Cannabis Use as Described by People with Multiple Sclerosis

S.A. Page, M.J. Verhoef, R.A. Stebbins, L.M. Metz, J.C. Levy

ABSTRACT: Background: Multiple sclerosis (MS) is one of the most common neurological diseases affecting young adults. The prevalence of MS in Alberta has been described as among the highest reported in the world, estimated at 217 per 100,000. Numerous anecdotal reports, and a few small empirical investigations have suggested that cannabis use may relieve the symptom experience of those with MS. The present study was undertaken to describe cannabis use by this patient group. Information on peoples’ beliefs, practices and experiences related to use were investigated. Methods: A questionnaire was mailed to a sample of 780 adults with MS in southern Alberta, Canada. Results: Completed questionnaires were returned by 420/673 eligible subjects (response rate 62%). Mean sample age was 48 years and 75% were women. Respondents ranged from mildly to severely impaired. The majority of respondents (96%) was aware cannabis was potentially therapeutically useful for MS and most (72%) supported legalization for medicinal purposes. Forty-three percent had tried cannabis at some point in their lives, 16% for medicinal purposes. Symptoms reported to be ameliorated included anxiety/depression, spasticity and chronic pain. Reasons given for not trying cannabis were the fact that it is an illegal substance, concern about side effects and lack of knowledge on how to obtain it. Conclusions: Subjective improvements in symptom experience were reported by the majority of people with MS who currently use cannabis. Further evaluation of this substance is warranted.

RÉSUMÉ: Utilisation du Cannabis par les patients atteints de sclérose en plaques. Introduction: La sclérose en plaques (SEP) est l’une des maladies neurologiques les plus fréquentes chez les jeunes adultes. La prévalence de la SEP en Alberta, estimée à 217 par 100 000, a été décrite comme l’une des plus élevées rapportées dans le monde. Plusieurs rapports anecdotiques et quelques études empiriques de petite taille ont suggéré que l’utilisation de cannabis soulage les symptômes des patients atteints de SEP. Cette étude a été entreprise dans le but de décrire l’utilisation du cannabis chez ces patients. Nous avons évalué l’information sur les croyances, les pratiques et les expériences relatives à son utilisation. Méthodes: Un questionnaire a été posté à un échantillon de 780 adultes atteints de SEP résidant dans le sud de l’Alberta, au Canada. Résultats: Quatre cent quarante des 673 sujets éligibles, soit un taux de réponse de 65%, ont retourné le questionnaire complété. L’âge moyen des participants était de 48 ans et 75% étaient des femmes. L’inaptitude chez les répondants était de légère à sévère. La majorité des répondants (96%) savaient que le cannabis pouvait avoir une valeur thérapeutique dans la SEP et la plupart (72%) étaient favorables à sa légalisation à des fins médicales. Quarante-trois pour cent avaient essayé le cannabis à un moment ou l’autre de leur vie, dont 16% à des fins médicales. Selon les utilisateurs, les symptômes qui étaient améliorés étaient l’anxiété/la dépression, la spasticité et la douleur chronique. Les raisons fournies pour ne pas avoir essayé le cannabis étaient le fait qu’il s’agit d’une substance illicite, l’inquiétude au sujet des effets secondaires et l’ignorance sur les moyens de s’en procurer. Conclusions: Une amélioration subjective de la symptomatologie a été rapportée par la majorité des patients qui utilisent actuellement le cannabis. Une évaluation plus poussée de cette substance dans ce contexte est justifiée.


Multiple sclerosis (MS) is a recurrent inflammation of the central nervous system white matter leading to myelin destruction and progressive neurological impairment. The prevalence of MS in Alberta has been described as high with an overall crude rate of 217 per 100,000 population. The available treatments for symptom management are of limited effectiveness and for many, have unpleasant side effects. Interest in cannabis as a therapeutic option for people with MS has coincided with the increasing acceptance of a wide variety of herbal and natural remedies. Most such substances lack medical endorsement due to a lack of empirical evidence for their efficacy and safety. The acceptance of cannabis as a therapeutic agent has been further hampered by its status as an illicit substance.
is derived from the resin secreted by the leaves and flowers of the plant. Cannabis contains over 400 compounds among which are nearly 100 cannabionoids. Delta-9-tetrahydrocannabinol (Δ⁹THC) is the most abundant and the most potent psychoactive of these. Marijuana strength, measured by Δ⁹THC content, varies from strain to strain and is also affected by breeding, the conditions under which it is grown, its processing and storage. Expressed as the percent Δ⁹THC, the potency has been found to vary from roughly 4 to 20%.Marijuana can be consumed in a number of ways: it can be smoked in cigarettes or pipes, eaten in foods, and extracted in teas or alcohol-based tinctures. Ingested, marijuana tends to have a slower onset of action, blunted high and longer duration of effect than when smoked.

**EMPIRICAL DATA**

A survey distributed by the Alliance for Cannabis Therapeutics in the US and UK examined the perceived effects of smoked cannabis on MS symptoms (response rate 132/255). More than 70% of the subjects reported that cannabis reduced spasticity, chronic pain of the extremities, acute paroxysmal phenomena, tremor and emotional dysfunction.

Two small clinical investigations have examined the effects of smoked cannabis on people with MS. The first, a case study, concluded that marijuana might have powerful beneficial effects on both spasticity and ataxia warranting further evaluation. A later study of 10 patients found that marijuana impaired objective ratings of posture and balance, although patients felt subjectively improved. Several very small clinical trials have compared the use of oral THC and/or nabilone, a synthetic cannabinoid, to placebo and have yielded varying results. Most participants reported at least subjective benefits and some investigations revealed objective improvements as well. The value of these results are limited by the small sample sizes, diversity in patient groups and dosing schedules, but collectively suggest that cannabis and/or its derivatives relieve symptoms of MS.

**CANADIAN LEGAL CONTEXT**

Under the Controlled Drugs and Substances Act, it is illegal to possess, seek and obtain, produce or traffic in cannabis, its preparations, derivatives or similar synthetic preparations.

Regulation of medicinal marijuana in Canada has been recently revised and the status of recreational cannabis use is under debate. In 2001, the Canadian government amended federal drug laws and the Medical Marihuana Access Regulations came into force. These regulations permit people with certain illnesses to apply for an exemption to use cannabis medicinally. Those obtaining an exemption may obtain marijuana by growing their own, or by designating another person to grow it for them.

**PURPOSE**

Little is known about the extent of cannabis use among this patient group in Canada. This paper reports on a survey conducted in a sample of adults with MS in Alberta, Canada, and describes the prevalence and perceptions of cannabis use in this group prior to the implementation of the Medical Marihuana Access Regulations.

**METHODS**

The data for this study are derived from a larger survey that looked at the use of complementary and alternative medicine by people with MS.

**Sample size determination:** Calculations were based on estimating the proportion of MS patients who used complementary therapies to ±5% with 95% confidence. Based on previous research, we conservatively estimated that complementary and alternative medicine is used by 50% of MS patients. To obtain our desired level of precision, a sample of approximately 390 people was needed. Allowing for a 50% response rate, 780 people were required for the survey.

**Study population.** The Calgary MS Clinic is the only regional source of neurological care and tertiary rehabilitation for patients with MS. At the time of sample selection, the clinic database contained information, including Expanded Disability Status Scale scores (EDSS), on 2600 people. Patients for whom an address was not known, those known to be deceased, and those who had not given blanket consent to be approached for research projects were dropped from the database. Exclusion criteria defined by the researchers were people under 18 years of age and those whose diagnosis was possible or probable MS (vs. clinically definite and lab-supported MS). After these exclusions, a sampling frame of 1335 remained. The database was then stratified by impairment level derived from the EDSS score yielding the distribution shown in Table 1. All people described as very severely impaired were included in the final sample as were the nine people for whom a score was not recorded. The remaining 742 subjects required were systematically and equally drawn from the remaining three impairment levels resulting in a total sample of 780. The distribution of the study sample is also illustrated in Table 1.

**Procedure.** A covering letter, questionnaire and postage-paid return envelope were distributed by mail in June, 2000. To

---

8 SC 1996c 19 as amended 2001 [SOR/2001-227]
enhance the response rate, a postcard reminder was sent out four weeks later.

**Questionnaire.** A self-report questionnaire developed for the purpose of the study was used to collect data. General sociodemographic information (e.g., marital status, age, sex, education) and information on disease characteristics (e.g., onset, diagnosis, pattern, symptom experience, disability, medication use, comorbidities) were collected. Questions regarding cannabis use assessed opinions on use, reasons for use, patterns of use and perceptions of effects. Questions were primarily close-ended although subjects were given the opportunity to provide additional detail in those cases where the response options provided did not contain a choice that described them.

For some questions, more than one response option could be endorsed. Finally, respondents were given the opportunity to provide additional detail in those cases where the question varies slightly. Sociodemographic and disease characteristics are illustrated in Table 2.

### Table 2: Demographic Information and Disease Characteristics

<table>
<thead>
<tr>
<th>Sex</th>
<th>(n, %)</th>
<th>Male</th>
<th>106 (26%)</th>
<th>Female</th>
<th>309 (74%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age — years (SD)</td>
<td>48 (10.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status (n, %)</td>
<td></td>
<td>Married/ common-law</td>
<td>301 (72%)</td>
<td>Never married/separated/divorced/widowed</td>
<td>116 (28%)</td>
</tr>
<tr>
<td>Education (n, %)</td>
<td></td>
<td>Less than high school</td>
<td>40 (10%)</td>
<td>High school or greater</td>
<td>377 (90%)</td>
</tr>
<tr>
<td>Employment status (n, %)</td>
<td></td>
<td>Working full/part-time</td>
<td>128 (31%)</td>
<td>On disability leave</td>
<td>99 (24%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Retired/unemployed</td>
<td>112 (27%)</td>
<td>Student/homemaker</td>
<td>74 (18%)</td>
</tr>
<tr>
<td>Median family income</td>
<td>$50-$59 000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age at diagnosis (SD)</td>
<td>36 (9.4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pattern (n, %)</td>
<td></td>
<td>Relapsing-remitting</td>
<td>178 (43%)</td>
<td>Secondary progressive</td>
<td>97 (24%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Primary progressive</td>
<td>41 (10%)</td>
<td>Progressive-relapsing</td>
<td>16 (4%)</td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td>Mild (fully functional, able to work)</td>
<td>36 (9%)</td>
<td>Moderate (limited independent walking ability)</td>
<td>197 (47%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe (require walking aids/wheelchairs)</td>
<td>136 (37%)</td>
<td>Very severe (no functional use of limbs, confined to bed)</td>
<td>28 (7%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Had a comorbidity</td>
<td>138 (34%)</td>
<td>Used conventional medication for MS symptoms</td>
<td>253 (60%)</td>
</tr>
</tbody>
</table>

Sample: Of the 780 surveys mailed, 107 were undeliverable (e.g., subjects had moved, were deceased). Four hundred and twenty people provided responses to the cannabis section (response rate 420/673=62%), although the number responding to each question varies slightly. Sociodemographic and disease characteristics are illustrated in Table 2.

Cannabis use: Most respondents believed that it should be legally permissible for people to use cannabis medicinally (72%). Slightly less than one quarter (23%) did not have an opinion, while the minority opposed (5%). The vast majority stated they were aware cannabis was potentially useful in relieving symptoms associated with MS (96%). Less than half of the respondents had tried cannabis at some point in their lives (43%) and this was not necessarily for medicinal purposes.

The most common reasons given for not using cannabis by those who were aware it might be therapeutically useful but who had not tried it (n=222) were: the fact it is an illegal substance (64%), concern about side effects (34%), lack of knowledge on how to obtain it (34%) and a disbelief that it would help symptoms (24%).

Considering those who stated they had tried cannabis (n=176), 35% (n=67) reported this had been to manage the symptoms of their MS. Among this latter group, 43 (64%) had used it within the past three months (current users) and 24 (36%) had discontinued use. The most common reasons endorsed for discontinuing use were cost (n=11), dislike of side effects (n=10), legal concerns (n=8) and lack of effectiveness (n=7).

Details of the experiences of current cannabis users are given in Table 3.

Multiple regression showed that cannabis users were not distinguished by marital status, education, or use of conventional medication. However, age, sex, disability level and income were predictive of cannabis use. Specifically, older people (OR=0.16: 95% CI=0.057-0.45) and those with higher incomes (OR=0.19: 95% CI=0.070-0.52) were less likely to use cannabis. Sex and disability interacted to predict cannabis use. Among those with less disability, women were significantly less likely to use cannabis (OR=0.17: 95% CI=0.055-0.52).

Written comments were made by 35 respondents. Most comments contained descriptions of the symptom relief experienced with cannabis use. A couple of people contrasted the effects of cannabis with those of conventional medication. For example, one person described the following: "Pharmaceutical treatments that I’ve experienced have been extremely intoxicating (extreme anxiety, sleeplessness) among other symptoms that have been severely negative to my mental well-being as well as physical well-being (stomach trouble, breathing shortness). With cannabis, I feel more in control of my mind and body. If the effect is too strong, it is easily remedied by a cookie associated with cannabis use (alpha =0.05). Content analysis was used to describe the textual comments.

The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary.

**RESULTS**

**Sample:**

Of the 780 surveys mailed, 107 were undeliverable (e.g., subjects had moved, were deceased). Four hundred and twenty people provided responses to the cannabis section (response rate 420/673=62%), although the number responding to each question varies slightly. Sociodemographic and disease characteristics are illustrated in Table 2.

Cannabis use:

Most respondents believed that it should be legally permissible for people to use cannabis medicinally (72%). Slightly less than one quarter (23%) did not have an opinion, while the minority opposed (5%). The vast majority stated they were aware cannabis was potentially useful in relieving symptoms associated with MS (96%). Less than half of the respondents had tried cannabis at some point in their lives (43%) and this was not necessarily for medicinal purposes.

The most common reasons given for not using cannabis by those who were aware it might be therapeutically useful but who had not tried it (n=222) were: the fact it is an illegal substance (64%), concern about side effects (34%), lack of knowledge on how to obtain it (34%) and a disbelief that it would help symptoms (24%).

Considering those who stated they had tried cannabis (n=176), 35% (n=67) reported this had been to manage the symptoms of their MS. Among this latter group, 43 (64%) had used it within the past three months (current users) and 24 (36%) had discontinued use. The most common reasons endorsed for discontinuing use were cost (n=11), dislike of side effects (n=10), legal concerns (n=8) and lack of effectiveness (n=7).

Details of the experiences of current cannabis users are given in Table 3.

Multiple regression showed that cannabis users were not distinguished by marital status, education, or use of conventional medication. However, age, sex, disability level and income were predictive of cannabis use. Specifically, older people (OR=0.16: 95% CI=0.057-0.45) and those with higher incomes (OR=0.19: 95% CI=0.070-0.52) were less likely to use cannabis. Sex and disability interacted to predict cannabis use. Among those with less disability, women were significantly less likely to use cannabis (OR=0.17: 95% CI=0.055-0.52).

Written comments were made by 35 respondents. Most comments contained descriptions of the symptom relief experienced with cannabis use. A couple of people contrasted the effects of cannabis with those of conventional medication. For example, one person described the following: "Pharmaceutical treatments that I’ve experienced have been extremely intoxicating (extreme anxiety, sleeplessness) among other symptoms that have been severely negative to my mental well-being as well as physical well-being (stomach trouble, breathing shortness). With cannabis, I feel more in control of my mind and body. If the effect is too strong, it is easily remedied by a cookie..."
A number of comments pertained to the perceived need for medicinal use to be legalized. It was suggested that benefits of legalization would be a decreased crime rate, a drop in prices and greater control of the substance. A few respondents indicated that legalizing cannabis for medicinal use might just be a means of legitimating its recreational use.

A couple of people described the personal, moral dilemma they experienced when deciding whether or not to use cannabis medicinally. As written by one person: “I am not sure of the use of cannabis whether good or bad. There are days in my life when I would use it. Thankfully, these are few and far between. There was a time when I seriously considered using cannabis and purchased some. I still have it although have never used it and feel now I have it, I don’t need or want to use it. There is a problem for me morally, I suppose or responsibly, I’m not sure but I can’t use it. Knowing I now have it is enough.”

**Discussion**

A substantial proportion of those responding to the questionnaire stated they had used cannabis at some point in their lives (43%). This is considerably higher than the 23% of Canadians reporting a similar pattern of use in a 1994 survey. This could be due to an actual increase in the proportion of people using cannabis generally, a trend that has been previously described, to people more readily disclosing use, or to people with MS being more likely to have used cannabis.

The majority of respondents stated they were aware that cannabis could be used medicinally for the treatment of MS and this is not surprising in light of the attention medicinal marijuana has received in the media recently. Most people (72%) were of the opinion that marijuana should be legalized for medical purposes and this is consistent with previous surveys indicating the majority of Canadians (78%) supported the federal government’s plan of legalizing medical marijuana. This is in contrast to the smaller proportion of Canadians (27%) who believe that cannabis should be legalized for recreational use.

Despite knowing that cannabis might help relieve their symptoms, most people had not tried it because of its illicit status. The Medical Marihuana Access Regulations have been implemented to facilitate access for certain patient groups and it is probable that the proportion of people with MS who use marijuana will increase. For some people, however, the legal sanctions were not a deterrent as evidenced by the proportion of individuals who used cannabis prior to the introduction of these new regulations. In fact, for many, medicinal use evolved from previous recreational use. It is, therefore, likely that some people will use cannabis without applying for, or without being granted, an exemption.

Smoking was the primary method of cannabis consumption reported by users. Certain advantages have been ascribed to smoked, versus orally ingested cannabis or THC. THC is absorbed more rapidly and reliably from the lungs, allowing patients a greater degree of control in titrating their own doses. The presence of other constituents in cannabis smoke may modify the subjective experience of THC, reducing anxiety and other negative effects. However, as with tobacco, smoking cannabis may give rise to a host of respiratory problems ranging from irritation of the respiratory tract to malignancies. The development and evaluation of alternative delivery systems, such

---

**Table 3: The experiences of current cannabis users**

<table>
<thead>
<tr>
<th>Decision to use cannabis prompted by:</th>
<th>Frequency of cannabis use:</th>
<th>Median duration of use</th>
<th>Symptoms perceived to be relieved:</th>
<th>Overall effect of cannabis on MS symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Article/news story about cannabis</td>
<td>Less than 1/day</td>
<td>4 (10%)</td>
<td>Anxiety/depression</td>
<td>Feel much better</td>
</tr>
<tr>
<td>Suggestion from someone else with MS</td>
<td>1/day</td>
<td>6 (16%)</td>
<td>Spasticity</td>
<td>22 (54%)</td>
</tr>
<tr>
<td>Suggestion from family member/friend</td>
<td>2-3 times/day</td>
<td>7 (18%)</td>
<td>Chronic pain</td>
<td>Feel a little better</td>
</tr>
<tr>
<td>Used recreationally: found out “by accident”</td>
<td>4-6 times/day</td>
<td>1 (3%)</td>
<td>Fatigue</td>
<td>16 (39%)</td>
</tr>
<tr>
<td></td>
<td>varies considerably/use as needed</td>
<td>20 (53%)</td>
<td>Walking/balance problems</td>
<td>No change</td>
</tr>
<tr>
<td></td>
<td>Grown on own</td>
<td>1 (3%)</td>
<td>Tremor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obtained elsewhere</td>
<td>27 (67%)</td>
<td>Visual problems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prefer not to answer</td>
<td>12 (30%)</td>
<td>Weight loss</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frequency of cannabis use:</td>
<td></td>
<td>Sexual problems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Asiab 1/100</td>
<td>4 (10%)</td>
<td>Bowel problems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1/day</td>
<td>6 (16%)</td>
<td>Bladder problems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2-3 times/day</td>
<td>7 (18%)</td>
<td>Memory loss</td>
<td></td>
</tr>
</tbody>
</table>
|                                      | 4-6 times/day             | 1 (3%)                | Other relief reported (side effects of conventional medication: headache, rash, stomach upset) | 2 (5%)
|                                      | varies considerably/use as needed | 20 (53%)              | 4 (9%)                           |                                         |
|                                      | Grown on own              | 1 (3%)                | 2 (5%)                           |                                         |
|                                      | Method by which cannabis was consumed: |                      | 4 (9%)                           |                                         |
|                                      | Smoked                    | 38 (88%)              | Other relief reported (side effects of conventional medication: headache, rash, stomach upset) |                                         |
|                                      | as cannabis               | 14 (33%)              | 6 (14%)                          |                                         |
|                                      | as hash                   | 6 (14%)               | 5 (12%)                          |                                         |
|                                      | Eaten (baked into brownies, cookies etc) | 2 (5%)              | 4 (9%)                           |                                         |
|                                      | Drunk (as a tea)          | 2 (5%)                | 2 (5%)                           |                                         |
|                                      | Method by which cannabis was obtained: |                      | 2 (5%)                           |                                         |
|                                      | Grown on own              | 1 (3%)                | 2 (5%)                           |                                         |
|                                      | Obtained elsewhere        | 27 (67%)              | 5 (12%)                          |                                         |
|                                      | Prefer not to answer      | 12 (30%)              | 1 (3%)                           |                                         |
|                                      | Median duration of use     |                      | 4 years (IQR 2.9)                |                                         |

**instead of hours of discomfort and anxiety from pharmaceutical treatments that take a long time to dissipate or level out. Cannabis is more effective and the dosage is easily controlled.”**

A few other people spoke about having tried cannabis in the past, but not liking the side effects. One person wrote “The marijuana seemed to help a fair amount with walking and stiffness. However the side effect of being ‘high’ was unacceptable (too much of a high).” Another person stated “I have nothing against pot or hash, I still wish I could. I have to take care of myself and being stoned and forgetting stuff can’t be part of my life.”
as nasal inhalers or skin patches, may be warranted if cannabis is found to be therapeutically effective.

Cost was the main reason cited for discontinuing use among those who had tried it for their MS but stopped. Although the new regulations permit people to possess cannabis, a legal supply still does not exist. While some people who have been granted exemptions grow their own, or have appointed a designate who has been granted an exemption to grow for them, these options are not always feasible given the equipment and expertise necessary to grow a sufficient, and healthy supply. Consequently, many still purchase the substance from others. Such transactions may be costly and may put purchasers at risk of buying a product of questionable quality. If cannabis is recognized as a medicinal product by the government, a legal supply should be accessible.

Dislike of side effects was the second most common reason endorsed for no longer using cannabis. Being able to enjoy cannabis, or use it effectively, has been described as a learned behavior. Indeed, in a previous survey of oncologists, it was observed that patients who had side effects using cannabis as an anti-emetic tended to be inexperienced with it. It has been recommended that new consumers be informed of the potential side effects prior to initial use in order to minimize anxiety when they are experienced. Similarly, it would seem important to take into consideration cannabis experience in future research.

Descriptions of the therapeutic benefits experienced with cannabis were consistent with those reported in earlier studies. In particular, subjects perceived reductions in spasticity and pain, and improved psychological well-being. These data are subjective and must be interpreted cautiously. They do suggest that further research is justified in evaluating the therapeutic properties of cannabis in people with MS.

Although lacking a firm evidence base, cannabis is being used as a medicine by people with MS. It will gain legitimacy within the medical arsenal with the establishment of its safety and efficacy, consistent with the standards applied to the development of other new drugs.

ACKNOWLEDGEMENTS

We thank all respondents for their time and effort. Funding for this study was provided by the Multiple Sclerosis Society of Canada.

REFERENCES