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Heart & Mind Medicine: Survey results on conventional and complementary medicine in multiple sclerosis

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CERTIFICATION OF APPROVAL

This is to certify that the MPH thesis of

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Abstract

Background: Multiple Sclerosis (MS) is the most common disabling neurologic disease of young and middle age adults in North America and Europe. Although conventional treatments for MS have been shown to be partially effective in decreasing disease activity, many patients still become disabled and have symptoms that decrease quality of life. Complementary and alternative medicine (CAM) use is high among people with multiple sclerosis (MS) and many MS patients that use CAM report benefit from these therapies. Given the prevalence of CAM use in MS, it is important to better understand the motivating factors for its use and its effect on quality of life.

Specific Aims: The first aim of this thesis include identifying differences in patient ratings, from respondents that utilized both, between conventional medicine and CAM on the following; benefit from therapies; benefit from providers; satisfaction from providers; ratings of provider's characteristics related to emotional support; visit time. The second aim of this thesis include identifying the following factors for their association with CAM use, demographic; MS-disease factors; physical well-being (PCS) and mental well-being (MCS).

Methods: A cross-sectional survey and SF-12 was used to collect data on demographics, CAM use, conventional medicine use, and Health Related Quality of Life (HRQL) from people who were members of the National MS Society, Oregon Chapter. Data was collected for six months after a single survey mailing.

Results: The survey response rate was 38.1% (2026/5316). The benefit rating of both conventional therapies and providers was significantly higher than for CAM therapies and providers ($p< 0.001$, $p< 0.001$, respectively). When stratifying satisfaction rating by MS disease severity patients with moderate disease severity gave their CAM providers a higher satisfaction rating than their neurologists ($p=0.014$), while patients with severe disease severity gave their neurologists a higher satisfaction than their CAM providers ($p=0.032$). CAM providers were rated significantly higher than neurologists and MS non-neurologists on the following provider characteristics: listening skills ($p<0.001$), care and concern ($p<0.001$), and patient empowerment ($p<0.001$). Multiple regression analysis revealed that female gender, high education level, longer MS duration, lower physical well-being (PCS) and not using DMT use were independent factors associated with CAM use.

Discussion: Although MS patients report significant benefit from conventional therapies and providers, they may seek CAM providers for emotional support. Longitudinal studies need to be implemented so that we can establish if HRQL is predictive for CAM use in MS and to better understand the impact of CAM use on HRQL. The study's results suggest that people with MS who use both CAM and conventional medicine have chosen to integrate the 'best' of both types of medicine to attain a more holistic healthcare.

Introduction

Complementary and Alternative Medicine (CAM) Use in the U.S.

The National Center for Complementary and Alternative Medicine (NCCAM) defines CAM as "...a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine". "Complementary medicine is used together with conventional medicine and alternative medicine is used in place of conventional medicine" [1].

CAM use in the general public is widespread with an estimated 15 million adults taking herbal remedies or high-dose vitamins in conjunction with their prescriptive medications [2]. It is estimated that over $27 billion is spent on out of pocket costs for CAM therapies [2] and in 1997, Americans made 649 million visits to alternative providers which amounted to 243 million more visits than made to their MD primary care providers [3]. There have been three studies that have used either large national databases or conducted surveys on CAM use from a random sample of the U.S. population to identify characteristics that predict CAM use in the general public. A summary of the findings from these studies identify the following characteristics as predictors of CAM use, female gender, high education, chronic pain or a chronic condition, poor reported health, and a holistic orientation to health [4-6].

Multiple Sclerosis

Multiple sclerosis is the most common disabling neurologic disease of young and middle aged adults in North America and Europe [7]. It is a disease of

the central nervous system (CNS) that affects over 350,000 Americans with an estimated prevalence of 1/750[8]. In about 85% of cases, MS starts with a relapsing remitting course and about 50% of patients with relapsing remitting MS will enter a progressive phase of the disease 5-15 years after onset [9]. Steady worsening characterizes the progressive phase of the illness, called secondary progressive MS. Patients with secondary progressive MS may or may not continue to have relapses. While MS is rarely fatal, it is often disabling with about 1/3 of patients losing the ability to walk 15-20 years after onset.

Treatments for MS typically are divided into disease modifying therapies, which seek to alter the course of the illness, and therapies designed to control particular symptoms. Current disease modifying therapies include corticosteroids to treat relapses or attacks of MS and human recombinant interferon-beta and glatiramer acetate, which have been shown to be partially effective in decreasing disease activity in relapsing MS [10, 11]. There are a number of therapies designed to help alleviate symptoms, such as oxybutinin to control urinary urgency, amantadine to improve fatigue and baclofen to reduce spasticity. Conventional therapies for MS typically entail using one of the disease modifying medications coupled with one or more symptomatic therapies. Despite the availabilities of these conventional treatment modalities, many patients still become disabled from MS and very often have symptoms that decrease their quality of life. MS disease modifying therapies (DMTs) are also costly at an estimated $15,000-$20,000 per year and as MS is a long-term, chronic condition, costs for DMTs over the a patient's lifetime is not insignificant.

CAM use and Health Related Quality of Life in MS

The prevalence of CAM use by MS patients in the U.S. is reported at 33-65% which is similar to CAM use reported in the general population [6, 12, 13]. The majority of people with MS that use CAM report using it as an adjunct to conventional therapies rather than as an alternative to their conventional treatments [14-16] and many report benefit from CAM therapies [14, 17].

Patient characteristics that are predictive of CAM use in MS are similar to those reported in the general population and include, female gender, high education, poor reported health [14-17]. Although prevalence and predictors of CAM use have been reported in people with MS, there are no reports on the association of CAM use and health related quality of life (HRQL) in MS. Because perceived well-being is significantly decreased in MS, more attention is now being focused on factors that impact HRQL in MS. Mitchell, et. al., reviewed over 90 published studies evaluating HRQL in MS and found that patients with MS have a lowered HRQL compared to the general public and compared to patients with other chronic disease [18]. In MS, both psychological and physical components of well-being are lowered and lowered scores on the SF-36 are predictive of disease-specific decline [19, 20]. To date, more than twenty MS-specific HRQL instruments have been used and there is no consensus on which measure is best designed to measure HRQL in MS. The disease-specific measures can more precisely quantify how MS-symptoms impact well-being but are often cumbersome and may not be useful when trying to compare HRQL in MS to other populations. The SF-36, which is a well-validated, generic HRQL

measure, has been used in many of the large MS-disease modifying treatment trials because it is easy to use and the outcomes can be compared to other populations, although it also has limitations for use in MS as significant floor and ceiling effects have been found [21] . There is general agreement among clinicians and researchers that HRQL is an important outcome measure in MS as it is correlated with disease status and it is a multidimensional indicator of well-being that takes into account the impact of physical, psychosocial, and emotional factors on health [18].

What people are seeking from CAM and how CAM may improve the current medical system

Although very little is known about the what motivates people to use CAM it is clear that many people seek out CAM and willing to pay out of pocket for both CAM therapies and providers.

In 2001, the Institute of Medicine (IOM) published a report addressing the abysmal state of the current health care system and titled this report "Crossing the Quality Chasm: A New Health System for the 21st Century". The IOM report states "As medical science and technology have advanced at a rapid pace, however, the health care delivery system has floundered in its ability to provide consistently high-quality care to all Americans" [22]. One of the six aims the IOM's committee recommended for implementation to improve the current health care system was that the care be "patient-centered - providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that the patient values guide all clinical decisions." In an opinion article,

Snyderman and Weil state that an "unintentional outcome" of biomedical care is the "erosion" of the patient-physician relationship [23]. Managed care, capitation, increased need for documentation and productivity, and constraints in health care funding have all been implemented as cost-effective strategies to manage the expense of medical technology and the consequence in implementing these cost-saving strategies is a significant limitation on a patient's visit time with their doctor which can adversely affect relationship building [23].

The average visit to a family practitioner is now reported at 18.6 minutes [24] while the average visit to an acupuncturist is 60 minutes and to a naturopath 40 minutes [25, 26]. As high patient-volume health care delivery systems such as managed care health systems are reducing a patient's visit time it is conceivable that shorter patient visits may negatively impact the patient-provider relationship by allowing less time for communication resulting in less patient-satisfaction.

Barriers to relationship building, such as significantly limiting the time a physician can spend with patients, has also been reported to have negative legal repercussions for physicians. When evaluating communication skills and visit time between primary care physicians that had no malpractice claims to those that had malpractice claims, it was found that the 'no claims' physicians used humor and facilitated communication with their patients more than the 'claims' physicians. The 'no claims' physicians also had significantly longer visit times with their patients than the 'claims' physicians [27]. In a survey of people with physical disabilities (multiple sclerosis, cerebral palsy, and spinal cord injury)

patients receiving managed care services were less satisfied with their providers communications skills than those receiving fee for service care [28].

There are a number of factors in the general population reported to be significantly associated with patient satisfaction including, office wait times [29, 30], provider listening and communication skills [31-33], and visit time with the provider [34], these are also factors that are important in maintaining a good patient-provider relationship.

Eisenberg, L, states that the popularity of CAM may reflect "biomedicine's failure to give patients the time they need to tell their story and to the explain the nature of the problems they face..." [35]. Biomedicine, viewed as "rational" and impersonal, is the medicine that has its roots in science and experimentation. It is lab tests, magnetic resonance imaging, computed tomography scans, and drug design, it is well planned and well thought out, it the medicine of the rational "mind". The medicine provided through the patient-physician relationship is personal, it is about communication, trust, compassion, it promotes wellness and healing, it is the medicine of the "heart". As care becomes more specialized and focused on the pathophysiologic basis of disease, the "heart" medicine appears to have been dissected out, restricting a patient's choice to "mind" or biomedicine. People may be choosing CAM as a way of reintegrating the "heart" back into their "mind" medicine, as both are needed.

Specific Aims

The first aim of this thesis include identifying differences in patient ratings, from respondents that utilized both, between conventional medicine and CAM on

the following: benefit from therapies; benefit from providers; satisfaction from providers; ratings of provider's characteristics related to emotional support; visit time. We hypothesized that we would see a difference in patient ratings for conventional medicine and CAM. Specifically we hypothesized that CAM providers would be rated higher on characteristics related to emotional support and have a longer reported visit time. The second aim of this thesis include identifying the following for their association with CAM use, demographic factors; MS-disease factors; physical well-being (PCS); mental well-being (MCS). We hypothesized that physical well-being (PCS) and mental well-being (MCS), components of HRQL, would be different between CAM users and CAM non-users.

Identifying these factors is the first step to designing more definitive studies evaluating characteristics that are predictive of CAM use and to designing studies that can better evaluate the specific benefits CAM offers for people with MS. Identifying these factors are warranted, as CAM may be an avenue by which patients with MS can broaden their health care and improve their quality of life.

Materials & Methods

The study population

The study population was comprised of people with MS who were members of the Oregon Chapter of the National MS Society (NMSS) which includes those living in Oregon and Clark County, Washington. Members that were on the Oregon Chapter's mailing list, as of August 2001, were sent both a

survey and an SF-12. Of the returned and completed surveys, only those that answered 'yes' to the question "Have you been diagnosed with MS?" were included in the study sample; those that answered "no" or "unsure" were excluded. Data was collected for six months, between September, 2001 and March, 2002, from eligible respondents after a single survey mailing.

Instruments

The eight page survey was developed by a panel consisting of CAM practitioners (six naturopaths), neurologists (three MS-specialists), and an epidemiologist in Portland, Oregon. The survey was approved by the Institutional Review Board at OHSU.

Majority consensus by the panel was used to include the types of both CAM and conventional therapies and providers on the survey. All types of therapies or providers that would not be considered part of standard conventional care for MS were classified as CAM.

CAM therapies included 5-HTP, ayurvedic herbs, beta-carotene, bioflavonoids, carnitine, Chinese herbs, cod liver/fish oil, coenzyme Q-10, dehydroepiandrosterone (DHEA), essential fatty acids, evening primrose oil, ginkgo, ginseng, kava, licorice, alpha lipoic acid, magnesium, melatonin, selenium, soy, St. John's wort, valerian, vitamin A, vitamin B12, vitamin C, vitamin B-complex, vitamin E, zinc, food allergy diet, high protein/low carbohydrate diet, low fat/low cholesterol diet, macrobiotic diet, Swank diet, vegetarian diet, wheat or gluten free diet, bee sting, biofeedback, dental

amalgam removal, guided imagery, heavy metal chelation, hyperbaric oxygen, hypnosis, meditation, plasma infusions, Procarin®, and yoga.

CAM providers included acupuncturist, aromatherapist, ayurvedic practitioner, chiropractor, Christian Science practitioner, faith healer, herbalist, homeopath, hypnotherapist, massage therapist, and naturopath.

Conventional therapies included interferon beta-1a (Avonex®), interferon beta-1b (Betaseron®), glatiramer acetate (Copaxone®), mitoxantrone (Novantrone®), prednisone/Solu-Medrol®, immunosuppressants (e.g. azathioprine, cyclophosphamide, methotrexate), intravenous gamma globulins, plasmapheresis, stretching, swimming, walking, water aerobics, and multi-vitamin.

Conventional providers included neurologist, MD non-neurologist, nurse, nutritionist, occupational therapist, physical therapist, occupational therapist, psychiatrist, and psychologist/counselor. *DMT use* included using one of the following: interferon beta-1a, interferon beta-1b, and glatiramer acetate (See Appendix A: Questionnaire on Treatments for Multiple Sclerosis, pp. 47-55).

The survey was accompanied by a cover letter and a SF-12 form. The cover letter decribed the SF-12 as a general health survey and the 8-page survey as a questionnaire about the use and benefit of conventional and alternative therapies for MS and MS-related symptoms. Because this study was interested in the use and benefit of conventional therapies for MS the following statement was included in the cover letter, "Even if you have never used an alternative

therapy for MS, please fill out the survey for we are very interested in how beneficial conventional medication has been for your MS".

The survey asked respondents whether they had used specific types of therapies and providers 'currently', 'in the past', or 'never'. A defined time frame for what constituted "current' use and 'past' use was not specified on the survey. Survey topics included the following: demographics; MS characteristics (e.g. type, duration, severity); dietary supplements; type of diet used for MS; CAM providers; Conventional MS disease modifying therapies (DMT); Conventional providers; type of exercise; spiritual beliefs; provider communication about dietary supplementation use; healthcare decisions; rating provider characteristics (listening skills, care and concern, and empowerment); rating provider satisfaction (alternative, MD-neurologist, MD non-neurologist); time spent with provider (alternative, MD-neurologist, MD non-neurologist). The survey did not define the meaning of 'Benefit' or 'Satisfaction' but asked respondent to "indicate how beneficial you feel these therapies/providers have been for your MS" and to "indicate how satisfied you have been with the care you received from the following providers". Benefit was rated on a four point scale: 1-Very Beneficial; 2-Somewhat Beneficial; 3-Unsure of Benefit; 4-Not Beneficial. Satisfaction was rated a four point scale: 1-Very satisfied; 2-Somewhat satisfied; 3-Not sure; 4-Not satisfied. 'Listening skills', 'Care and Concern', and 'Patient Empowerment' were rated a four point scale: 1-Excellent; 2-Very good; 3-Good; 4-Poor. The survey allowed respondents to use a proxy to fill out the surveys if they were unable to

do so. Prior to mailing, the survey was given to ten English speaking MS patients to test for comprehension and any other functional limitations.

HRQL was measured by using the SF-12, which is a 12-item validated shorten version of the SF-36 and was design to provide a HRQL measure that was quick and easy to administer in large population studies [36]. The SF-12 contains a subset of the 12 items from the SF-36 and information from this subset of questions is used to construct a physical and mental component summary score (PCS and MCS, respectively) (See Appendix B: SF-12 form, pp. 56-57).

Disease Severity Rating

Survey respondents were asked to choose one of six categories of disease severity that best described their ambulatory ability and MS-symptom severity. The six disease severity categories included: None/Mild, Mild, Moderate, Some support needed for walking, Walker/two-handed crutch, Unable to walk (Table 1. Disease severity choices). The disease severity categories were modeled after the Expanded Disability Status Scale (EDSS) [37]. The EDSS is an ordinal scale giving a measure of neurological impairment on a scale that runs between 0 (normal neurological examination) to 10.0 (dead), patients with scores in the 0-4.0 range have mild disability and can walk at least 500 meters without aid or rest; patients with scores in the 4.5-6.0 range have increasing limitations in their ability to walk; patients with scores > 6.0 have very limited walking ability, or are confined to a wheelchair or bed.

Table 1. Disease severity choices

1. None/Minimal I have no or minimal MS-related symptoms, no limitations in walking ability, and no limitations on daily activities.
2. Mild I have noticeable MS-related symptoms but no limitations in walking ability and no limitations on daily activities.
3. Moderate I have many MS-related symptoms that affect my daily activities but can walk at least 1 block without support.
4. Some support needed for walking I have significant MS-related symptoms that limit physically demanding activities. I need support (e.g. cane, touching a wall, leaning on someone's arm) to walk ½-1block.
5. Walker/two-handed crutch I have significant MS-related symptoms that limit daily activities. I can walk only short distances with a walker or two-handed crutches.
6. Unable to walk I have many severe MS-related symptoms and am restricted to a wheelchair or bed.

To evaluate how well self-reported disease severity correlated with EDSS, forty-two patients at the MS Center of Oregon were seen by a neurologist and given an EDSS score, these patients also filled out the 8-page survey. The patients did not know their EDSS score prior to filling out the 8-page survey and the neurologist was blinded to the patient's choice of disease severity. The correlation between self-reported disease severity and Expanded Disability Status Scale (EDSS) was then analyzed [38]. The survey data from these subjects was not included in the data received from respondents who returned mailed surveys and SF-12s because the data collection methods differed slightly.

Data Analysis

Statistical analysis was performed using SPSS version 12.0. Descriptive statistics was used to summarize demographic information. Some of the respondents returned surveys without answering all of the questions, therefore we do not have data from all respondents on all of the demographic variables. All comparison data between CAM and conventional therapies and providers was limited to a subset of survey respondents that reported using both types of therapies or providers. Paired t-tests were used to compare the following: benefit rating between conventional and CAM therapies; benefit rating between conventional and CAM providers; satisfaction rating between CAM providers and Neurologists; satisfaction rating between CAM provider and MD nonneurologists. To analyze the effect of disease severity on satisfaction ratings, the six disease severity ratings were categorized into three group, 1. mild (combining none and mild), 2. moderate (combining moderate and some support for walking), 3. Severe (combining walker and unable to walk). Paired t-test was then used to compare satisfaction rating between CAM providers and neurologists, CAM providers and MD non-neurologists, for each disease severity group. Paired t-tests were also used to compare patient ratings on 'listening skills'; 'care and concern'; 'patient empowerment' between CAM providers and neurologists and CAM providers and MD non-neurologists. Cocharan's linear trend analysis was used to compare time spent per visit between CAM practitioners, MD non-neurologists, and neurologists. Significance was maintained at 0.05 using a two-tailed probability.

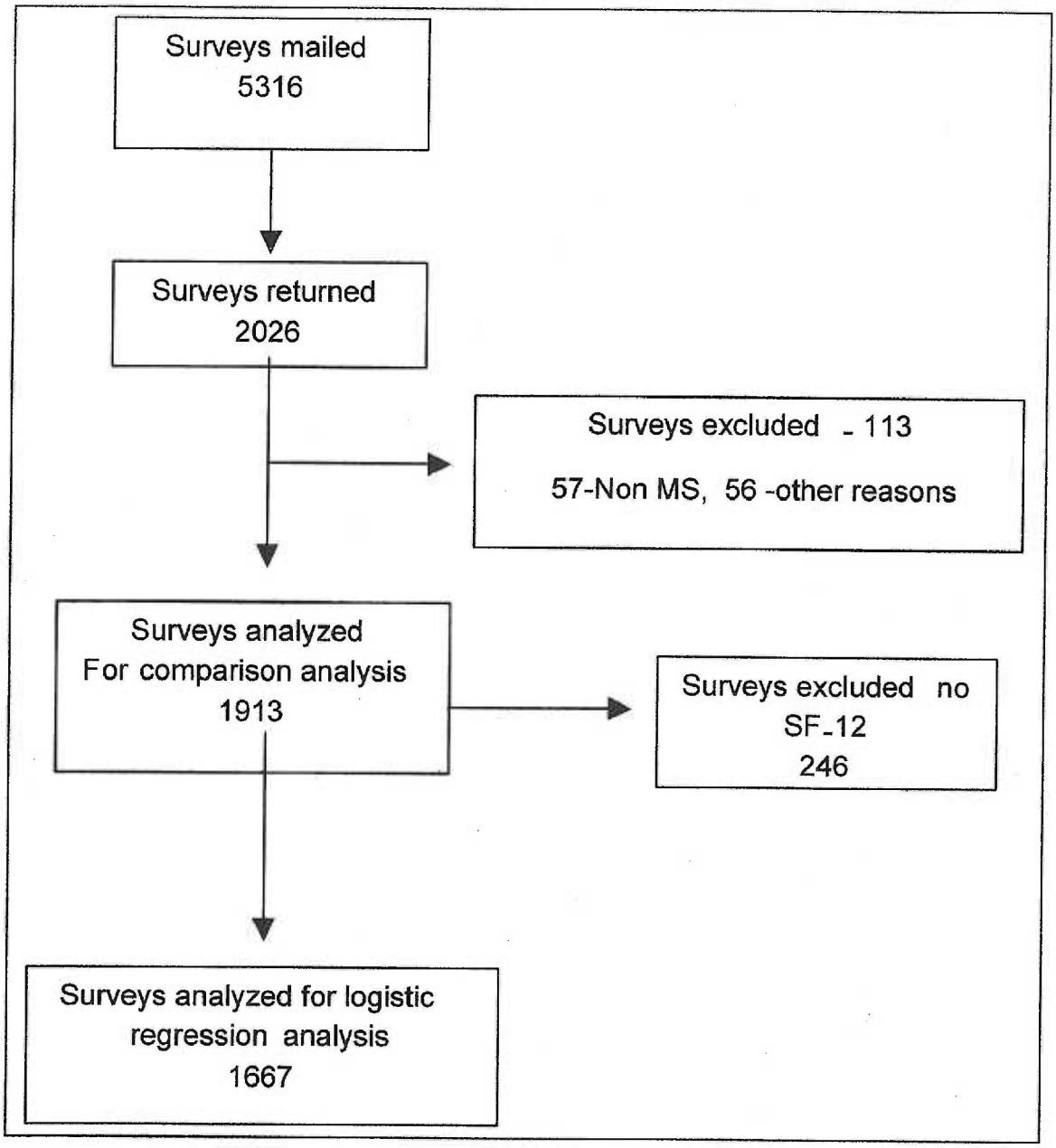
Multiple logistic regression analysis was used to determine the association between HRQL subcategories of physical well-being (PCS) and mental well-being (MCS), demographic and MS disease factors using 'ever' CAM use, 'current' CAM use, or 'past' CAM use as the dependent variable. For the dependent variable of 'CAM use', subjects that reported use of any CAM therapy or provider were coded as a '1' and subjects that reported 'never' using a CAM therapy or provider were coded as a '0'. Independent variables entered in the regression model included, age, gender, race, self-reported disease severity, DMT use, MS duration, MS type, education level, PCS, and MCS. All independent variables were entered into the model simultaneously (as a block) to identify factors that were significantly associated with each type of CAM use. Variables that had a significance of $p \leq 0.10$ were then entered into the model in a forward conditional fashion and were retained in the model if $p \leq 0.05$. Hosmer-Lemeshow test was used to assess model fit.

Results

Study sample description

A total of 5,316 surveys were mailed and 2,026 surveys were returned for a response rate of 38.1%. Returned surveys were excluded from analysis for the any of the following reasons: wrong address, deceased, returned after more than 6 months of after mailing (n=56); does not have MS (n=57); did not fill out a SF-12 (n=246) (Figure 1. Profile of surveys used for data analysis).

Figure 1. Profile of surveys used for data analysis



Most of the respondents were female (78.1%) and were white (96.5%). The average age was 51.0 yrs. ± 11.4 and average MS duration was 19.9 yrs ± 11.9. The education level was high with 38.0 % having a college education or greater. The majority had used DMT (59.1 % ever used, 48.2 % currently used) and had used CAM (87.9 % ever used, 71.1 % currently used). About half

reported a relapsing remitting type (49.2 %) with 14.3 % reporting secondary progressive, 10.0% reporting primary progressive types, and 22.6% reporting unsure of MS type. The mean PCS score was 35.3 (SD=10.9) and the mean MCS score was 45.7 (SD=11.5). There were 31.7 % that reported 'none/mild' disease severity, 45.2 % that reported moderate and 22.7 % that reported severe disease severity (Table 2. Subject Demographics, p. 17).

Validation of self-rated disease severity

Self-rated disease severity from the 42 MS patients who filled out the survey in clinic was well correlated with the neurologist rated EDSS, r = 0.85 (Figure 2. Correlation between self-rated disease severity and EDSS).

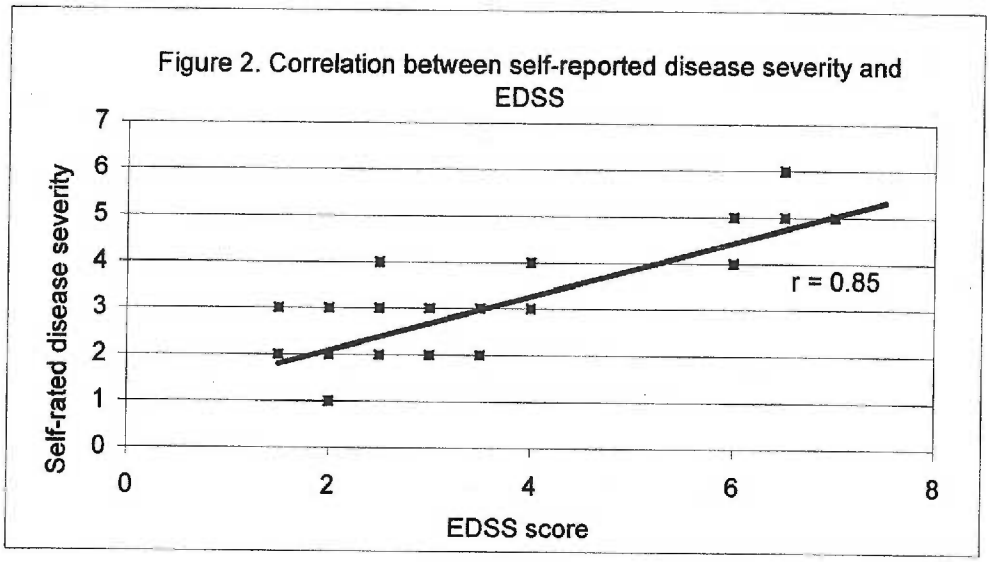


Table 2. Subject Demographics

Variable	mean (SD) or n (%)
AGE (in years)	51.0 (11.4)
GENDER	
Female	1302 (78.1%)
EDUCATION	
College grad or greater	634 (38.0%)
RACE	
White	1608 (96.5%)
MS DURATION (in years)	19.9 (11.9)
MS TYPE	
Relapsing remitting	820 (49.2%)
Secondary progressive	238 (14.3%)
Primary progressive	147 (10.0%)
Unsure of type	376 (22.6%)
SEVERITY OF MS	
None/Mild	528 (31.7%)
Moderate	754 (45.2%)
Severe	378 (22.7%)
DMT USE	
Ever Used	985 (59.1%)
Currently Used	803 (48.2%)
CAM USE	
Ever Used	1466 (87.9%)
Currently Used	1188 (71.1%)
Past Used	281 (16.9%)
Never Used	201 (12.1%)
QUALITY OF LIFE	
Physical well-being (PCS)	35.3 (10.9)
Mental well-being (MCS)	45.7 (11.5)

Comparison of benefit rating for CAM and conventional therapies and providers

Respondents that used both CAM and conventional therapies and rated the benefit for both, perceived conventional therapies as being significantly more beneficial than their CAM therapies ($p<0.001$). Respondents that used both CAM and conventional providers and rated the benefit for both, perceived conventional providers as being significantly more beneficial than CAM providers ($p<0.001$) (Table 3).

Table 3. Comparison of Benefit Ratings for Respondents Using both CAM and Conventional Therapies and Providers

	n	mean	s.d	p-value
Conventional therapies	1512	1.39	0.65	
CAM therapies	1512	1.78	0.88	p<0.001
Conventional Providers	908	1.41	0.67	
CAM Providers	908	1.83	0.98	p<0.001

Comparison of Provider Satisfaction

For respondents that rated both a CAM provider and a neurologist, there was no significant difference in mean satisfaction rating between the two types of providers ($p = 0.549$). Respondents that rated both a CAM provider and an MD non-neurologist reported being significantly more 'satisfied' with their CAM provider ($p=0.014$) (Table 4).

Table 4. Comparison of Satisfaction Rating for Respondents Using both a CAM provider and a Neurologist or a CAM provider and an MD non-neurologist

Satisfaction Rating	n	mean	sd	p-value
CAM Providers	226	1.75	1.11	0.549
Neurologists	226	1.80	0.90	
CAM Provider	169	1.84	1.19	0.014
MD non-neurologists	169	2.08	1.02	

Comparison of Provider Satisfaction stratified by respondent's rating of disease severity

For respondents that rated both a CAM provider and a neurologist or a CAM provider and an MD non-neurologist, that also reported having mild disease severity there was no difference in mean satisfaction rating between the types of providers (CAM vs neurologist: p=1.00, CAM vs MD non-neurologist, p=0.542). For respondents that rated both a CAM provider and a neurologist or a CAM provider and an MD non-neurologist, that also reported having moderate disease severity there was a significant difference in mean satisfaction rating between the types of providers (CAM vs neurologist: p=0.014, CAM vs MD non-neurologist, p<0.001). Respondents reported being significantly more 'satisfied' with their CAM provider than their neurologist or MD non-neurologist.

For respondents that rated both a CAM provider and a neurologist or a CAM provider and an MD non-neurologist, that also reported having severe disease severity there was a significant difference in mean satisfaction rating between CAM providers and neurologist, with respondents being significantly more 'satisfied' with their neurologist, p=0.032. There was no significant difference in

mean satisfaction between CAM providers and MD non-neurologists, p=0.142, (Table 5).

Table 5. Comparison of satisfaction rating for respondents using both CAM providers and a neurologist or a CAM provider and an MD non-neurologist stratified by MS-disease severity level (mild, moderate, and severe)

Mild Disease Severity	n	mean	sd	p-value
CAM Providers	57	1.74	1.19	1.000
Neurologist	57	1.74	0.97	
CAM Provider	41	1.85	1.30	0.542
MD non-neurologists	41	1.98	1.04	

Moderate disease severity	n	mean	sd	p-value
CAM Providers	119	1.55	0.94	0.014
Neurologist	119	1.81	0.89	
CAM Provider	87	1.55	0.96	<0.001
MD non-neurologists	87	2.08	0.99	

Severe disease severity	n	mean	sd	p-value
CAM Providers	50	2.26	1.26	0.032
Neurologist	50	1.86	0.88	
CAM Provider	40	2.50	1.28	0.142
MD non-neurologists	40	2.20	1.09	

Comparison of provider characteristics, 'Listening Skills', 'Care and Concern', 'Patient Empowerment'

Respondents that rated both a CAM provider and a neurologist or a CAM provider and an MD non-neurologist on 'Listening skills', 'Care and Concern', and 'Patient Empowerment', gave their CAM provider a significantly higher rating on all three provider characteristics (CAM vs. neurologist: $p<0.001$, CAM vs. MD non-neurologist: $p<0.001$) (Table 6).

Table 6. Comparison of Ratings of Provider Characteristics for Respondents Using both a CAM provider and a Neurologist or a CAM provider and an MD non-neurologist

Listening Skills	n	mean	sd	p-value
CAM Providers	209	1.63	0.94	<0.001
Neurologists	209	2.24	1.08	
CAM Providers	155	1.68	0.98	<0.001
MD non-neurologists	155	2.30	1.05	

Care and Concern	n	mean	sd	p-value
CAM Providers	199	1.64	0.97	<0.001
Neurologists	199	2.19	1.08	
CAM Providers	151	1.61	0.96	<0.001
MD non-neurologists	151	2.19	1.03	

Patient Empowerment	n	mean	sd	p-value
CAM Providers	198	1.79	1.03	<0.001
Neurologists	198	2.49	1.18	
CAM Providers	150	1.83	1.01	<0.001
MD non-neurologists	150	2.53	1.04	

Comparison of CAM providers, Neurologists, and MD non-neurologists on Visit time

Respondents that rated both a CAM provider and a neurologist or a CAM provider and a MD non-neurologist on 'Visit Time' reported spending significantly more time per visit with their CAM provider than with either their neurologist or MD non-neurologist ($p < 0.001$, $p < 0.001$, respectively) (Table 7).

Table 7. Time Spent per visit

	n	≤ 20 min (%)	40 min (%)	60 min (%)	>60 min (%)
*CAM practitioner	173	28.9	28.9	26.6	15.6
Neurologist	173	61.9	30.1	6.4	1.7
	n	≤ 20 min (%)	40 min (%)	60 min (%)	>60 min (%)
*CAM practitioner	124	29.9	26.8	29.0	15.3
MD no-nneurologist	124	83.1	15.3	1.6	0

*Cochran's Linear Trend, $p < 0.001$

Logistic Regression Analysis

Table 8 shows the five factors that had a significant and independent association with 'ever' CAM use in the final regression model. Respondents that were female (OR= 1.70, p=0.003), a college graduate (OR= 1.84, p=0.008), had a longer MS duration (OR=1.15 for every five years of duration, $p < 0.001$), lower PCS (OR=1.25 for every 10 point decrease, p=0.003), and did not currently use DMT (OR=1.40, p=0.042), had higher odds of having 'ever' used CAM than those that did not use CAM.

Table 8. Logistic regression model describing significant factors associated with 'ever' CAM use

Variable	Adjusted odds ratio	95% CI for adjusted for entire model	p-value
Female	1.70	1.19, 2.42	0.003
College grad	1.84	1.17, 2.88	0.008
5-yr MS duration	1.15	1.11, 1.20	<0.001
No DMT use	1.40	1.01, 1.90	0.042
10-pt. decrease PCS	1.25	1.16, 1.33	0.003

Hosmer-Lemeshow test, p=0.426

Table 9 show the five factors that had a significant and independent association with 'current' CAM use in the final regression model, which are the same factors found to be associated with 'ever' CAM use. Respondents that were female (OR= 1.83, p=0.001), a college graduate (OR= 2.06, p= 0.002), had a longer MS duration (OR=1.16 for every five years of duration, p=0.023), lower PCS (OR=1.21 for every 10 point decrease, p=0.011), and did not currently use DMT (OR=1.47, p=0.023), had higher odds of having 'currently' used CAM than those that did not use CAM.

Table 9. Logistic regression model describing significant factors associated with 'current' CAM use

Variable	Adjusted odds ratio	95% CI for adjusted for entire model	p-value
Female	1.83	1.28, 2.63	0.001
College grad	2.06	1.30, 3.26	0.002
5-yr MS duration	1.16	1.12, 1.21	0.023
No DMT use	1.47	1.06, 2.05	0.023
10-pt. decrease PCS	1.21	1.12, 1.31	0.011

Hosmer-Lemeshow test, p=0.470

Table 10 show that the two factors that had a significant and independent association with 'past' CAM use. Respondents that had a longer MS duration (OR=1.13 for every five years of duration, p=0.013), and lower PCS (OR=1.30 for every 10 point decrease, p=0.005), had a higher odds of having used CAM in the past than those that did not use CAM.

Table 10. Logistic regression model describing significant factors associated with 'past' CAM use

Variable	Adjusted odds ratio	95% CI for adjusted for entire model	p-value
5-yr MS duration	1.13	1.07, 1.18	0.013
10-pt. decrease PCS	1.30	1.18, 1.42	0.005

Hosmer-Lemeshow test, p=0.824

All three models were assessed for goodness-of-fit using the Hosmer-Lemeshow test [39], and none of the models showed any overt lack of fit, p=0.426, p=0.470, p=0.824, respectively.

Discussion

Specific Aim 1: To identify differences in patient ratings of benefit, satisfaction for conventional and CAM therapies and providers. To evaluate whether differences exist between neurologists, MD non-neurologists, and CAM providers in patient's ratings of skills related to emotional support (listening, care & concern, empowerment).

When comparing benefit, satisfaction, and reports of provider characteristics between CAM and conventional medicine in MS, the study results present an interesting paradox, people with MS who used and rated both, perceived greater benefit from their conventional treatments and providers, yet they perceived their CAM providers to be better at skills related to emotional

support. The question remains, why do respondents perceive higher benefit from their conventional therapies and providers, yet rate their CAM providers higher in skills related to emotional support? A speculative answer, supported by the data, is that MS patients may choose to improve the overall quality of their health care by incorporating what they perceive as the 'best' of CAM and conventional medicine. These results do not reflect a dichotomous choice in healthcare, rather they reflect an integrative choice of healthcare by people with MS.

From the subset of MS patients who reported use of both CAM and conventional medicine, higher perceived benefit from conventional medicine may reflect a patient's belief in scientifically proven therapies and diagnostics for MS, the rational mind or "Mind Medicine", while higher perceived skill of CAM providers in characteristics related to emotional support may reflect a need for "Heart Medicine". Stratifying benefit rating by self-reported MS disease severity did not change our findings (data not shown).

There are a number of large clinical studies on the three most widely used types disease-modifying therapies (DMTs) for MS, interferon beta-1a, interferon beta-1b, and glatiramer acetate [11, 40, 41]. All of these therapies are FDA approved for use in relapsing remitting MS, which is a mild, early, and intermittently progressive form of MS. These clinical studies were done on MS patients that were ambulatory and had a very minimal symptom severity. The scientific evidence for efficacy of disease-modifying therapy for the secondary progressive form of MS is less robust [42]. This form occurs after the relapsing remitting phase of the disease and is associated with moderate disease severity and impairments

in ambulation (limited walking, cane use). The benefit rating results may reflect a patient's knowledge of the scientific evidence for DMT therapy and for conventional symptomatic treatments used in MS (e.g. baclofen for spasticity, modafinil for fatigue) and the belief in the evidence.

The data on ratings of provider satisfaction when stratifying respondents by disease severity is interesting in that the major significant differences in ratings between a patient's CAM provider and their neurologist, and CAM provider and MD non-neurologist was in the moderate and severe disease severity groups. This result may support the already mention hypothesis, that the satisfaction ratings reflect patient's beliefs about what conventional and CAM providers have to offer.

MS patients who reported mild disease severity are able to walk and have symptoms that minimally impact their daily activities may be equally satisfied with both their conventional providers, who are providing the 'scientifically proven" drug therapies, and their CAM providers, who may be providing additional emotional support, though listening, care and concern, and patient empowerment.

MS patients who reported moderate disease severity have impairments in their ability to walk and have symptoms that are affecting their daily activities, both of which can lower quality of life. The scientific evidence for DMT for this group (secondary progressive MS) report a less robust effect in delaying disease progression than in the relapsing remitting group (a mild disease severity group). It may be that patients who report moderate disease severity are more

significantly 'satisfied' with their CAM providers than with their conventional providers (neurologists, MD nonneurologists) because conventional DMTs have less to offer, quality of life is declined and they are looking for increased emotional support offered by CAM providers. This is also the group that is not yet wheelchair-bound and it may be that patients are more hopeful and satisfied with therapies that may offer any delay in further disease progression whether or not the therapy is scientifically proven.

MS patients who reported severe disease severity are very limited in their ability to walk or are wheelchair-bound with significant symptoms that impair daily activities. This group gave their neurologist a significantly higher satisfaction rating than they did for their CAM providers. There are no FDA-approved disease modifying drugs for this group but conventional medicine offers a fair number of medications for symptomatic relief. It may be that CAM therapies tried have not prevented disease progression. Neurologists, and especially MS specialists, can better coordinate MS-specific care with other providers (e.g. physical therapists) than CAM providers, which may be more satisfactory to patients in this group.

Although this is a hypothesis that has not yet been tested in the MS population, there is evidence from other studies reporting similar types of results. A study evaluating CAM use in rheumatoid arthritis (RA) patients reported that 73.3% of survey respondents used CAM but perceived more benefit from conventional prescription medications than from complementary therapies [43]. The authors point out that although perceived benefit from conventional medications

was higher compared to CAM therapies, these respondents reported spending as much for CAM therapies as for conventional medications suggesting factors other than "perceptions of effect" in motivating CAM use.

They proposed the following factors as possible motivating factors in CAM use: 1. a desire to take control over treatments, 2. a lack of empathy, counseling and time in consultations with conventional practitioners, 3. a slow onset of action (effect) of long-term CAM therapies.

Many of the suggested factors motivating CAM use from the RA study have been explored in this MS survey. CAM providers did have better perceived skills related to 'empowerment', 'care and concern', and 'listening skills' than neurologists or MD non-neurologists. They were also reported to have longest time per office visits than either of these providers. This survey did not ask respondents whether these factors motivated CAM use but the results do indicate that CAM providers were rated higher on these skills than neurologists or MD non-neurologists suggesting that these may be important factors in CAM use for MS.

It is not known if time per visit is a factor that contributed to CAM providers receiving a higher rating in characteristics related to emotional support. Our results show that CAM providers are spending significantly more time per visit that either neurologists or MD non-neurologists. It is conceivable that more time per visit allows for a stronger patient-provider relationship to develop that may lead to more supportive encounter for the patient. A consequence of modern biomedical care, that has been shaped more by business demands (insurance

companies, health maintenance organizations) and less by practitioners, is that patients do not have time to develop relationships with their providers because of visit time constraints.

The average visit to a family practitioner is now reported at 18.6 minutes [24] while the average visit to an acupuncturist is 60 minutes and to a naturopath 40 minutes [25, 26]. A survey of 231 family physicians in Missouri reported inadequate time and training as a barrier to addressing spiritual issues with their patients, even though 96% of physician's surveyed believed that spiritual well-being was important in health [44]. It has been reported that the average visit with most CAM providers is significantly longer than the average visit with conventional providers which is also reflected in our survey results [25, 26].

Reports gathered from the Primary Care Assessment Survey (PCAS), conducted between 1996-2000, indicate that patients did not find that their primary care physician knew much about "their life circumstances, daily role responsibilities, or values" and recommended that primary care be "whole-person oriented" [45]. A reported motivating factor in CAM use has been its "holistic nature" or "whole-person orientation" [4, 46, 47]. Adequate training in a "holistic" perspective of medicine and more time per visit may contribute to fostering emotional support which may lead a stronger patient-physician relationship, thus CAM practitioners may be providing a type of healthcare service that is not supported by the current biomedical infrastructure.

Specific Aim 2: To identify the following factors for their association with CAM use, demographics; MS disease factors; physical well-being (PCS); mental well-being (MCS).

When we examined components of HRQL (PCS and MCS), demographic, and disease factors for their association with CAM use, the most significant finding was that physical well-being, as measured by PCS of the SF-12, was independently associated with respondents that reported using CAM regardless of when the CAM use had occurred. Because the majority of respondents used in this analysis were 'current' CAM users (71%) and 'ever' CAM users included both 'current' and 'past' users, it is not a surprise that the logistic regression models for both 'current' and 'ever' CAM use were almost identical. We also found that respondents not currently using DMT had a 40% increased odds of 'current' and 'ever' CAM use. Current DMT use was not associated with 'past' CAM use.

The finding that decreased PCS increases the odds of CAM use is a unique finding in MS as no other study has looked at this association. There are, however, several studies that have included HRQL as a factor when examining the characteristics of CAM users in the general public. These studies have reported that chronic illness, chronic pain, higher disability, poorer health status, being female, being highly educated, and having a higher income level, are factors predictive of CAM use [4, 5, 48, 49].

Ong *et al.* reported that it was physical well-being, PCS, but not mental well-being, MCS, that was a significant predictor of CAM use in a randomly selected

population of 18-64 year olds living in four English counties [49]. This finding is similar to this study's findings in which it was PCS, but not MCS, that was significantly associated with CAM use in MS. The increased odds of CAM use in those that have a lowered PCS found in this study may reflect characteristics of CAM users in general rather than MS-specific characteristics as MS-specific factors like disease severity and type, were not significantly associated with CAM use.

Although MS disease severity has been reported to be highly predictive of lowered physical well being, PCS [50-52], it was not found to be associated with CAM use in our model. In designing our logistic regression model, we first added ten variables simultaneously to identify significant independent variables associate with CAM use. When doing this disease severity did not emerge as a variable significantly associated with CAM use, therefore we did not further evaluate it in subsequent regression models. We took the five significantly associated variables, sex, education, MS duration, PCS, and current DMT use, and entered them stepwise into the model to further evaluate the significance of each variable's association with CAM use and found that these variables were significantly associated with 'ever' and more importantly 'current' CAM use. Using this method to build our model, disease severity never emerged as a significantly associated variable.

To test whether or not disease severity would be significant in the final model of 'current' CAM use, we entered it first in the stepwise model, so that all other variables were adjusted for this variable. When doing this, the overall

category of disease severity and the subcategories of 'mild' and 'severe' disease severity were not significantly associated with 'current' CAM use, although the 'moderate' group was significantly associated (data not shown). When disease severity was entered in the model first, PCS was no longer retained in the model, all other variables were retained. If we entered PCS into the 'current' CAM use model first and then added disease severity into the model, followed by the other variables, disease severity was no longer retained in the model (data not shown). This suggest that there is an interaction between disease severity and PCS, which is not surprising since PCS and MCS have been found to be predictive of MS disease severity [20]. Even when forced into the final model, disease severity is not maintained as a variable that is significantly associated with 'current' CAM use, which suggest that patients that use CAM may be seeking it for reasons other than to improve disease severity or to change the course of their disease.

Marrie *et al.* in evaluating predictors of CAM use in a very large, nonrandom sample of MS patients, found that sociodemographic and disease factors, although significant, played a small role in CAM choice and other more important factors should be explored. These factors included, "...the degree of emotional support received from an alternative provider compared with a conventional provider, or the need to exercise some control over one's health status" [16].

Jain and Austin conducted a cross-sectional survey of a random sample of Stanford University alumni to evaluate the factors associated with CAM disuse. Although their response rate was low (35.8% response), they report that being in

good health, being male, having a belief that CAM therapies are ineffective or inferior to conventional methods, and having perceptions that conventional physicians are not supportive of CAM treatments were weak but significant predictors of why this cohort did not use CAM [53]. It may be that in general, people who perceive their health to be poor are more motivated to seek ways to improve quality of life while those in good health are not as strongly motivated to do so.

People with MS score lower on quality of life measures than the general population [19] and the mean PCS score in this study was quite low, 35.3 (SD=10.9). This may be why PCS emerges as a significant and independent factor associated with CAM use while MS disease severity and MS type do not. Since PCS is a reflection of how physical well-being impacts quality of life, people with MS may be looking for ways to increase their quality of life, given the fact that MS symptoms have a definite impact on activities of daily living.

This study's unique finding that the odds of CAM use is significantly increased by not currently using a DMT is interesting and puzzling. Reports from studies that have examined the association between MS medication use and CAM use are mixed. Schwartz *et al.* found an increased odds of CAM use in those using more MS medications [15] and Page *et al.* did not find conventional medications a significant predictor of CAM use [54]. Both studies report data from specific geographic cohorts, the difference in findings with regards to medication use in these two studies and ours, may reflect a cohort effect.

There are probably other factors related to CAM use that may be correlated with DMT use that this study did not explore which include, treatment side effects, cost of treatments, accessibility of treatments, use of symptomatic treatments (e.g. modafinil for fatigue), and feelings about health empowerment. In a systematic review of inteferons in relapsing remitting MS, the authors mention that although interferons have evidence for reduction of exacerbations, their use is related a number of uncomfortable side effects which can decrease quality of life [55]. These factors would need to be explored in sorting out whether or not DMT is indeed associated with CAM use and in explaining why a decrease in DMT use would be associated with an increased odds in CAM use in this cohort.

Study Limitations

The interpretation of the results presented from this study have several limitations. We are not certain that the mailing list provided by the Oregon Chapter of the National MS Society contained only people diagnosed with MS. The unvalidated estimate of prevalence of MS in Oregon and Clark county, Washington is reported by this chapter to be approximately 1/600 or approximately 6,000 people in the region which is higher than the national prevalence of 1/750 [8]. If this prevalence estimate is correct then it is likely that the mailing list of 5,316 included the majority of people in the region that have MS.

The relatively low response rate coupled with fact that only a subset of the respondents reported utilizing both a CAM provider and a conventional provider

may have introduced selection bias that would limit the both the generalizability and validity of the results. The respondents may reflect a group that had some experience with CAM use as reflected by the high prevalence of CAM use in this cohort, while those that did not have experience with CAM may not have responded. If this were the case then the prevalence of CAM use for this cohort would be significantly inflated and since it is unclear if CAM users and non-CAM users are demographically similar, demographic characteristics may not accurately represent people with MS in this region.

This survey has the highest reported CAM use in MS, although data from one Canadian study reported a similar frequency of CAM use (70%) [54]. The metropolitan Portland area is one of the few cities in the U.S. that houses schools for traditional Chinese medicine, massage, chiropractic, and naturopathy. High CAM use in our cohort may be a reflection of the relatively easy access to CAM providers in Oregon, rather than reflect a selection bias.

To prevent selection bias, the cover letter that accompanied the survey expressed the study's interest in the use and benefit from both conventional and CAM therapies, the study was not soliciting only those that used CAM. The demographics from our respondents well matches data collected from a large national MS survey [16] (n=20,778) in gender, race, and education level, the mean age of this study's respondents were significantly older than that reported in the national survey (data not shown). Agreement of our survey demographics to this national MS survey on all comparable demographic characteristics, except for

age, give us more confidence in the generalizabilty and validity of this study's results.

We did not ask how CAM therapies were administered, why CAM therapies or providers were chosen, or about barriers to either CAM or conventional therapies, all of which may have an impact on benefit and satisfaction ratings. Although it would have been useful to evaluate whether or not there were differences in satisfaction ratings between conventional providers in respondents that only used a conventional provider and respondents that used both a CAM and conventional provider, the sample size for the comparison comprised $\leq$ 1% of the total respondents, which did not allow for a meaningful analysis.

The SF-12, a general measure of quality of life, is not as sensitive as MS-specific tools, but it is well-validated measure [56]. As a shorter instrument, the SF-12 was better suited for this mailed survey than longer instruments.

Although this study did not include in-clinic measures or other validated measures of disease severity [57, 58], we did find that patient's report of disease severity, from choices on the survey, was well-correlated with EDSS in the subset of clinic subjects.

We used one instrument that asks participants to report on past and current events (the survey) and another instrument that asks about current quality of life (SF-12) and derived associations between these two data sets, which could introduce varying degrees of recall bias. The regression models for 'ever' CAM use (which includes recall of past CAM use) and 'current' CAM use

were virtually identical and the majority of respondents reported 'current' CAM use, which gives us confidence that recall bias was not a significant limitation. Many of the factors that were found to be independently associated with CAM use in our 'current' and 'ever' CAM use models have been reported in other studies examining predictors of CAM in MS. Increased odds of using CAM in females and the more highly educated has been reported in four studies [14-17]. There are two studies that report an increase MS duration as one of the factors predicting CAM use [16, 17]. Nayak, et al. reported an OR for MS duration, OR=1.05, which is very similar to the odds ratio that we found for MS duration per year, OR=1.03. Finding factors associated with CAM use reported by other groups also gives us confidence in the validity of our model.

As this was a cross sectional study and not a longitudinal study we are limited to interpreting our results as 'factors associated with CAM' rather than 'predictors of CAM'. In the discussion of this study we have explored the possibility that people with lower perceived quality of life seeking out CAM to improve quality of life, making the assumption that poor HRQL preceded CAM use in MS, but it is possible that the temporal arrow points in the other direction and that CAM use induces a lower HRQL.

Summary and Conclusions

The long-term trends in CAM use show both an increase and persistence of use since the 1950s in the general population [4]. Given that at least one third of people with MS use CAM and that HRQL may be a significant factor associated with CAM use in MS, more studies are warranted to better

understand its association with HRQL. Longitudinal studies need to be implemented so that we can establish if HRQL is predictive for CAM in MS and to better understand the impact of CAM on HRQL.

Although this study was exploratory in nature, the results of this survey warrants further investigation because of the potential impact of emotional support and holistic care on the patient-provider relationship and on quality of life in people with MS. Data from studies in patient-centered care report that a positive patient-physician relationship has a positive influence on health outcomes [59-61].

This survey results suggest that people with MS who choose to utilize both CAM and conventional medicine have integrated both "heart" and "mind" medicine to attain holistic healthcare. If this is the case, people with MS may be seeking to lessen the "chasm" in the quality of their health care by incorporating CAM along with their current biomedical healthcare.

References

1. NCCAM. Available at: http://nccam.nih.gov/health/whatiscam.
2. Committee on the use of complementary and alternative medicine by the American public. *Complementary and Alternative Medicine in the United States*. Washington, DC: National Academy of Sciences, Institute of Medicine; 2005.
3. Gordon JS. The White House Commission on Complementary and Alternative Medicine Policy and the future of healthcare. *Altern Ther Health Med*. 2004; 10(5): 20-3.

4. Astin JA. Why patients use alternative medicine: results of a national study. *JAMA*. 1998; 279(19): 1548-53.

5. Bausell RB, Lee WL, Berman BM. Demographic and health-related correlates to visits to complementary and alternative medical providers. *Med Care*. 2001; 39(2): 190-6.

6. Tindle HA, Davis RB, Phillips RS, Eisenberg DM. Trends in use of complementary and alternative medicine by US adults: 1997-2002. *Altern Ther Health Med*. 2005; 11(1): 42-9.

7. Noseworthy J, Lucchinetti C, Rodriguez M, Weinshenker B. Multiple sclerosis. *New England Journal of Medicine*. 2000; 343(13): 938-52.

8. National MS Society. Available at www.nationalmssociety.org.

9. Lublin FD, Reingold SC. Defining the clinical course of multiple sclerosis: results of an international survey. *Neurology*. 1996; 46: 907-911.

10. Jacobs LD, Cookfair D. Results of a phase III trial of intramuscular recombinant beta interferon as treatment for multiple sclerosis. *Ann Neurol.* 1994; 35: 259-262.

11. Johnson KP, Brooks BR, Cohen JA, Ford CC, Goldstein J, Lisak RP, Meyers LW, Panitch HS, Rose JW, Schiffer AB. Copolymer 1 reduces relapse rate and improves disability in relapsing-remitting multiple sclerosis: results of a phase III multicenter, double-blind placebo-controlled trial. The Copolymer 1 Multiple Sclerosis Study Group. *Neurology*. 1995; 45(7): 1268-76.

12. Eisenberg DM, Davis RB, Ettner SL, Appel S, Wilkey S, Van Rompay M, Kessler RC. Trends in alternative medicine use in the United States, 1990-1997: results of a follow-up national survey. *JAMA*. 1998; 280(18): 1569-75.

13. Eisenberg DM, Kessler RC, Foster C, Norlock FE, Calkins DR, Delbanco TL. Unconventional medicine in the United States. Prevalence, costs, and patterns of use. *New England Journal of Medicine*. 1993; 328(4): 246-52.

14. Berkman C, Pignotti M, Cavallo P, Holland N. Use of Alternative Treatments by People with Multiple Sclerosis. *Neurorehabilitation and Neural Repair*. 1999; 13(4): 243-254.

15. Schwartz CE, Laitin E, Brotman S, LaRocca N. Utilization of unconventional treatments by persons with MS: is it alternative or complementary? *Neurology*. 1999; 52(3): 626-9.

16. Marrie RA, Hadjimichael O, Vollmer T. Predictors of alternative medicine use by multiple sclerosis patients. *Mult Scler*. 2003; 9(5): 461-6.

17. Nayak S, Matheis RJ, Schoenberger NE, Shiflett SC. Use of unconventional therapies by individuals with multiple sclerosis. *Clin Rehabil*. 2003; 17(2): 181-91.

18. Mitchell AJ, Benito-Leon J, Gonzalez JM, Rivera-Navarro J. Quality of life and its assessment in multiple sclerosis: integrating physical and psychological components of wellbeing. *Lancet Neurol*. 2005; 4(9): 556-66.

19. Nortvedt MW, RiiseT, Myhr KM, Nyland HI. Performance of the SF-36, SF-12, and RAND-36 summary scales in a multiple sclerosis population. *Med Care*. 2000; 38(10): 1022-8.

20. Visschedijk MA, Uitdehaag BM, Klein M, van der Ploeg E, Collette EH, Vleugels L, Pfennings LE, Hoogervorst EL, van der Ploeg HM, Polman CH. Value of health-related quality of life to predict disability course in multiple sclerosis. *Neurology*. 2004; 63(11): 2046-50.

21. Hobart J, Freeman J, Lamping D, Fitzpatrick R,Thompson, A. The SF-36 in multiple sclerosis: why basic assumptions must be tested. *J Neurol Neurosurg Psychiatry*. 2001; 71(3): 363-70.

22. Committee on Quality of Health Care in America, Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy of Sciences, Institute of Medicine;2001.

23. Snyderman R, Weil AT. Integrative medicine: bringing medicine back to its roots. *Arch Intern Med*. 2002; 162(4): 395-7.

24. Cherry D, Burt CW, Woodwell DA. National Ambulatory Medical Care Survey: 2001 Summary. *Adv Data*. 2003; 337: 1-44.

25. Yeh GY, Phillips RS, Davis RB, Eisenberg DM, Cherkin DC. Visit time as a framework for reimbursement: time spent with chiropractors and acupuncturists. *Altern Ther Health Med*. 2003; 9(5): 88-94.

26. Cherkin DC, Deyo RA, Sherman KJ, Hart LG, Street JH, Hrbek A, Davis RB, Cramer E, Milliman B, Booker J, Mootz R, Barassi J, Kahn JR,

Kaptchuck TJ, Eisenberg DM. Characteristics of visits to licensed acupuncturists, chiropractors, massage therapists, and naturopathic physicians. *J Am Board Fam Pract.* 2002; 15(6): 463-72.

27. Levinson W, Roter DL, Mullooly JP, Dull VT, Frankel RM. Physician-patient communication. The relationship with malpractice claims among primary care physicians and surgeons. *JAMA.* 1997; 277(7): 553-9.

28. Kroll T, Beatty PW, Bingham S. Primary care satisfaction among adults with physical disabilities: the role of patient-provider communication. *Manag Care Q.* 2003; 11(1): 11-9.

29. Forrest CB, Shi L, von Schrader S, Ng J. Managed care, primary care, and the patient-practitioner relationship. J Gen Intern Med. 2002; 17(4): 270-7

30. Probst JC, Greenhouse DL, Selassie AW. Patient and physician satisfaction with an outpatient care visit. *J Fam Pract.* 1997; 45(5): 418-25.

31. Bertakis KD, Roter D, Putnam SM. The relationship of physician medical interview style to patient satisfaction. *J Fam Pract.* 1991; 32(2): 175-81.

32. Keating NL, Green DC, Kao AC, Gazmararian JA, Wu VY, Cleary PD. How are patients' specific ambulatory care experiences related to trust, satisfaction, and considering changing physicians? *J Gen Intern Med. 2002*; 17(1): 29-39.

33. Krupat E, Rosenkranz SL, Yeager CM, Barnard K, Putnam SM, Inui TS. The practice orientations of physicians and patients: the effect of doctor-

patient congruence on satisfaction. *Patient Educ Couns*. 2000; 39(1): 49-59.

34. Zyzanski SJ, Stange KC, Langa D, Flocke SA. Trade-offs in high-volume primary care practice. *J Fam Pract*. 1998; 46(5): 397-402.

35. Eisenberg L. Complementary and alternative medicine: what is its role? *Harv Rev Psychiatry*. 2002; 10(4): 221-30.

36. Ware J, Jr., Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care*. 1996; 34(3): 220-33.

37. Kurtzke J. Rating neurological impairment in multiple sclerosis: an expanded disability status scale (EDSS). *Neurology*. 1983; 33: 1444-1452.

38. Shinto L, Yadav V, Morris C, Lapidus JA, Senders A, Bourdette D. Demographic and Health-related Factors Associated with Complementary and Alternative Medicine (CAM) Use in Multiple Sclerosis. *Mult Scler*. 2005; In press.

39. Hosmer D, Lemeshow S. Applied Logistic Regression, 2nd Ed. Wiley Series in Probability and Statistics. 2000, New York: John Wiley & Sons, Inc. 147-156.

40. PRISMS Study Group. Randomised double-blind placebo-controlled study of interferon beta-1a in relapsing/remitting multiple sclerosis. *Lancet*. 1998; 352(9139): 1498-504.

41. The IFNB Multiple Sclerosis Study Group and The University of British Columbia MS/MRI Analysis Group. Interferon beta-1b is effective in relapsing-remitting multiple sclerosis. *Neurology*. 1995;45:1277-85.

42. SPECTRUMS Study Group. Randomized controlled trial of interferon - beta-1a in secondary progressive MS: Clinical results. *Neurology*. 2001; 56(11): 1496-504.

43. Buchbinder R, Gingold M, Hall S, Cohen M. Non-prescription complementary treatments used by rheumatoid arthritis patients attending a community-based rheumatology practice. *Intern Med J*. 2002; 32(5-6): 208-14.

44. Ellis MR, Vinson DC, Ewigman B. Addressing spiritual concerns of patients: family physicians' attitudes and practices. *J Fam Pract*. 1999; 48(2): 105-9.

45. Safran DG. Defining the future of primary care: what can we learn from patients? *Ann Intern Med*. 2003; 138(3): 248-55.

46. Barrett B, Marchand L, Scheder J, Appelbaum D, Chapman M, Jacobs C, Westergaard R, St. Clair N. Bridging the gap between conventional and alternative medicine. *J Fam Pract*. 2000; 49(3): 234-9.

47. Kelner M, Wellman B. Health care and consumer choice: medical and alternative therapies. *Soc Sci Med*. 1997; 45(2): 203-12.

48. Gray CM, Tan AW, Pronk NP, O'Connor PJ. Complementary and alternative medicine use among health plan members. A cross-sectional survey. *Eff Clin Pract*. 2002; 5(1): 17-22.

49. Ong CK, Petersen S, Bodeker GC, Stewart-Brown S. Health status of people using complementary and alternative medical practitioner services in 4 English counties. *Am J Public Health*. 2002; 92(10): 1653-6.

50. Miller DM, Rudick RA, Baier M, Cutter G, Doughtery DS, Weinstock-Guttman B, Mass MK, Fisher E, Simonian N. Factors that predict health-related quality of life in patients with relapsing-remitting multiple sclerosis. *Mult Scler*. 2003; 9(1): 1-5.

51. Chang CH, Cella D, Fernandez O, Luque G, de Castro P, de Andres C, Casanova B, Hernandez MA, Prieto JM, Fernandez VE, de Ramon E. Quality of life in multiple sclerosis patients in Spain. *Mult Scler*. 2002; 8(6): 527-31.

52. Nortvedt MW, Riise T, Myhr KM, Nyland HI. Quality of life in multiple sclerosis: measuring the disease effects more broadly. *Neurology*. 1999; 53(5): 1098-103.

53. Jain N, Astin JA. Barriers to acceptance: an exploratory study of complementary/alternative medicine disuse. *J Altern Complement Med*. 2001; 7(6): 689-96.

54. Page SA, Verhoef MJ, Stebbins RA, Metz LM, Levy JC. The use of complementary and alternative therapies by people with multiple sclerosis. *Chronic Dis Can*. 2003; 24(2/3): 75-79.

55. Filippini G, Munari L, Incorvaia B, Ebers GC, Polman C, D'Amico R, Rice GP. Interferons in relapsing remitting multiple sclerosis: a systematic review. *Lancet*. 2003; 361(9357): 545-52.

56. Gandek B, Ware JE, Aaronson NK, Apolone G, Bjorner JB, Brazier JE, Bullinger M, Kaasa S, Leplege A, Prieto L, Sullivan M. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. *J Clin Epidemiol.* 1998; 51(11): 1171-8.

57. Schwartz CE, Vollmer T, Lee H. Reliability and validity of two self-report measures of impairment and disability for MS. North American Research Consortium on Multiple Sclerosis Outcomes Study Group. *Neurology.* 1999; 52(1): 63-70.

58. Hobart JC, Riazi A, Lamping DL, Fitzpatrick R, Thompson AJ. Measuring the impact of MS on walking ability: the 12-Item MS Walking Scale (MSWS-12). *Neurology.* 2003; 60(1): 31-6.

59. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. *J Fam Pract.* 2000; 49(9): 796-804.

60. Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, Payne S. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ.* 2001; 323(7318): 908-11.

61. Kaplan SH, Greenfield S, Ware JE, Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care.* 1989; 27(3 Suppl): S110-27.

Appendix A: Questionnaire on Treatments for Multiple Sclerosis

Oregon Center for Complementary and Alternative Medicine in Neurological Disorders (ORCCAMIND)
Oregon Health and Sciences University, Dept. of Neurology
3181 SW Sam Jackson Park Rd., Mail Code L226
Portland, OR 97201-3098

Instructions: Please complete the following questionnaire about the therapies you use to treat MS and MS-related symptoms. Do your best to answer all the questions on this 8-page questionnaire. We have included a quality of life questionnaire (SF-12), please fill out this form along with the MS-treatment questionnaire. If you need assistance in filling out these forms a caregiver may fill them out with you or for you. For questions that ask for a number value, write the number in the box. For questions that ask to mark a circle, using black pen or a pencil, darken the circle.

Descriptive Information

1.Your sex oMale oFemale

2. Your Age _____years

3.Your Racial/Ethnic Background
oCaucasian
oAfrican American
oHispanic
o Asian or Pacific Islander
oNative American or Alaskan native
oOther

4. Your highest educational degree:
oSome High School
oHigh School Diploma or GED
oSome College
oCollege Graduate
oSome Graduate School
oMasters Degree or Higher

5. What type of health insurance do you have?
oNone oEmployer provided o Self-provided oDept. of Veterans Affairs
oMedicare oMedicaid oOther_____
(please specify)

6.Does your health insurance cover any part of the cost of MS-related prescriptions?
o Yes o No oUnsure

7.Does your health plan cover any part of alternative treatments for MS?
o Yes o No oUnsure

Multiple Sclerosis Medical History

8.Have you been diagnosed with MS? oYes oNo o Unsure

9.Were you diagnosed with MS by a neurologist? o Yes o No o Unsure

10.How old were you when you were first diagnosed with MS? _____years

11.How old were you when you experienced your first MS symptoms? _____years

12. What type of MS do you currently have?
o Relapsing Remitting o Primary Progressive oSecondary Progressive o Not sure

13. During the past 6 months how many times did you go to the medical doctor (MD).
Specifically for MS_____times
For all other reasons_____ times

14. From the choices below, mark the circle that best fits your condition.

o **None/Minimal**
I have no or minimal MS-related symptoms, no limitations in walking ability, and no limitations on daily activities.

o **Mild**
I have noticeable MS-related symptoms but no limitations in walking ability and no limitations on daily activities.

o **Moderate**
I have many MS-related symptoms that affect my daily activities but can walk at least 1 block without support.

o **Some support needed for walking**
I have significant MS-related symptoms that limit physically demanding activities. I need support (e.g. cane, touching a wall, leaning on someone's arm) to walk ½-1block.

o **Walker/two-handed crutch**
I have significant MS-related symptoms that limit daily activities. I can walk only short distances with a walker or two-handed crutches.

o**Unable to walk**
I have many severe MS-related symptoms and am restricted to a wheelchair or bed.

If you have not used any herbs/nutritional supplements listed below please go to question #16.

15. Pertaining to the following list of herbs/nutritional supplements, please indicate which ones you are currently taking, which ones you have taken in the past and which ones you have never taken for your MS. For herbs/nutritional supplements you are currently taking or have taken in the past, please indicate how beneficial you feel these herbs/nutritional supplements have been for your MS. (Mark all that apply by filling in the circle)

Herbs/Nutritional Supplement for MS	Currently taking	Taken in the past	Never taken	Very beneficial	Somewhat beneficial	Unsure of benefit	Not beneficial
5-HTP	o	o	o	o	o	o	o
Ayurvedic herbs	o	o	o	o	o	o	o
Beta-carotene	o	o	o	o	o	o	o
Bioflavonoids	o	o	o	o	o	o	o
Carnitine	o	o	o	o	o	o	o
Chinese Herbs	o	o	o	o	o	o	o
Cod Liver oil/Fish oil	o	o	o	o	o	o	o
Co-Q-10	o	o	o	o	o	o	o
DHEA	o	o	o	o	o	o	o
Essential fatty acids (eg.flax etc.)	o	o	o	o	o	o	o
Evening Primrose oil	o	o	o	o	o	o	o
Ginkgo	o	o	o	o	o	o	o
Ginseng	o	o	o	o	o	o	o
Kava	o	o	o	o	o	o	o
Licorice	o	o	o	o	o	o	o
Lipoic acid	o	o	o	o	o	o	o
Magnesium	o	o	o	o	o	o	o
Melatonin	o	o	o	o	o	o	o
Multiple vitamin	o	o	o	o	o	o	o
Selenium	o	o	o	o	o	o	o
Soy or soy isoflavone	o	o	o	o	o	o	o
St. John's Wort	o	o	o	o	o	o	o
Valerian	o	o	o	o	o	o	o
Vitamin A	o	o	o	o	o	o	o
Vitamin B12	o	o	o	o	o	o	o
Vitamin B-Complex	o	o	o	o	o	o	o
Vitamin C	o	o	o	o	o	o	o
Vitamin E	o	o	o	o	o	o	o
Zinc	o	o	o	o	o	o	o
Other (please specify)	o	o	o	o	o	o	o

16. From the following list of disease-modifying drugs, please indicate which ones you are currently taking, which ones you have taken in the past and which ones you have never taken for your MS. For disease-modifying drugs that you are currently taking or have taken in the past, please indicate how beneficial you feel these medications have been for treating your MS. (Mark all that apply by filling in the circle)

Disease-modifying drugs for MS	Currently taking	Taken in the past	Never taken	Very beneficial	Somewhat beneficial	Unsure of benefit	Not beneficial
Interferon Beta-1a (Avonex)	o	o	o	o	o	o	o
Interferon Beta-1b (Betaseron)	o	o	o	o	o	o	o
Glatiramer acetate (Copaxone)	o	o	o	o	o	o	o
Mitoxantrone (Novantrone)	o	o	o	o	o	o	o
Gamma Globulins (Intravenous)	o	o	o	o	o	o	o
Sterods (Solu-Medrol, prednisone)	o	o	o	o	o	o	o
Other Immunosuppressants (Imuran, Cytoxan, Methotrexate)	o	o	o	o	o	o	o
Plasmapheresis	o	o	o	o	o	o	o
Other (specify)	o	o	o	o	o	o	o

17. Pertaining to the following list of diets, please indicate which ones you are currently using, which ones you have used in the past and which ones you have never used for your MS. For diets that you are currently using or have used in the past, please indicate how beneficial you feel these diets have been for your MS. (Mark all that apply by filling in the circle)

Type of diet for MS	Currently using	Used in the past	Never used	Very beneficial	Somewhat beneficial	Unsure of benefit	Not beneficial
Food allergy diet	o	o	o	o	o	o	o
High protein, low carbohydrate	o	o	o	o	o	o	o
Low fat, low cholesterol	o	o	o	o	o	o	o
Macrobiotic	o	o	o	o	o	o	o
Swank diet	o	o	o	o	o	o	o
Vegetarian	o	o	o	o	o	o	o
Wheat or Gluten free	o	o	o	o	o	o	o
Other (please specify)	o	o	o	o	o	o	o

18. Pertaining to the following list of providers, please indicate which ones you are currently seeing, which ones you have seen in the past and which ones you have never seen for your MS. For providers that you are currently seeing or have seen in the past please indicate how beneficial you feel these providers have been for treating your MS. (Mark all that apply by filling in the circle)

Provider seen for MS	Currently seeing	Have seen in the past	Have never Seen	Very beneficial	Somewhat beneficial	Unsure of benefit	Not beneficial
Acupuncturist	o	o	o	o	o	o	o
Aromatherapist	o	o	o	o	o	o	o
Ayurvedic physician	o	o	o	o	o	o	o
Biofeedback practitioner	o	o	o	o	o	o	o
Chiropractor	o	o	o	o	o	o	o
Christian science practitioner	o	o	o	o	o	o	o
Faith Healer	o	o	o	o	o	o	o
Herbalist	o	o	o	o	o	o	o

Homeopath	o	o	o	o	o	o	o
Hypnotherapist	o	o	o	o	o	o	o
Massage therapist	o	o	o	o	o	o	o
MD-neurologist	o	o	o	o	o	o	o
MD-neurologist-MS specialist	o	o	o	o	o	o	o
MD-non-neurologist	o	o	o	o	o	o	o
Naturopath	o	o	o	o	o	o	o
Nurse	o	o	o	o	o	o	o
Nutritionist	o	o	o	o	o	o	o
Occupational therapist	o	o	o	o	o	o	o
Physical therapist	o	o	o	o	o	o	o
Psychiatrist	o	o	o	o	o	o	o
Psychologist/Counselor	o	o	o	o	o	o	o
Other (please specify)	o	o	o	o	o	o	o

19. Please indicate how satisfied you have been with the care you receive from the following providers who you currently see regularly for <u>your MS</u> by filling in the appropriate circle (answer for each type of provider you see regularly for your MS).

Provider you see regularly for MS	**Very satisfied**	**Somewhat satisfied**	**Not satisfied**	**Not sure**
Alternative provider (specify type of provider)	o	o	o	o
MD-neurologist	o	o	o	o
MD-non-neurologist	o	o	o	o
Other (specify type of provider)	o	o	o	o

20. Please rate the providers you currently see regularly for your MS on the characteristics listed below by filling in the appropriate circle (answer for each type of provider you see regularly for your MS).

Characteristic	Provider you see regularly for MS	Excellent	Very Good	Good	Poor
Listening Skills	Alternative practitioner (specify type of provider)	o	o	o	o
	MD-neurologist	o	o	o	o
	MD-non-neurologist	o	o	o	o
	Other (specify type of provider)	o	o	o	o
Care and Concern	Alternative practitioner	o	o	o	o
	MD-neurologist	o	o	o	o
	MD-non-neurologist	o	o	o	o
	Other	o	o	o	o
Ability to instill a sense of self-control over my health	Alternative practitioner	o	o	o	o
	MD-neurologist	o	o	o	o
	MD-non-neurologist	o	o	o	o
	Other	o	o	o	o

21.For the providers you currently see regularly for your MS, what is the average amount of time you spend with the provider during an office visit? (answer all that apply by filling in the appropriate circle)

Provider you see regularly for MS	20 minutes	40 minutes	60 minutes	More than 60 minutes
Alternative practitioner (specify type of provider)	o	o	o	o
MD-neurologist	o	o	o	o
MD-non-neurologist	o	o	o	o
Other (specify type of provider)	o	o	o	o

If you do not use any of the therapies listed below please skip to question # 23

22.Pertaining to the following list of therapies, please indicate which ones you are currently using, which ones you have used in the past and which ones you have never used for your MS. For therapies that you are currently using or have used in the past, please indicate how beneficial you feel these therapies have been for your MS. (Mark all that apply by filling in the circle)

Therapy used for MS	Currently using	Have used in the past	Never used	Very beneficial	Somewhat beneficial	Unsure of benefit	Not beneficial
Bee Sting	o	o	o	o	o	o	o
Biofeedback	o	o	o	o	o	o	o
Dental amalgam removal	o	o	o	o	o	o	o
Guided Imagery	o	o	o	o	o	o	o
Heavy metal detoxification (chelation therapy)	o	o	o	o	o	o	o
Hyperbaric oxygen chamber	o	o	o	o	o	o	o
Hypnosis	o	o	o	o	o	o	o
Meditation	o	o	o	o	o	o	o
Plasma or whole blood infusions	o	o	o	o	o	o	o
Procarin	o	o	o	o	o	o	o
Other (please specify)	o	o	o	o	o	o	o

23. Pertaining to the following list of exercises, please indicate which ones you are currently using, which ones you have used in the past and which ones you have never used for your MS. For exercises that you are currently using or have used in the past, please indicate how beneficial you feel these exercises have been for your MS. (Mark all that apply by filling in the circle)

Exercise used for MS	Currently using	Have used in the past	Never used	Very beneficial	Somewhat beneficial	Unsure of benefit	Not beneficial
Stretching	o	o	o	o	o	o	o
Swimming	o	o	o	o	o	o	o
Walking	o	o	o	o	o	o	o
Water aerobics	o	o	o	o	o	o	o
Yoga	o	o	o	o	o	o	o
Other (please specify)	o	o	o	o	o	o	o

24.With whom do you discuss your use of herbs and/or nutritional supplements taken for your MS? **(Mark all that apply)**

oAlternative provider oMD-neurologist oMD-non-neurologist
oNurse oNo healthcare professional
oOther healthcare professional_____(please specify)

25.Do you hold any of the following religious/spiritual beliefs? **(please mark all that apply)**

o I believe in a connection between spirituality and health.
oSpirituality is important in my life.
oI believe in God or a higher power.
oI believe in the power of prayer.
o do not hold any of the beliefs listed above.

26. Please mark the statement below which <u>best</u> fits how you prefer to make your health care decisions.

oI keep my health care decisions in my own control.
oI have an equal partnership between myself and my doctor on health care decisions.
oI have an equal partnership among myself, my family/friends and my doctor on health care decisions.
oI primarily let my doctor guide health care decisions.
oI primarily let my family/friends guide health care decisions.

27. Who filled out this questionnaire?

oMyself oMyself plus a caregiver (eg. family, friend) oA caregiver (eg. family, friend)

Appendix B: SF-12 Form

OHSU Where Health Learning and Discovery Come Together — OREGON HEALTH SCIENCES UNIVERSITY

SF-12 Health Survey

Oregon Center for Complementary and Alternative Medicine in Neurological Disorders (ORCCAMIND)
MS Center of Oregon
Oregon Health & Science University, Dept. of Neurology
3181 SW Sam Jackson Park Rd., Mail Code L226
Portland, OR 97201-3098

Instructions: Please answer every question by filling in the appropriate circle using a blue or black pen. If you find a question confusing, simply answer the best you can.

Shade circles like this: ● **Not like this:** ✓ ✗ ⊖

1. In general, would you say your health is:
   - O Excellent
   - O Very good
   - O Good
   - O Fair
   - O Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:
   - O Yes, limited a lot
   - O Yes, limited a little
   - O No, not limited at all

3. Climbing several flights of stairs:
   - O Yes, limited a lot
   - O Yes, limited a little
   - O No, not limited at all

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

4. Accomplished less than you would like:
   - O Yes
   - O No

5. Were limited in the kind of work or other activities:
   - O Yes
   - O No

2639596190 **Please turn over and continue** ☐☐☐☐

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you would like:
   - O Yes
   - O No

7. Didn't do work or other activities as carefully as
   - O Yes
   - O No

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
   - O Not at all
   - O A little bit
   - O Moderately
   - O Quite a bit
   - O Extremely

The next several questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the Time	Most of the Time	A good Bit of the Time	Some of the Time	A little of the Time	None of the Time
9. Have you felt calm and peaceful?	O	O	O	O	O	O
10. Did you have a lot of energy?	O	O	O	O	O	O
11. Have you felt downhearted and blue?	O	O	O	O	O	O

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
   - O All of the time
   - O Most of the time
   - O Some of the time
   - O A little bit of the time
   - O None of the time

Thank You For Completing This Questionnaire
Please return it in the enclosed envelope.

2448596198