Use and Self-Reported Benefit of Complementary and Alternative Medicine Among Multiple Sclerosis Patients

Vijayshree Yadav, MD, Lynne Shinto, ND, Cynthia Morris, PhD, Angela Senders, ND, Sara Baldauf-Wagner, BS, Dennis Bourdette, MD

We conducted a survey to study the prevalence and types of complementary and alternative medicine (CAM) therapies used by multiple sclerosis (MS) patients in Oregon and southern Washington. We mailed questionnaires to 5316 people using the mailing list of the Oregon Chapter of the National Multiple Sclerosis Society (NMSS). The survey enquired about demographic and clinical characteristics, use of various CAM and conventional therapies for MS by the respondents, and the respondents’ self-perceived benefit ratings for the various therapies. We received 2026 responses (38%). Eighty-four percent of the respondents reported using one or more CAM therapies at some time after diagnosis of MS (CAM users), the most common being diet (59%), nutritional supplements (46%), herbal treatments (36%), and mind-body therapies (32%). CAM therapies rated as very beneficial included yoga; meditation; Swank, vegetarian and low-fat/low-cholesterol diets; and vitamin B12. Respondents also used conventional exercise (86%) and disease-modifying therapies (77%). Our survey confirms the common use of various CAM therapies by MS patients. CAM therapies such as low-fat diets, essential fatty acid supplements, yoga, and meditation appear to be frequently used and considered very beneficial by a significant number of MS patients and may warrant further exploration. Int J MS Care. 2006;8:5–10.

Multiple sclerosis (MS) is a chronic and disabling neurological condition that affects about 400,000 Americans. Despite significant advancement in conventional treatment options, many MS patients continue to experience MS-related symptoms that negatively affect their quality of life. Several surveys have demonstrated that MS patients often explore complementary and alternative medicine (CAM) treatment options.1–7 Most of these surveys analyzed the various CAM therapies and the characteristics of patients using CAM therapies, but only a few have assessed the self-reported benefit for individual CAM therapies.1,2,5,8

The purpose of this survey was to explore the prevalence of use of different CAM therapies among people with MS in Oregon and southern Washington and assess the self-reported benefit that these patients attributed to the CAM therapies. We also explored the differential benefit of conventional versus CAM therapies for MS as assessed by patients.

Methods

Data Collection

We mailed a survey in September 2001 to 5316 people through a single mailing to individuals with MS who were registered members of the Oregon Chapter of the National MS Society (NMSS), which includes residents of Oregon and of Clark County in southwest Washington. Data were collected for 6 months, between September 2001 and March 2002, after a single survey mailing.

Questionnaire Development

The eight-page survey was developed by two neurologists, an epidemiologist, and a naturopathic physician and was

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approved by the institutional review board at Oregon Health and Science University (OHSU). The survey listed CAM and conventional therapies used by MS patients and asked the respondents about current and past use of individual therapies. Respondents were asked to rate each therapy according to their self-perceived benefit on a 4-point scale: 1 = very beneficial, 2 = somewhat beneficial, 3 = unsure of benefit, 4 = not beneficial. Respondents were asked to rate their disability according to six categories: no or minimal disability, mild disability, moderate disability, need walking support, need walker/hand crutch, and unable to walk. This self-assessment was compared to a neurologist-determined Expanded Disability Status Scale (EDSS)\(^9\) score in a pilot study of 42 patients at the OHSU MS clinic. EDSS correlated well with the results of the self-reported disability score on these patients \((r = 0.85)\.10\)

**Definitions.** Table 1 lists various CAM and conventional therapies referred to in the survey. For the purpose of analysis, we categorized interferon beta and glatiramer acetate together as disease-modifying therapies (DMTs) of MS. We did not collect information about use of prescription medications taken for symptomatic therapy (eg, oxybutynin for symptoms of a neurogenic bladder).

We define CAM users as respondents who reported having ever (current or past) used any of the above-mentioned CAM therapies. Current CAM users refers to respondents who were taking one or more of the CAM therapies at the time of the survey. CAM nonusers indicates respondents who have never used any of the CAM therapies referred to in the survey.

**Data management and analysis**

Statistical analysis was performed with SPSS version 11.5. Descriptive statistics was used to summarize demographic information and determine frequencies. To determine the frequency of use of each therapy, we used the total number of respondents \((N = 1913)\) for the denominator even if the respondent did not answer the question. Our assumption was that respondents who did not answer a particular question in the survey most likely never used that therapy. \(\chi^2\)-Analysis was used to compare conventional MS treatments with CAM therapies.

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**Table 1. Complementary and alternative medicine (CAM) and conventional therapy for multiple sclerosis**

<table>
<thead>
<tr>
<th>CAM therapy</th>
<th>Conventional therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nutritional supplements</strong></td>
<td><strong>Herbs</strong></td>
</tr>
<tr>
<td>Cod liver oil/fish oil</td>
<td>Ayurvedic herbs</td>
</tr>
<tr>
<td>Evening primrose oil</td>
<td>Bioflavonoids</td>
</tr>
<tr>
<td>Essential fatty acids (eg, flax)</td>
<td>Chinese herbs</td>
</tr>
<tr>
<td>Soy</td>
<td>Gingko</td>
</tr>
<tr>
<td>Melatonin</td>
<td>Ginseng</td>
</tr>
<tr>
<td>Coenzyme Q10</td>
<td>Kava</td>
</tr>
<tr>
<td>Dehydroepiandrosterone</td>
<td>Licorice</td>
</tr>
<tr>
<td>Lipoic acid</td>
<td>St. John’s wort</td>
</tr>
<tr>
<td>Carnitine</td>
<td>Valerian</td>
</tr>
<tr>
<td>5-Hydroxytryptophan</td>
<td>Mind-body</td>
</tr>
<tr>
<td>Beta-carotene</td>
<td>Meditation</td>
</tr>
<tr>
<td>Magnesium</td>
<td>Guided imagery</td>
</tr>
<tr>
<td>Vitamin B complex; vitamins B₁₂, C, E</td>
<td>Biofeedback</td>
</tr>
<tr>
<td>Selenium</td>
<td>Hypnosis</td>
</tr>
<tr>
<td>Zinc</td>
<td>Yoga</td>
</tr>
</tbody>
</table>

**Miscellaneous**
- Dental amalgam removal
- Plasma infusions
- Procarin
- Heavy metal detoxication
- Bee stings
- Hyperbaric oxygen chamber treatment

**Diet**
- Low fat
- Swank
- High protein
- Vegetarian
- Food allergy
- Wheat free
- Macrobiotic

**Exercise**
- Stretching
- Walking
- Swimming
- Aerobics

**Nutritional supplements**
- Cod liver oil/fish oil
- Evening primrose oil
- Essential fatty acids (eg, flax)
- Soy
- Melatonin
- Coenzyme Q₁₀
- Dehydroepiandrosterone
- Lipoic acid
- Carnitine
- 5-Hydroxytryptophan
- Beta-carotene
- Magnesium
- Vitamin B complex; vitamins B₁₂, C, E
- Selenium
- Zinc

**Herbs**
- Ayurvedic herbs
- Bioflavonoids
- Chinese herbs
- Gingko
- Ginseng
- Kava
- Licorice
- St. John’s wort
- Valerian
- Meditation
- Guided imagery
- Biofeedback
- Hypnosis
- Yoga

**Approved drug**
- Corticosteroids
- Interferon beta-1a and -1b
- Glatiramer acetate
- Mitoxantrone
- Other immunosuppressants (eg, azathioprine, methotrexate, cyclophosphamide)
- Intravenous immunoglobulin
- Plasmapheresis

**Multivitamins (as individual supplement, eg, Centrum)**

**Exercise**
- Stretching
- Walking
- Swimming
- Aerobics

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- Interferon beta-1a and -1b
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Results

Respondents

We mailed 5316 surveys and received 2026 surveys back, a response rate of 38% (Figure 1). One hundred thirteen surveys were excluded from analysis because of a wrong address; the addressee was deceased or the survey was returned more than 6 months after mailing (n = 56); or the respondent denied, was not sure of, or did not answer the question about MS diagnosis (n = 57).

Demographic and clinical characteristics of all the respondents that were included in the analysis (N = 1913) are presented in Table 2. Not all the respondents provided data for every variable. Mean age of the respondents was 51 years, with about two-thirds of the respondents between 40 and 59 years old. Analysis of the demographic and clinical characteristic differences between CAM nonusers and users revealed CAM users to be significantly older and have longer duration of MS, more severe disability from MS, and a lower frequency of use of DMTs.

The most frequently used CAM therapies included diet (59%), nutritional supplements (46%), herbal treatments (36%), and mind-body therapies (32%). Figure 2 lists all CAM therapies that were frequently used and the 15 CAM therapies with the highest percentage of users rating the treatment as very beneficial. Among the top-rated therapies, 2 involved meditation and 12 were diets or dietary supplements.

Table 2. Demographic and clinical characteristics of respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>All respondents</th>
<th>CAM users (n = 1668)</th>
<th>CAM nonusers (n = 245)</th>
<th>CAM users vs nonusers (P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y (mean ± SD)</td>
<td>51.6 ± 11.7</td>
<td>51.8 ± 11.4</td>
<td>49.9 ± 13.0</td>
<td>.027</td>
</tr>
<tr>
<td>Sex, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>77</td>
<td>78</td>
<td>73</td>
<td>.076</td>
</tr>
<tr>
<td>Male</td>
<td>23</td>
<td>22</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Education, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some/completed high school/GED</td>
<td>23</td>
<td>22</td>
<td>30</td>
<td>.023</td>
</tr>
<tr>
<td>Some college</td>
<td>40</td>
<td>41</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>21</td>
<td>20</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Some graduate school/master’s degree or higher</td>
<td>17</td>
<td>17</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Race, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>96</td>
<td>96</td>
<td>94</td>
<td>.097</td>
</tr>
<tr>
<td>Nonwhite</td>
<td>4</td>
<td>4</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>MS duration, y (mean ± SD)</td>
<td>19.5 ± 12.3</td>
<td>20.0 ± 12.3</td>
<td>15.7 ± 11.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>MS type, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapsing remitting</td>
<td>49</td>
<td>48</td>
<td>53</td>
<td>.502</td>
</tr>
<tr>
<td>Secondary progressive</td>
<td>16</td>
<td>16</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Primary progressive</td>
<td>11</td>
<td>10</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Disease severity, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/mild</td>
<td>30</td>
<td>29</td>
<td>38</td>
<td>.008</td>
</tr>
<tr>
<td>Moderate</td>
<td>57</td>
<td>58</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>13</td>
<td>13</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>ABC use, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current use</td>
<td>47</td>
<td>46</td>
<td>58</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Ever used</td>
<td>58</td>
<td>62</td>
<td>75</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>CAM use, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current use</td>
<td>68</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever used</td>
<td>84</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

ABC = interferon beta-1a, interferon beta-1b, and glatiramer acetate; CAM = complementary and alternative medicine; GED = general equivalency diploma; MS = multiple sclerosis; SD = standard deviation
A group of miscellaneous CAM therapies that are among the more controversial for MS were included in the survey. Fourteen percent of all CAM users reported ever using these therapies, but use dropped to 3% among the current users. The individual therapies used among all respondents were as follows: dental amalgam removal, 7.3%; plasma infusion, 4.3%; Procarin, 3.1%; heavy metal detoxication, 2.6%; bee sting therapy, 1.7%; and hyperbaric oxygen, 1.1%.

Fifty-eight percent of all respondents had used at least one DMT at some time since diagnosis of MS, and 47% were currently on DMT. The following DMTs were rated very beneficial by users: interferon beta-1a (37%), interferon beta-1b (26%), and glatiramer acetate (25%).

Eighty-six percent of respondents had used one or more conventional exercise therapies, and 51% were actively using one or more of them at the time of the survey. Stretching (68%) and walking (65%) were more frequently used than water aerobics (24%) and swimming (37%). The most frequently used therapies were not necessarily rated the most beneficial by these respondents. Very beneficial ratings were given to water aerobics (52%), swimming (48%), stretching (47%), and walking (44%).

Sixty-five percent of all respondents had used multivitamins. Twenty-seven percent reported their use to be very beneficial.

**CAM Versus Conventional Therapies**

To explore whether CAM users perceived the benefit of DMT use differently from CAM nonusers, we analyzed the very beneficial responses among those who had ever used a DMT. We found no significant difference in self-perceived benefit between the CAM users (38.6%) and nonusers (35.9%, \( P = .523 \)).

We also compared the ratings of CAM approaches such as yoga with conventional exercise modalities such as water aerobics, swimming, stretching, and walking. Significantly more respondents rated yoga (49%) very beneficial compared with walking (40%, \( P = .001 \)). The perceived benefit of yoga was similar to water aerobics (49%, \( P = .96 \)), swimming (45%, \( P = .17 \)), and stretching (44%, \( P = .06 \)). In a similar analysis, significantly more respondents perceived multivitamins (23.6%) to be very beneficial compared with vitamin A (17%, \( P = .01 \)) but not so with vitamins B₁₂ (25.9%, \( P = .28 \)), C (24.9%, \( P = .53 \)), B complex (22.3%, \( P = .54 \)), or E (21.5%, \( P = .28 \)).

**Other Factors**

We explored the patients’ choice of practitioners with whom they discussed CAM therapies. Few respondents (6.7%) reported discussing CAM with their neurologist, whereas 32% discussed it with their nonneurologist physician. Significantly more CAM users (91%) than nonusers (82%) reported that they preferred to have some control over health care decisions (\( P < .001 \)). A significantly higher percentage of CAM users (92%) than nonusers (86%) held spiritual beliefs (\( P = .002 \)).
Discussion

Our survey confirmed the findings reported previously that CAM use is common among people with MS.1–7 Fifty to 75% of respondents in these surveys had tried various CAM therapies.1–5,7 We found that 84% of respondents reported having used one or more CAM therapies for their MS. Given the relatively low (38%) response rate to the questionnaire, this estimate cannot reliably predict the prevalence of CAM use among the sampled population. However, if we assume that all nonrespondents were CAM nonusers, the minimum prevalence of CAM use among people with MS in Oregon and southern Washington is 30%.

The most frequently used CAM therapies in our survey were diet, nutritional supplements, herbs, and mind-body therapies. These results are similar to trends found in published surveys across the United States.2–5 Note that highly publicized and controversial therapies, such as bee sting therapy, dental amalgam replacement, and Procarin, were not widely used and were poorly rated in efficacy. The CAM therapies most likely to be rated very beneficial by CAM users were yoga, meditation, various low-fat diets, and dietary supplements. These findings are similar to previous surveys of CAM use among people with MS that assessed self-perceived benefit.2,3,5

The CAM therapies with the highest percentage of users reporting them to be very beneficial were yoga and meditation. Yoga involves both physical exercise and meditation. Several studies have demonstrated that conventional exercise programs are beneficial for MS patients.11–14 and the programs are now an essential part of the comprehensive multidisciplinary approach for MS care. Recently, yoga was shown to improve fatigue in MS.15 Meditation is effective in reducing symptoms of stress, anxiety, and depression.16,17 Studies of chronic illnesses such as cancer, psoriasis, fibromyalgia, and rheumatic diseases show that exercise and meditation may reduce stress.18–22 Psychological stress has long been reported to worsen symptoms in MS patients,9 but only recently have scientific studies suggested that stress can have an adverse effect on the disease.23–25 Therefore, exercise and meditation may be of benefit to MS patients.

Other CAM therapies that were rated very beneficial by a high percentage of users are various low-fat diets and essential fatty acid supplementation, for which there may be some scientific rationale. Numerous studies over the past 50 years have suggested some benefit from low-fat diets and essential fatty acid supplementation in MS.26–31 More recently, diets enriched with essential fatty acids and supplementation with ω-3 fatty acids have been shown to have anti-inflammatory effects.32,33 A recent trial by Weinstock-Guttman and colleagues34 suggested that low-fat-diet intervention with ω-3 fatty acid supplementation positively

affected quality of life in relapsing-remitting MS patients. Larger well-designed studies are needed to support the scientific rationale for these interventions.

A unique purpose of this survey was to explore whether any perceptual differences exist as to the benefit of CAM and conventional therapies between CAM users and nonusers. To our knowledge, no comparisons of self-reported benefit in MS have been made until now. We found that DMTs were perceived to be equally beneficial by CAM users and nonusers, although CAM users were somewhat less likely to use DMTs than the nonusers. Although we did not explore reasons why respondents used conventional or CAM therapies, we believe that widespread use of conventional therapies such as stretching or walking is related to their being low impact and of easy access to MS patients.

Our survey had some limitations. First, as expected for a “single drop” survey with no follow-up letters or telephone calls, we had a low response rate. Our results may therefore not be representative of the surveyed population and may have a selection bias, with CAM users preferentially completing the questionnaire. However, the questionnaire enabled us to establish a minimum prevalence of CAM use among the surveyed population of about 30%. Second, specific details and reasons for use as well as for subjective benefit for the individual therapy were not explored in this survey. Future surveys addressing this important aspect of CAM use among our MS population may be worthwhile. Third, this was a regional survey, so the results may not be reflective of trends in other regions of the United States. Finally, biases are inherent in the self-perceived benefit rating.

Despite the limitations, the survey was an important step toward understanding the needs of our patients. It highlighted some of the commonly used CAM therapies in our population that respondents perceived to be beneficial. We found our observation of very beneficial therapy such as yoga, meditation, and the Swank diet among respondents to be interesting in that the emerging scientific data may support patients’ subjective benefit perception to have a valid physiological basis. Many clinicians may attribute these perceived benefits to a placebo effect. We argue that patients may be getting a placebo effect, but not all the benefit could be accounted for by this phenomenon alone.

The survey also revealed that only 6.7% of MS patients discussed the use of CAM with their neurologists. This finding, in addition to the fact that DMT use between CAM users and nonusers was similar, suggests that patients try to seek the most and best of therapies available for MS regardless of whether the conventional medicine specialists recommend them. To better serve our MS patients, health care providers should have some knowledge about the use of CAM therapies. Highly publicized therapies such as replacement of amal-

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References


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