

Sources of Cannabis Information and Medical Guidance for Neurologic Use

NARCOMS Survey of People Living With Multiple Sclerosis

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Abstract

Background and Objectives

As cannabis products become increasingly accessible across the United States, understanding how patients obtain medical information on cannabis and view the role of their health care provider in providing information is important.

Methods

Participants with multiple sclerosis (MS) from the North American Research Committee on Multiple Sclerosis registry completed a supplemental survey on Δ^9 -tetrahydrocannabinol-containing cannabis use between March and April 2020. Participants reported dialogue with health care providers regarding cannabis use, information sources used to make product decisions, and expenditure on cannabis. Findings are reported using descriptive statistics.

Results

Overall, 3,249 participants responded (47% response rate), of whom 31% ever used cannabis and 20% currently used cannabis for MS. To determine presumed cannabis contents, respondents who had ever used cannabis (ever users) most often used dispensary-provided information (39%), word of mouth/dealer/friend (29%), and unregulated product labels (24%). For general information on cannabis for MS, ever users most often used dispensary staff (38%) and friends (32%). The primary source of medical guidance among ever users was most often “nobody or myself” (48%), followed by a dispensary professional (21%); only 12% relied on their MS physician, although 70% had discussed cannabis with their MS physician. Most current users (62%) typically sourced their cannabis from a dispensary. The most common factor in selecting a cannabis product was perceived quality and safety (70%).

Discussion

Participants most often received information on cannabis for MS from dispensaries, unregulated product labels, and friends; only a small proportion used health care providers. Evidence-based patient and physician education is needed.



Interest in cannabis use for symptom management in neurologic conditions, such as multiple sclerosis (MS) and epilepsy,^{1,2} is increasing as more data become available and access eases from a legal perspective.^{3,4}

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Among people with MS (PwMS), the high prevalence of pain, sleep disturbance, and comorbid symptoms, coupled with the lack of sufficiently effective treatment options for those symptoms, there has been increased interest in cannabis products.⁵ In our 2020 survey of participants in the North American Research Committee on Multiple Sclerosis (NARCOMS) self-report registry, 31% of PwMS had ever used cannabis to treat MS symptoms, and 20% had used cannabis within 30 days of survey administration.⁶ The survey definition of cannabis/marijuana did not include products marketed as only cannabidiol (CBD) or hemp CBD.

The source of patient information about cannabis products is relatively unknown. We report how PwMS communicate about cannabis use with their health care providers, which information sources they use to make product decisions, the types of product they are choosing, and how much they spend on cannabis products. We hypothesized that participants in our NARCOMS survey obtained cannabis product information and medical guidance from sources other than their health care provider.

Methods

Study Design

The NARCOMS registry is a voluntary self-report registry for PwMS.⁷ Participants are asked to update their information semiannually. Participants may also be invited to participate in supplemental surveys.

Active, US-based participants as of February 28, 2020 (N = 6,934) were invited to participate in this online supplemental survey; no other eligibility criteria were applied. The survey was conducted using REDCap hosted at Washington University.⁸

Standard Protocol Approvals, Registrations, and Patient Consents

The survey was approved by the Washington University Institutional Review Board. By responding to the survey, participants gave informed consent to participate in the research. As cannabis use is not legal throughout the United States, NARCOMS obtained a certificate of confidentiality⁹ to protect the privacy of research subjects by prohibiting disclosure of identifiable, sensitive research information to anyone not connected to the research, except when the subject consented, or in limited other specific situations.

Demographic and Clinical Data

For participants who agreed to link their existing information with the cannabis survey, their semiannual update responses from 2019 were used to ascertain annual household income, employment status, alcohol use, smoking status, region of residence, disability status, clinical course, and disease-modifying therapy (DMT) use (yes/no).

Annual household income was reported as <\$15,000, \$15,000–\$30,000, \$30,001–\$50,000, \$50,001–\$100,000, >\$100,000, or “I do not wish to answer.” Current employment status was categorized as full time, part time, or not employed. Alcohol use was categorized as never, monthly or less, 2–4 times per month, 2–3 times per week, or >4 times per week. Smoking status was categorized as not at all, some days, or every day. Region of residence was categorized as to whether the use of cannabis for medical purposes was currently legal.¹⁰ Disability status was categorized using the Patient Determined Disease Steps: normal, mild disability, moderate disability, gait disability, early cane, late cane, bilateral support, wheelchair/scooter, and bedridden. Clinical course was categorized as clinically isolated syndrome, relapsing-remitting, secondary progressive, primary progressive, do not know or unsure, MS diagnosis not confirmed by a physician, or other. Methodology relating to demographics information collected has been previously reported.⁶

Cannabis Use

Participants were instructed that in this survey, “cannabis/marijuana” referred to products derived from the cannabis/marijuana plant and did not include products marketed as only CBD or hemp CBD. This will be henceforth referred to as simply “cannabis.” Where possible, questions regarding cannabis were sourced from national US surveys^{11–14} to ensure that the questions were validated⁶ and enhance comparability.

Information Sources

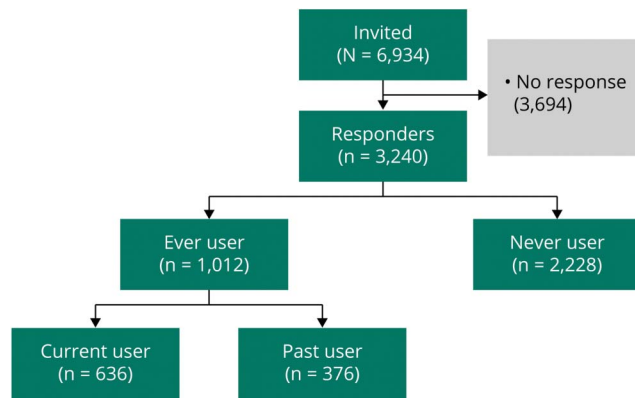
Participants who reported ever using cannabis indicated what information they used to determine the cannabis product contents used to treat MS symptoms: the product label, product website, certificate of analysis, dispensary-provided information, word of mouth/dealer/friend, health care provider, or other. They also reported where they obtained general information about how to use cannabis as follows: health care provider, dispensary staff, product packaging or website, internet, friends, scientific publications, advocacy group, online communities, or other.

Medical Guidance on Cannabis Use

Participants reported the primary person who provided them with medical guidance regarding cannabis use as follows: physician (MS provider or other physician), other licensed health care professional, pharmacist, dispensary professional, other patients with MS, or nobody/myself.

Participants reported whether they had discussed their cannabis use to treat MS symptoms with their MS physician, and whether they would feel comfortable discussing their cannabis use with this physician as follows: “yes, very comfortable,” “yes, comfortable,” “no, uncomfortable,” and “no, very uncomfortable.” Participants reported potential reasons for not feeling comfortable discussing cannabis with their MS physician including the belief that the physician would not approve of the cannabis use, concerns around stigma of raising this topic, discomfort initiating the conversation around cannabis use, not being interested in discussing it/lack of relevance, or the physician having never raised the topic. All participants reported whether

Figure 1 Survey Respondents Flow Diagram



they thought that their MS provider would feel comfortable with their cannabis use as follows: believing that the physician would be/is comfortable with it, would not be/is not comfortable with it, or that they would/would not be comfortable with it if the participant used cannabis.

Participant Preferences

Participants reported their typical source of cannabis as follows: I grow my own, someone grows it for me, from a dispensary, online, from an acquaintance, from a family member or friend, from a dealer, or other. They also reported the most important factors when selecting a source from which to purchase cannabis (such as low price, quality and safety, sales support, location, accessibility, ability to purchase online, anonymity/discretion, access to preferred potency/formulation, access to preferred strain, and access to products not available in licensed stores or online).

Spending on Cannabis

Participants reported how much they spend on cannabis in an average month. Options included nothing, \$1–\$10, \$11–\$25, \$26–\$50, \$51–\$100, \$101–\$150, \$151–\$250, \$251–\$500, \$501–\$750, \$751–\$1,000, or >\$1,000.

Statistical Analysis

Descriptive statistics were used to summarize responses with mean (SD) or median (25th, 75th percentiles) for continuous variables and frequency (percentage) for categorical variables. Differences between groups were determined by the *t* test or Wilcoxon test for continuous variables and χ^2 or Fisher exact test, as appropriate, for categorical variables. The association between legal medical use of cannabis and physician comfort and dialogue among never vs ever and past vs current users was examined using a Cochran-Mantel-Haenszel test.

Data Availability

Patient-level data cannot be provided in keeping with the certificate of confidentiality, but aggregated data that support

these findings will be made available to qualified researchers on request to the corresponding author.

Results

Participants

Of the 6,934 invited participants, 3,249 (46.9%) responded, of whom 3,240 (99.7%) responded to the item regarding cannabis use for MS (Figure 1). Small differences between respondents and nonrespondents to the survey in the NARCOMS population were identified for age, race, and education level.⁶

As reported previously,⁶ most respondents were female and White (Table 1). Approximately two-thirds had a bachelor's degree or higher and were unemployed. The mean (SD) age was 61.3 (10.0) years; the mean (SD) age at MS symptom onset was 31.2 (10.3) years; and the median (25th, 75th percentile) disability level was 3-Gait Disability (1-Mild Disability, 6-Bilateral Support). Almost two-thirds of the respondents were taking a DMT. Most respondents (76.1%) lived in a state where the medical use of cannabis was currently legal, and 55.3% of respondents used cannabis before their MS diagnosis.

Cannabis Use

Of the 3,240 respondents, 1,012 (31%) reported ever using cannabis to treat MS symptoms (ever users), 636 (20%) reported current use (current users [within 30 days of the survey]), 376 (12%) reported past use (past users), and 2,228 (69%) reported having never used it (never users). A higher proportion of ever users resided in a state where cannabis use was currently legal compared with never users (81.2% vs 73.7%, $p < 0.0001$) and between current and past users (84.0% vs 76.6%, $p = 0.009$).

Information Sources

To determine cannabis contents, ever users were most likely to use dispensary-provided information (39%), word of mouth/dealer/friend (29%), and unregulated product label (24%) (Table 2). Among ever users, current users were more likely than past users to determine contents from dispensary-provided information (45% vs 29%; $p < 0.001$) and the unregulated product label (27% vs 18%; $p = 0.002$).

To obtain general information about cannabis use for MS, <15% of ever users relied on health care providers; instead, dispensary staff (38%) and friends (32%) were the most frequently reported sources (Table 2). Current users vs past users more often cited dispensary staff (43% vs 30%; $p < 0.001$) and the internet (20% vs 13%; $p = 0.007$) as sources of information on using cannabis for MS.

The primary source of medical guidance among the 1,012 ever users was most often cited as “nobody or myself” (48%), followed by a dispensary professional (21%) (Table 2). Only

Table 1 Demographics and Clinical Characteristics

Characteristic	Total ^a (N = 3,240)	Never users (N = 2,228)	Ever users (N = 1,012)	Past users (N = 376)	Current users (N = 636)
Demographics					
Female, n (%) ^{b,c}	2,516 (78.5)	1,745 (79.1)	771 (77.1)	306 (82.7)	465 (73.8)
Age at survey (y), mean (SD) ^{b,c}	61.3 (10.0)	62.0 (10.1)	59.7 (9.6)	60.7 (10.0)	59.1 (9.4)
Age groups at survey (y), n (%)^{b,c}					
18–24	1 (0.03)	0 (0.0)	1 (0.1)	1 (0.3)	0 (0.0)
25–34	37 (1.2)	22 (1.0)	15 (1.5)	6 (1.6)	9 (1.4)
35–44	170 (5.30)	112 (5.1)	58 (5.8)	19 (5.1)	39 (6.2)
45–54	532 (16.6)	343 (15.6)	189 (18.8)	56 (15.1)	133 (21.0)
55–64	1,148 (35.8)	741 (33.6)	407 (40.5)	146 (39.3)	261 (41.3)
65–74	1,099 (34.3)	807 (36.6)	292 (29.1)	124 (33.3)	168 (26.6)
≥75	221 (6.9)	179 (8.1)	42 (4.2)	20 (5.4)	22 (3.5)
Race, n (%)^{b,c}					
White	2,844 (88.5)	1,989 (89.9)	855 (85.4)	318 (85.5)	537 (85.4)
African American	56 (1.7)	28 (1.3)	28 (2.8)	11 (3.0)	17 (2.7)
Other	314 (9.8)	196 (8.9)	118 (11.8)	43 (11.6)	75 (11.9)
Bachelor's degree or higher, n (%) ^{b,c}	1,885 (60.6)	1,353 (63.0)	532 (55.1)	205 (56.3)	327 (54.4)
Resides in a state with legal use of cannabis for medical use, n (%)^{b,c}					
Yes	2,464 (76.1)	1,642 (73.7)	822 (81.2)	288 (76.6)	534 (84.0)
No	743 (22.9)	565 (25.4)	178 (17.6)	84 (22.3)	94 (14.8)
Unknown	33 (1.0)	21 (0.9)	12 (1.2)	4 (1.1)	8 (1.3)
Employed past 6 mo, n (%)^{b,c}					
Full time	685 (22.6)	520 (24.6)	165 (18.1)	54 (15.6)	111 (19.5)
Part time	329 (10.9)	235 (11.1)	94 (10.3)	30 (8.7)	64 (11.3)
Not employed	2,015 (66.5)	1,360 (64.3)	655 (71.7)	262 (75.7)	393 (69.2)
Clinical data					
Age at symptom onset, mean (SD) ^{b,c}	31.2 (10.3)	31.7 (10.2)	30.0 (10.3)	30.3 (10.2)	29.8 (10.4)
Age at diagnosis, mean (SD) ^{b,c}	38.7 (9.8)	38.8 (9.8)	38.3 (9.7)	38.9 (9.7)	38.0 (9.6)
MS clinical course, n (%)^{b,c}					
CIS	51 (1.7)	40 (1.9)	11 (1.2)	5 (1.4)	6 (1.0)
RRMS	1,745 (56.5)	1,261 (58.5)	484 (51.9)	180 (50.6)	304 (52.8)
SPMS	832 (27.0)	534 (24.8)	298 (32.0)	111 (31.2)	187 (32.5)
PPMS	259 (8.4)	172 (8.0)	87 (9.3)	40 (11.2)	47 (8.2)
Do not know/unsure	156 (5.1)	116 (5.4)	40 (4.3)	14 (3.9)	26 (4.5)
MS diagnosis not confirmed	9 (0.29)	7 (0.32)	2 (0.21)	0 (0.0)	2 (0.35)
Other	34 (1.1)	24 (1.1)	10 (1.1)	6 (1.7)	4 (0.69)
Take DMT, n (%)^{b,c}					
Yes	1,914 (62.5)	1,349 (63.4)	565 (60.4)	208 (58.6)	357 (61.6)
No	1,148 (37.5)	778 (36.6)	370 (39.6)	147 (41.4)	223 (38.4)

Continued

Table 1 Demographics and Clinical Characteristics (continued)

Characteristic	Total ^a (N = 3,240)	Never users (N = 2,228)	Ever users (N = 1,012)	Past users (N = 376)	Current users (N = 636)
PDDS scale, median [25th, 75th percentiles]^{b,c}	3.0 [1.00, 6.0]	3.0 [1.00, 5.0]	4.0 [2.0, 6.0]	4.0 [2.0, 6.0]	4.0 [2.0, 6.0]
Ever used cannabis before MS diagnosis, n (%)^{b,c}					
Yes	1,663 (55.3)	937 (45.1)	726 (77.8)	257 (73.4)	469 (80.5)
No	1,329 (44.2)	1,127 (54.3)	202 (21.7)	91 (26.0)	111 (19.0)
Unknown	17 (0.6)	12 (0.6)	5 (0.5)	2 (0.6)	3 (0.5)

Abbreviations: CIS = clinically isolated syndrome; DMT = disease-modifying therapy; max = maximum; min = minimum; MS = multiple sclerosis; NRS = numerical rating scale; PDDS = Patient Determined Disease Steps; PPMS = primary progressive multiple sclerosis; RRMS = relapsing-remitting multiple sclerosis; SPMS = secondary progressive multiple sclerosis.

^a Nine participants did not respond to the question.

^b For total, never users, and ever users, data were not available for all participants. Missing values: sex = 35, age at survey = 32, race = 26, education level = 127, employed past 6 mo = 211, age at symptom onset = 61, age at diagnosis = 66, MS clinical course = 154, take DMT = 178, PDDS = 171, and ever used cannabis before MS diagnosis = 231.

^c For ever users, past users, and current users, data were not available for all participants. Missing values: sex = 12, age at survey = 8, race = 11, education level = 47, employed past 6 mo = 98, age at symptom onset = 24, age at diagnosis = 17, MS clinical course = 80, take DMT = 77, PDDS = 68, and ever used cannabis before MS diagnosis = 152.

112 (12%) relied on their MS physician (Figure 2), with no difference between past and current users. Current users were more likely than past users to rely on a physician different from their MS provider (11% vs 4.6%; Table 2).

Of the ever users, most (70%) had discussed cannabis with the physician who treats their MS (Figure 2). The proportion of participants who discussed cannabis with their physician was higher among current users vs past users (75% vs 60%; $p < 0.001$).

Comfort and Dialogue With Physician

Of the 3,240 total respondents, 1,755 (56%) reported being very comfortable discussing cannabis use for symptom management with their MS physician (Table 3). More ever users (72%) reported feeling very comfortable than never users (50%) ($p < 0.001$). More current users were likely to feel very comfortable (74%) than past users (67%) ($p = 0.042$).

Among ever users, a small minority provided reasons for not feeling comfortable discussing cannabis with their MS provider, including a belief that their MS physician does not approve of cannabis use (3.4%), concern about the stigma of raising this topic with their MS physician (3.2%), or that their MS physician had never raised the topic of cannabis (2.9%).

More ever users than never users responded positively to questions regarding their care providers beliefs, except for the question “I am not interested in discussing it/it is not relevant to me,” where more never users answered “yes” compared with ever users (9.6% vs 1.2%; $p < 0.001$). For the option “My MS physician has never raised the topic of cannabis,” never and ever users did not differ significantly (“yes” answers: 4.2% vs 2.9%; $p = 0.070$). Responses did not differ significantly between past and current users, except for “I am not interested in discussing it/it is not relevant to me,”

where a higher percentage of past users answered “yes” than current users (2.7% vs 0.3%; $p < 0.001$).

Most never and ever users believed that their MS physician would be comfortable with their cannabis use (66% and 78%). Among ever users, more past users vs current users believed that their MS physician would not be comfortable with their cannabis use (29% vs 19%; $p < 0.001$). Residence in a state where cannabis use was currently legal was associated with more frequent belief that their MS physician would be comfortable with cannabis use (eTable 1, links.lww.com/CPJ/A326).

Product Preferences, Sources, and Cost

Of the 636 current users, 393 (62%) typically source cannabis from a dispensary, 112 (18%) from a family member or friend, and 82 (13%) from an acquaintance (eFigure 1, links.lww.com/CPJ/A326).

The most common factor in selecting a source to purchase cannabis was perceived quality and safety ($n = 448$ [70%]), followed by access to preferred Δ^9 -tetrahydrocannabinol (THC) and/or CBD potencies/formulations ($n = 252$ [40%]), location ($n = 246$ [39%]), and sales support ($n = 194$ [31%]) (eFigure 2, links.lww.com/CPJ/A326).

Spending per month on cannabis was reported as nothing (get it for free or trade) for 11% of participants, \$1–\$25 for 17%, \$26–\$50 for 18%, \$51–\$100 for 24%, \$101–\$250 for 23%, \$251–\$500 for 6%, and \$501–\$1,000 for 1%.

Discussion

The prevalence of cannabis use by PwMS is rising.^{5,15} Although one-third of respondents reported ever using cannabis to treat MS symptoms, 20% reported current use. Ever

Table 2 Product Information Sources and Primary Medical Guidance on Cannabis Use Among Ever, Past, and Current Users

Information source	Ever users for MS (N = 1,012)	Past users for MS (N = 376)	Current users for MS (N = 636)
What information do you use to determine what exactly is in the cannabis product you use? (check all that apply)			
Dispensary-provided information	396 (39.1)	109 (29.0)	287 (45.1)
Word of mouth/dealer/friend	295 (29.2)	99 (26.3)	196 (30.8)
Product label	240 (23.7)	69 (18.4)	171 (26.9)
Certificate of analysis	126 (12.5)	48 (12.8)	78 (12.3)
Health care provider	87 (8.6)	34 (9.0)	53 (8.3)
Other	73 (7.2)	29 (7.7)	44 (6.9)
Claims on website of product	64 (6.3)	20 (5.3)	44 (6.9)
Where do you get general information about cannabis and/or advice about how to use cannabis? (check all that apply)			
Dispensary staff	383 (37.8)	111 (29.5)	272 (42.8)
Friends	326 (32.2)	111 (29.5)	215 (33.8)
Internet	177 (17.5)	50 (13.3)	127 (20.0)
Scientific publications	168 (16.6)	57 (15.2)	111 (17.5)
Health care provider	141 (13.9)	56 (14.9)	85 (13.4)
Medical claims on the packaging or manufacturer website	81 (8.0)	29 (7.7)	52 (8.2)
Other	65 (6.4)	22 (5.9)	43 (6.8)
Advocacy group	60 (5.9)	20 (5.3)	40 (6.3)
Online communities	34 (3.4)	14 (3.7)	20 (3.1)
Who is the primary person that provides you with medical guidance for your cannabis use for MS?^a			
Nobody or myself	458 (47.5)	167 (48.4)	291 (46.9)
Dispensary professional	203 (21.0)	77 (22.3)	126 (20.3)
Physician (same as the MS provider)	112 (11.6)	40 (11.6)	72 (11.6)
Physician (different from the MS provider)	81 (8.4)	16 (4.6)	65 (10.5)
Other patients with MS	74 (7.7)	32 (9.3)	42 (6.8)
Other licensed health care provider	27 (2.8)	10 (2.9)	17 (2.7)
Pharmacist	10 (1.0)	3 (0.87)	7 (1.1)

Abbreviation: MS = multiple sclerosis.

Participants could indicate multiple responses for this question.

Values presented as N (column %).

^a Responses were missing for 47 ever users, 31 past users, and 16 current users.

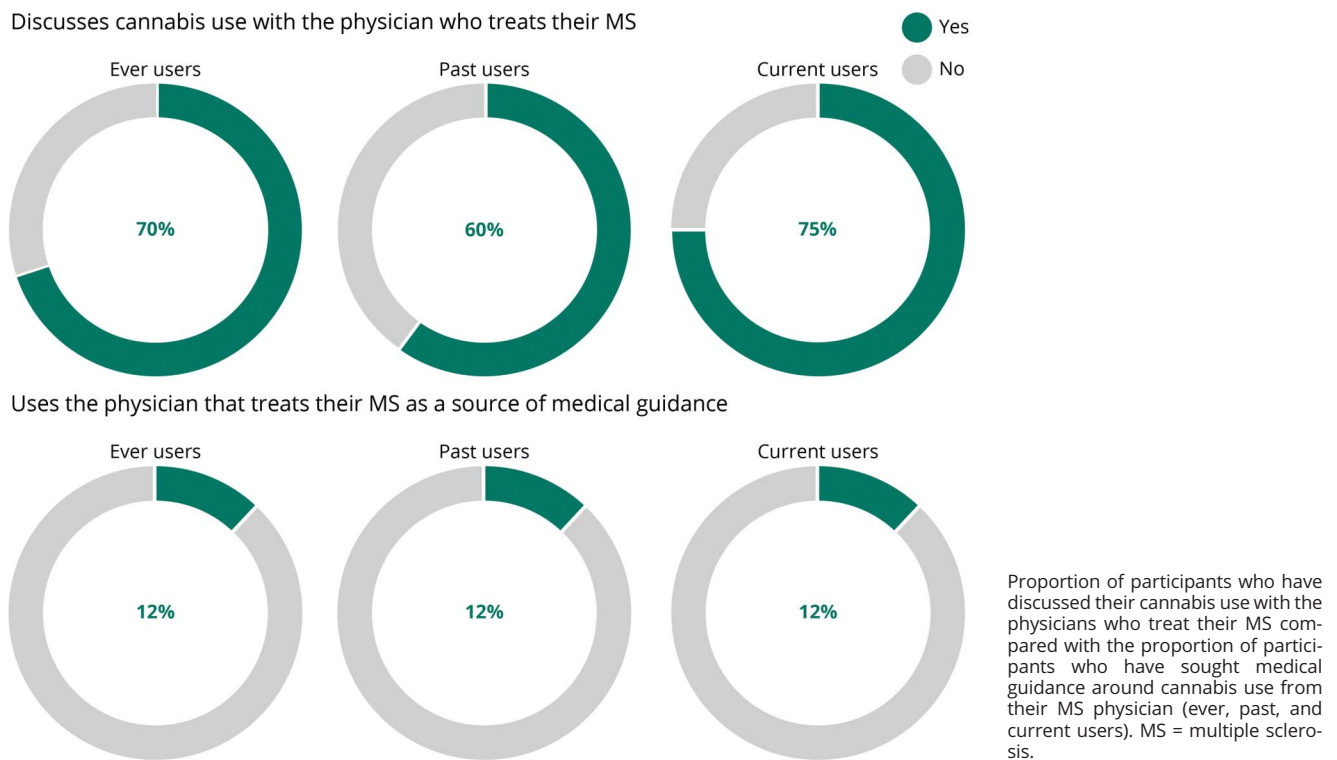
use and current use of cannabis were higher in this survey compared with previous NARCOMS reports,¹³ possibly reflecting increasing acceptance of cannabis use and/or the increasing number of states with legalized cannabis possession and use.

Sources of information used by PwMS broadly reflected where participants acquired cannabis products, which was most often a dispensary. Family, friends, acquaintances,

dealers, and word of mouth were also reported as product information sources, but <10% of participants reported obtaining product information from health care providers. In another recent survey of cannabis use in PwMS in the United States, <1% of participants received assistance from their provider regarding selection of cannabinoid formulations.⁵

Participants reported low reliance on their physicians for medical guidance regarding cannabis use. In another recent

Figure 2 Proportion of Participants Who Have Discussed Cannabis Use With/Sought Medical Guidance From Their MS Physician



survey of cannabis use in PwMS in the United States, 18% of participants reported discussing cannabinoids for MS symptom management with a health care provider.⁵ The low reliance on clinicians for guidance on therapeutic cannabis use may reflect the lack of a prescription product in the United States. Also, clinicians generally lack knowledge of the THC, CBD, and other contents of specific cannabis products and data regarding efficacy, safety, dosing, and patient selection and therefore may not provide guidance, even while remaining open to more general discussion of cannabis. Moreover, despite PwMS being comfortable discussing cannabis use, a substantial minority believe that their MS physician would not be comfortable with their cannabis use, particularly in states where use was not currently legal, and are therefore unlikely to seek medical guidance on the topic. These findings have important implications for clinical care of PwMS taking cannabinoids, highlighting the gap between the rapid dissemination of informal sources of information on cannabis products compared with less accessible (though more trustworthy) health care provider-based information.¹⁶

Ongoing physician education is recognized as important to the “shared decision-making” paradigm, to provide patients with the most current information.¹⁷ This model has been implemented in MS care, in which the clinician and patient decide on DMT regimens together, considering the patient’s

individual needs, preferences, and values.¹⁸ Despite the prevalence of cannabis use among PwMS, lack of health care provider knowledge or awareness may hamper decision making in MS care. A recent cross-sectional analysis of health care provider’s knowledge regarding cannabis use for medical purposes indicated considerable gaps in knowledge regarding clinical effects, risks and harms, pharmacology, and effects on pain, MS spasticity, and seizures.¹⁹ A recent survey supports this idea, with most Australian general practitioners feeling that their knowledge of medical cannabis was inadequate, and only 29% feeling comfortable discussing cannabis use with patients.²⁰ Consistent with those studies, our findings highlight the need for further education of health care providers regarding the risks and benefits of cannabis and cannabinoid use.

PwMS often have symptom management regimens and may also take herbal and other supplements.^{21,22} Thus, the possibility of pharmacologic interactions is high.²³ CBD and THC affect common targets for drug metabolism (such as cytochrome P450 [CYP]3A4/2C19 enzymes), which may affect the pharmacokinetics/pharmacodynamics of other drugs that interact with these pathways.^{24,25} CBD or marijuana use decreases clearance of drugs and their metabolites that use CYP2C19 (e.g., warfarin), increases clearance of CYP1A2-metabolized drugs, and may result in adverse additive effects in combination with sympathomimetics (e.g.,

Table 3 Physician Communication Regarding Cannabis Use Among Never, Ever, Past, and Current Users

	Total (N = 3,240)	Never users for MS (N = 2,228)	Ever users for MS (N = 1,012)	Never vs ever users p Value	Past users for MS (N = 376)	Current users for MS (N = 636)	Past vs current users p Value
Would you be comfortable with your doctor who primarily manages your MS talking with you about cannabis to help treat your MS symptoms?^a							
Yes, very comfortable	1,755 (56.0)	1,067 (49.2)	688 (71.5)	<0.001	231 (67.0)	457 (74.1)	0.042
Yes, comfortable	1,019 (32.5)	819 (37.7)	200 (20.8)		89 (25.8)	111 (18.0)	
No, uncomfortable	237 (7.6)	180 (8.3)	57 (5.9)		19 (5.5)	38 (6.2)	
No, very uncomfortable	121 (3.9)	104 (4.8)	17 (1.8)		6 (1.7)	11 (1.8)	
Potential reasons for not feeling comfortable discussing cannabis use with your MS provider:							
I believe my MS physician does not approve of cannabis use							
No	3,174 (98.0)	2,196 (98.6)	978 (96.6)	<0.001	365 (97.1)	613 (96.4)	0.56
Yes	66 (2.0)	32 (1.4)	34 (3.4)		11 (2.9)	23 (3.6)	
I am concerned about the stigma of raising this topic with my MS physician							
No	3,193 (98.5)	2,213 (99.3)	980 (96.8)	<0.001	369 (98.1)	611 (96.1)	0.069
Yes	47 (1.5)	15 (0.67)	32 (3.2)		7 (1.9)	25 (3.9)	
I am not comfortable initiating the conversation about cannabis							
No	3,192 (98.5)	2,204 (98.9)	988 (97.6)	0.005	369 (98.1)	619 (97.3)	0.41
Yes	48 (1.5)	24 (1.1)	24 (2.4)		7 (1.9)	17 (2.7)	
I am not interested in discussing it/it is not relevant to me							
No	3,014 (93.0)	2,014 (90.4)	1,000 (98.8)	<0.001	366 (97.3)	634 (99.7)	<0.001
Yes	226 (7.0)	214 (9.6)	12 (1.2)		10 (2.7)	2 (0.3)	
My MS physician has never raised the topic of cannabis							
No	3,118 (96.2)	2,135 (95.8)	983 (97.1)	0.070	369 (98.1)	614 (96.5)	0.14
Yes	122 (3.8)	93 (4.2)	29 (2.9)		7 (1.9)	22 (3.5)	
As someone who does NOT currently use cannabis/marijuana for your MS, what do you believe your MS provider's comfort level with the use of cannabis/marijuana is?^b							
I believe my MS physician would be comfortable if I used cannabis	—	1,359 (65.7)	—	—	—	—	—
I believe my MS physician would NOT be comfortable if I used cannabis	—	711 (34.3)	—	—	—	—	—

Continued

Table 3 Physician Communication Regarding Cannabis Use Among Never, Ever, Past, and Current Users (continued)

	Total (N = 3,240)	Never users for MS (N = 2,228)	Ever users for MS (N = 1,012)	Never vs ever users p Value	Past users for MS (N = 376)	Current users for MS (N = 636)	Past vs current users p Value
As someone who currently uses cannabis/marijuana for your MS, what do you believe your MS provider's comfort level with your cannabis/marijuana use is?*							
I believe my MS physician would be comfortable if I used cannabis	—	—	729 (77.9)	—	229 (71.1)	500 (81.4)	<0.001
I believe my MS physician would NOT be comfortable if I used cannabis	—	—	207 (22.1)	—	93 (28.9)	114 (18.6)	

Abbreviation: MS = multiple sclerosis.

Values presented as N (column %), p Values derived from the χ^2 test.

^a Responses were missing for 108 total, 58 never users, 50 ever users, 31 past users, and 19 current users.

^b Responses were missing for 158 never users.

^c Responses were missing for 76 ever users, 54 past users, and 22 current users.

hypertension), alcohol and opioids (e.g., ataxia), and anticholinergics (e.g., tachycardia).²⁵ Thus, it is important that health care providers are aware of all concomitant therapies and that patients are comfortable discussing their cannabis use with their MS physician.

Although informal sources of information were reported, participants cited quality and safety as the most important factor in selecting products, followed by preferred THC and/or CBD potencies/formulations, location, and sales support. This suggests that PwMS are eager to have more information, but the lack of adequate controlled studies makes it difficult for PwMS to obtain medical guidance regarding a specific THC:CBD ratio or dose. Furthermore, content in unregulated products frequently does not match the label.²⁶⁻²⁸

This survey has several limitations. NARCOMS is a voluntary registry, so may not represent the general MS population. However, the participant population has an age distribution close to the peak age in MS prevalence previously reported.²⁹ Women were overrepresented in this study with a female to male ratio of 3.6:1, even after accounting for the greater prevalence of MS in women than in men (2.6:1).²⁹ Despite stringent efforts to ensure confidentiality, response bias may have affected some responses. As this was a single survey, it represents a snapshot in time; patterns of cannabis use and the trends discussed in this article are likely to be dynamic. Our comparisons of information sources across groups (e.g., current and past users) cannot account for obtaining that information at different points in time nor for changes in the type or accessibility of information provided by dispensaries. Additionally, we do not know if cannabis use was legal in a participant's state at the time of use as laws have rapidly changed recently. Only data for use of cannabis products (containing THC in addition to CBD and excluding products reported to contain CBD alone) were collected. We were unable to evaluate whether PwMS would use cannabis less often if studies were to show a harmful impact in MS, but this warrants future study once randomized trials are performed and published. The analyses were limited by incomplete responses for some elements. Health care providers' perspectives regarding their comfort in discussing cannabis use for MS were not captured. A recent systematic review suggested that practitioners, although generally supportive of the use of medicinal cannabis, self-perceived a lack of knowledge and limited accessible information as barriers.³⁰ A survey of Canadian physicians showed that over two-thirds would feel more comfortable discussing medical cannabis with their patients if they had access to more formal education on the topic.³¹

Our findings indicate that PwMS use "informal" sources for information on cannabis products. Involvement of health care providers in decision making surrounding cannabis use by PwMS is limited, despite patient willingness to discuss cannabis with providers. Evidence-based education is needed to increase clinician knowledge, and further information is

needed to determine what is most needed to take a more active role in providing medical guidance to their patients.

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Amber Salter, PhD	UT Southwestern Medical Center, TX	Designed and conceptualized the study; analyzed the data; and drafted the manuscript for intellectual content.
Gary Cutter, PhD	The University of Alabama at Birmingham	Interpreted the data and revised the manuscript for intellectual content.
Ruth Ann Marrie, MD, PhD	Max Rady College of Medicine, Manitoba, Canada	Interpreted the data and revised the manuscript for intellectual content.
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Robert J. Fox, MD	Mellen Center for Multiple Sclerosis, Cleveland, OH	Interpreted the data and revised the manuscript for intellectual content.

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NARCOMS Survey of People Living With Multiple Sclerosis**

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