-last use)		
Prescribed-prescribed ("always prescribed")	18 (17.6)	14 (58.3)
Prescribed-illicit		
Prescribed-dual	1 (1.0)	0 (0.0)
Illicit-illicit ("always illicit")	20 (19.6)	4 (18.2)
Illicit-prescribed	25 (24.5)	2 (4.2)
Illicit-dual	8 (7.8)	0 (0.0)
Dual-dual ("always dual")	3 (2.9)	0 (0.0)
Dual-prescribed	5 (4.9)	0 (0.0)
Dual-illicit		
Previously used MC (first use-last use)		
Prescribed-prescribed ("always prescribed")	2 (2.0)	3 (12.5)
Prescribed-illicit	1 (1.0)	0 (0.0)
Prescribed-dual		
Illicit-illicit ("always illicit")	8 (7.8)	0 (0.0)
Illicit-prescribed	3 (2.9)	1 (4.2)
Illicit-dual	3 (2.9)	0 (0.0)
Dual-dual ("always dual")	2 (2.0)	0 (0.0)
Dual-prescribed	3 (2.9)	0 (0.0)
Dual-illicit		

Values are presented as number (%).

PWE, people with epilepsy; MC, medicinal cannabis.

MC products for their epilepsy ('dual'). There was no dual use reported among caregivers of PWE. Both PWE (79.4% [81/102]) and caregivers of PWE (87.5% [21/24]) primarily used MC as an adjunct to standard ASMs ($p < 0.001$) (Table 2). Only 3.9% (4/102) PWE and 26.3% (5/19) of caregivers of a PWE reported accessing PBS-subsidised Epidyolex (Jazz Pharmaceuticals) for the treatment of epilepsy.

Patient journey with MC

The survey data revealed three main MC respondent types: 'always illicit' (PWE, 27.5% [28/102]; caregivers of PWE, 16.7% [4/24]), 'illicit to prescribed' (PWE, 27.5% [28/102]; caregivers of PWE, 12.5% [3/24]), and 'always prescribed' (PWE, 19.6% [20/102]; caregivers of PWE: 70.8% [17/24]). The most common user type overall was 'always prescribed' (29.4% [37/126]) (Table 4). Among those who had previously used MC to treat epilepsy but had since stopped, the

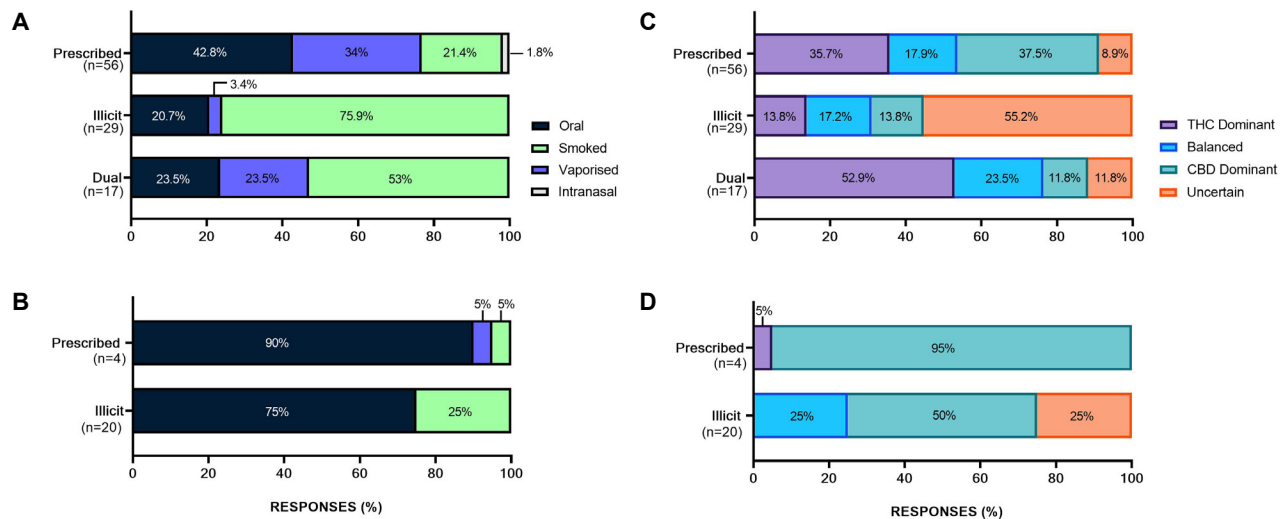


Figure 1. Main route of administration of the last used MC product among (A) PWE (n=102) and (B) caregivers of a PWE (n=24), categorized by 'prescribed', 'illicit', or 'dual' use. Perceived cannabinoid composition of the last MC product used among (C) PWE (n=102) and (D) caregivers of a PWE (n=24). No caregivers of a PWE reported 'dual' use. THC, tetrahydrocannabinol; CBD, cannabidiol; MC, medicinal cannabis; PWE, people with epilepsy.

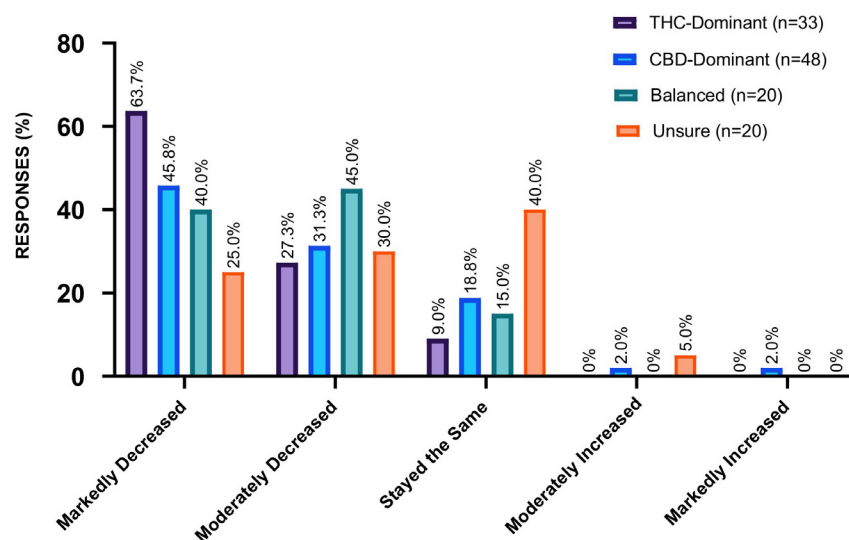


Figure 2. Perceived change in seizure frequency following the use of the last MC product. THC, tetrahydrocannabinol; CBD, cannabidiol; MC, medicinal cannabis.

primary reason for discontinuation was cost (44.4% [8/18]).

Fig. 1 illustrates the main route of administration and cannabinoid composition of the last MC product used, categorised by respondent type. Oral administration was most common when the MC product was prescribed, whereas smoking was the most frequent method when an illicit MC product was used. There was a significant association between caregivers of a PWE and oral routes of administration ($p < 0.001$). In contrast, inhaled forms of MC were more commonly used by PWE ($p < 0.001$). Chi-square *post-hoc* testing revealed a significant association between PWE who used 'illicit' MC and smoking cannabis ($p < 0.001$). Caregivers of a PWE were more likely than PWE to self-report using CBD-dominant MC products ($p < 0.001$), while most PWE using 'illicit' MC products were uncertain about the cannabinoid content (51.7% [15/29]). Self-reported use of THC-dominant products was most prevalent among participants accessing both prescribed and illicit products ('dual') (52.9% [9/17]), whereas THC-dominant and CBD/THC equivalent products were equally common among those using prescribed MC products (35.7% [19/56]).

Perceived efficacy

The majority of respondents reported overall improvement in epilepsy since commencing MC, with 85.7% reporting that it had positively impacted their condition. Fig. 2 illustrates the perceived change in seizure frequency by composition after commencing MC. Overall, the majority of respondents reported a reduction in seizure frequency, particularly those using THC-dominant (63.7% [21/33]) and CBD-dominant products (45.8% [22/48]), where a significant proportion noted a 'markedly decreased' frequency in seizures. Very few respondents reported any increase in seizures after commencing

MC use, with only three cases identified. There were no between-group differences in perceived efficacy.

Fig. 3 illustrates the perceived efficacy of MC at treating comorbid conditions, independent of the composition of the last MC product type used. For caregivers of a PWE, the majority response across most variables was 'no change', though 'much better' was the next most common response for all comorbidities except headaches. In contrast, for PWE, the majority response for most variables was 'much better', with the exception of cognitive ability and fatigue, where 'no change' was the predominant response. In terms of change in the use of ASMs, an equal number of caregivers of a PWE reported that ASM use 'stayed the same' or 'markedly decreased' (37.5% [9/24]). For PWE, the majority indicated that ASM use 'stayed the same' (48.4% [59/122]), although a decrease in ASM use following MC was also commonly reported: 'moderately decreased' (18.9% [23/122]) and 'markedly decreased' (26.2% [32/122]). Only a small minority of participants reported an increase in ASM use after commencing MC products (PWE, 5.7% [7/122]; caregiver of a PWE, 12.5% [3/24]).

Attitudes towards MC

Fig. 4 illustrates the self-reported barriers to accessing prescribed MC products. The most frequently reported barrier for both PWE (67.6% [69/102]) and caregivers of a PWE (75.0% [18/24]) was the 'cost of the cannabis product'. For caregivers of a PWE, the second most common barrier was 'finding a doctor who was willing to prescribe MC' (45.8% [11/24]), whereas for PWE, the second most common barrier was 'other associated costs' (47.1% [48/102]). Additionally, 'concerns about driving' (46.1% [47/102]) emerged as

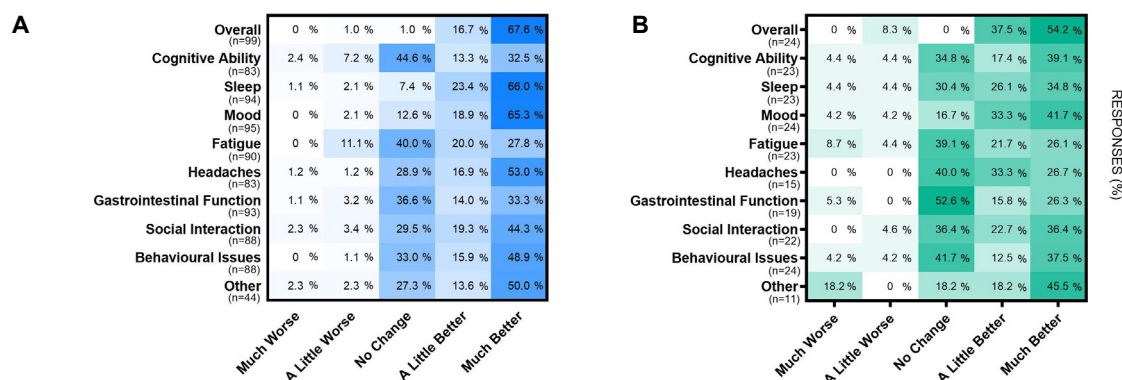


Figure 3. Perceived effectiveness of MC products in treating overall symptoms and various comorbid symptoms of epilepsy, as reported by: (A) PWE (n=98) and (B) caregivers of a PWE (n=24). MC, medicinal cannabis; PWE, people with epilepsy.

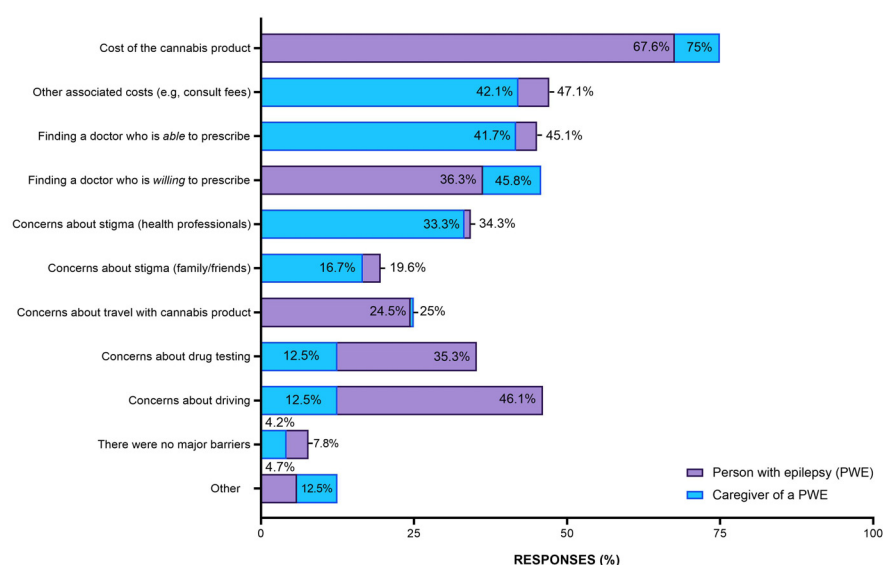


Figure 4. Barriers to accessing prescribed MC in Australia among PWE (n=93) and caregivers of a PWE (n=24). Respondents could select multiple barriers to accessing prescribed MC. MC, medicinal cannabis.

a frequent barrier for PWE. Binary logistic regression showed that participants who were currently employed were significantly less likely to identify cost as a barrier to accessing MC compared to those who were currently unemployed (odds ratio, 2.74; 95% confidence interval, 1.08-6.88; $p=0.032$) (Supplementary Table 1). None of the other socioeconomic variables, including age, sex, education level, or annual household income, were significant predictors.

Perceived knowledge and expertise of prescriber

The majority of PWE obtained their MC prescription through a cannabis clinic (73.3%), either via a general practitioner (GP) or a medical specialist within the cannabis clinic. In contrast, caregivers of a PWE were more likely to obtain an MC prescription from a medical specialist in a general health setting (60.0% [12/20]) ($p<0.001$). Most respondents rated their prescribers as having either “exceptional” (30.0% PWE and 37.5% caregivers of PWE) or “adequate” (35.0% PWE and 25.0% caregiver of a PWE) knowledge and experience in prescribing MC for the treatment of epilepsy.

Discussion

This study provides a comprehensive snapshot of MC use patterns and experiences among PWE in Australia, conducted during a period of significant expansion in prescribed MC use, 8 years after legislative changes. Our survey reveals that both PWE and their caregivers

view MC products as effective interventions, reporting reductions in seizures, alleviation of co-morbid symptoms, and in some cases, reduced reliance on conventional ASMs. This perceived efficacy was consistent regardless of MC product composition, route of administration, or source, aligning with previous surveys by our group^{30,31} and other international studies.^{51,52}

Compared to earlier surveys,^{30,31} this study identified a shift towards prescribed MC use, with over 60% of respondents holding a prescription. This trend aligns with data from the Australian medicines regulator, the Therapeutic Goods Administration (TGA), and other recent surveys,^{30,31} which show a notable increase in Australians accessing prescribed MC products and transitioning from illicit to prescribed use.^{44,53} The distribution of product types in our study (26.5% illicit; 12.8% dual; 60.7% prescribed) closely mirrors recent findings from the ‘Cannabis as Medicine (CAMS)-22 survey’ of more than 3,000 Australians using MC (23.8% illicit; 11.6% dual; 64.6% prescribed)⁵³ which documented a marked decline in illicit MC use compared to the ‘CAMS-20 survey’ (conducted 2 years earlier), which reported 63.9% illicit; 22.8% dual; 13.3% prescribed MC use.⁴⁴ An uptick in the use of prescribed MC in Australia was also highlighted in the most recent National Drug Strategy Household survey (2022-2023).⁴⁶ This trend is thought to reflect improved access to prescribed MC products due to an expanding national network of cannabis clinics, as well as the recent development of cost parity between illicit and prescribed products.⁵⁴⁻⁵⁸ This competitive pricing be-

tween illicit and prescribed MC products is reminiscent of historical trends in the Canadian market,^{43,55} although the legalised adult-use market in Canada adds additional complexity.

Prescribed MC use was particularly evident among caregivers of a PWE, with the 'always prescribed' category accounting for 70.8% (17/24) of respondents. These caregivers typically administered prescribed oral CBD. In contrast, adult PWE were more likely to use THC-dominant or THC/CBD equivalent formulations via inhaled routes, especially when using illicit MC. This difference in MC product profile and route of administration is unsurprising, given that the caregivers were primarily administering cannabinoids to individuals under 18 years of age. There were no dual (i.e., prescribed and illicit) users reported among caregivers of a PWE, whereas 16.7% (17/102) PWE reported dual use. Dual use, also commonly observed in the recent CAMS-20 and CAMS-22 surveys,^{44,53} likely reflects individuals transitioning from illicit to prescribed use or those who cannot afford exclusive use of prescribed products. Among this group, the majority were consuming THC-dominant products (52.9% [9/17]) via inhalation (76.5% [13/17]).

Publicly available data from the TGA's SAS-B scheme, one of the major legal pathways for MC prescription in Australia, indicate that epilepsy and seizure management rank as the 13th and 15th most common conditions treated with MC, with oral formulations being more commonly prescribed than dried flower.⁵⁹ A substantial proportion of those treated are under 18 years of age. Epilepsy treatment with MC accounts for only approximately 0.9% of total prescribing under this scheme.⁵⁹ Our findings largely align with the SAS-B data in terms of location, age, and dosage form, although the use of THC-dominant and THC/CBD equivalent MC was higher among our respondents. TGA data also show a recent rapid increase in the use of THC-dominant flower products across the Australian community for various medical conditions. Notably, however, the SAS-B data only represents a minority of the overall MC prescriptions in Australia due to the large and significant increase in doctors prescribing under the alternative Authorised Prescriber scheme, for which available data are less detailed and precise.⁶⁰

An important observation from the current survey is that the perceived efficacy of MC is not limited to CBD-dominant preparation. Most respondents rated MC as highly effective, irrespective of whether their product was illicit or prescribed, or whether it was inhaled or orally administered. The greater use of inhaled THC-dominant cannabis in adults compared to caregivers of PWE may reflect the lack of clinical evidence supporting CBD's anticonvulsant effects

in adult PWE or the relatively high cost of CBD products when dosed at equivalent therapeutic levels in adults (e.g., 25 mg/kg). However, there is also limited clinical evidence for THC's anticonvulsant effects in adults with epilepsy, and concerns remain that synthetic cannabinoid receptor 1 agonists can be strongly pro-convulsant in animal models.^{26,61,62} Despite these concerns, THC products are generally more affordable and are used at much lower doses than CBD,^{56,63,64} and our results suggest they are perceived to have anticonvulsant and ASM-sparing properties. The willingness of GPs in cannabis clinics to prescribe high-THC flower for inhalation by PWE is perhaps surprising but reflects the broader disconnect between current MC prescribing practices in Australia and the available clinical evidence.⁶⁵

Despite the widespread use of prescribed MC in this survey, approximately three-quarters of respondents cited cost as the main barrier to accessing these products. Our findings suggest that financial barriers disproportionately affect unemployed individuals, emphasizing the need for targeted policies and support systems to ensure equitable access to prescribed MC. Only a small percentage of survey respondents were accessing the government-subsidised CBD product, Epidyolex (Jazz Pharmaceuticals) (7.1% [9/126]). Increased market competition, with more than 800 MC products now available for prescription in Australia, has led to a drop in wholesale pricing for cannabis from \$0.20/mg of cannabinoid in 2017 to under \$0.03/mg of cannabinoid by late 2021.⁵⁷ Additionally, the price per gram of flower has dropped to as low as \$7.90/g on the market, irrespective of any additional disability or veterans' discounts.^{56,58} Given the high prevalence of inhaled use among PWE (80% illicit; 76.5% dual; 55.4% prescribed) identified, addressing the barrier of cost will be a focal point of discussion in the coming years as economies of scale compound. Despite steady reductions in price since legalisation in 2016, the prescribed market only reached cost parity with the illicit market in the last 12-18 months,^{39,41,42} suggesting that respondents who cited cost as a barrier may be referring to a time before this parity was achieved, or they may be unaware of the recent price alignment between illicit and prescribed MC.^{55,57,58} A lack of awareness about the rapidly decreasing costs of prescribed cannabis in Australia may be due to the TGA's ban on advertising specific MC products and pricing to the general public.⁶⁶

Another common barrier for PWE using MC was 'concerns about driving' (46.1% [47/102]), and this reflects current legal prohibitions in Australia against driving with any detectable THC in blood or oral fluid. Only one state in Australia, Tasmania, allows patients with a legal MC prescription an exemption from such laws.⁶⁷ In other states

and territories, a positive result in a roadside drug test can result in automatic disqualification of the driver's licence, fines, and possible imprisonment. This is despite evidence that patients using prescribed MC products under medical supervision generally do not exhibit impaired driving abilities according to objective tests and self-reports.^{44,67,68}

Limitations

Several limitations should be noted. Firstly, this study employed a convenience sampling method, which may limit its generalisability to the broader population of people with epilepsy in Australia.⁶⁹ This approach could introduce selection bias, as those with favourable MC experiences may be more likely to participate and complete the survey. The reported improvements in epilepsy, reduction in seizures, and decreased ASM use following MC initiation are consistent with this potential bias.⁷⁰ Other MC surveys and observational studies relying on self-selection and self-report similarly tend to report very positive effects of MC.^{42-44,64,71} Future research employing randomised controlled trials or more representative sampling methods would help validate these findings and reduce potential bias. Second, the survey relied on anonymous, self-reported data, which could be susceptible to inaccuracies (e.g., epilepsy diagnosis) and misinterpretations of perceived efficacy and may therefore not be generalisable to individuals with a clinically confirmed diagnosis of epilepsy. Finally, the study was constrained by a small sample size, with significant attrition of respondents across the five sections of the survey. The unequal participation by PWE and caregivers of a PWE further limited the statistical power to draw clear conclusions about differences in these populations, particularly when comparing the perceived efficacy and use of illicit versus prescribed MC.⁷²

Future directions

This study affirms the ongoing trend in Australia towards legal, prescribed use of MC products, consistent with findings from other sources.^{45,53,59,60} Access to MC for PWE is primarily through cannabis clinics, and current prescribing practices often lack a strong evidence base. Despite improved access, many individuals continue to rely on MC products, with cost cited as a significant barrier. This barrier could be mitigated by expanding the range of MC products registered on the Australian Register of Therapeutic Goods, allowing for additional PBS subsidies similar to those provided for Epidyolex (Jazz Pharmaceuticals). Many respondents are self-medicating with unregistered MC products, including THC-dominant and CBD/THC equivalent formulations, which they perceive as effective for manag-

ing their comorbid symptoms. Given that clinical research has largely focused on CBD-dominant products for paediatric epilepsies, there is an urgent need for additional investigation into the safety and efficacy of THC-containing products, particularly for adult populations where such products are already in widespread use. Overall, the current MC regulatory framework appears to be supporting individuals with epilepsy by enabling access to this alternative treatment option. However, further improvements in access pathways, cost reduction, and evidence-based safety and efficacy data-particularly regarding THC-are clearly needed.

Conflicts of Interest

All other authors have no competing financial or non-financial interests to declare.

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