Complementary Therapies in Medicine

# Complementary and alternative medicines and dietary interventions in multiple sclerosis: What is being used in South Australia and why?[☆]

E.M. Leong[a], S.J. Semple[a,*], M. Angley[a], W. Siebert[b], J. Petkov[c], R.A. McKinnon[a]

[a] Quality Use of Medicines and Pharmacy Research Centre, Sansom Institute, University of South Australia, North Terrace, Adelaide, SA 5000, Australia
[b] Flinders Medical Centre, Flinders Drive, Bedford Park, SA 5042, Australia
[c] Applied Statistics Unit, Centre for Regional Engagement, University of South Australia, Whyalla Campus, Whyalla Norrie, SA 5608, Australia

Available online 21 April 2009

**Summary**

*Objectives:* To investigate the usage patterns of complementary and alternative medicines (CAMs), as well as dietary interventions, by South Australian people with multiple sclerosis (MS).
*Design:* Self-administered postal survey.
*Setting:* Questionnaire mailed to recipients of the South Australian (SA) MS Society newsletter ($n = 1230$).
*Main outcome measures:* Patterns of CAMs use and dietary interventions, reasons for using/not using CAMs in MS, sources of CAMs information and monthly expenditure on CAMs/dietary interventions.
*Results:* A total of 428 surveys were returned (response rate 34.8%) of which 416 met the inclusion criteria for analysis. The majority of SA people with MS who responded reported using CAMs/dietary interventions (64.7%). Respondents with tertiary education and those with mild and moderate disease reported highest CAM use. The most frequently used CAM product categories were vitamins (81.8%), essential fatty acids (80.7%) and minerals (62.5%). Commonly used herbal products included *Ginkgo biloba* (18.2%) and valerian (16.4%). Popular diets were the low fat (39.8%), low/no sugar (23.8%) and gluten-free (16.4%) diets. The majority of those using CAMs/dietary interventions did so concurrently with conventional treatments (72.1%). Reasons for use included: general health and well-being; to alleviate 'general' as well as specific MS symptoms such as muscle weakness, urinary or memory problems and mobility. Conventional health professionals, and friends/family, were the most common sources of information. Monthly expenditure was most commonly AUD$20—49/month.

*Conclusion:* This study reports frequent use of CAM/dietary intervention amongst SA people with MS. The majority of users did so in conjunction with conventional treatments.

## Introduction

Multiple sclerosis (MS) is a chronic, demyelinating central nervous system (CNS) disease that is more common in women. Onset typically occurs between the ages of 20 and 40.[1,2] Data indicates that MS is more prevalent at higher latitudes.[3] Symptoms of MS include fatigue, vertigo, imbalance, muscle weakness/spasm, incontinence, memory loss and visual disturbance.[1,4] Conventional MS treatments are limited and many have significant adverse effects,[4] prompting the increased use of complementary and alternative medicines (CAMs)[5–8] and dietary interventions.[9]

Studies have revealed that an array of CAMs is frequently used in MS.[5–8,10–12] The largest study was conducted in the US by Nayak et al. (*n* = 3140)[6] finding that 64.9% of individuals with MS used at least one CAM. Other smaller studies conducted in Germany,[13] Spain[12] and Italy[7] reported that 67.4%, 40.9% and 35.7% of MS respondents used at least one CAM, respectively. One small Australian study (*n* = 40) conducted in 1996 reported that 82.5% of individuals with MS employed CAM.[14]

Demographic and health-related factors have been associated with CAM use in MS. Female gender and higher education are predictors for CAM use.[6,11] Three US studies[6,11,15] reported that CAM use is higher amongst those living longer with a MS diagnosis. US studies by Nayak et al.[6] and Berkman et al.[10] found that disease severity had no significant influence on the use of CAMs/dietary interventions in MS. In contrast, Apel et al.[5] in Germany and Marrie et al.[11] in the US found that those with higher disease severity scores reported higher use.

Generally, previous studies have considered a broad definition of CAMs including complementary therapies, such as behavioural/physical therapies, in addition to interventions administered orally such as herbals and vitamins. This study was undertaken to specifically investigate the patterns of use of CAM products, supplements and dietary interventions in people with MS in Australia and excluded physical therapies such as acupuncture and magnetic therapy. The MS Society of SA and Northern Territory (SA/NT) had identified the need for an evidence-based resource to guide health care providers (HCPs) and clients in the selection of CAMs/dietary interventions for MS management. By reporting patterns of use of CAMs/diets in the SA MS population, it is hoped that both complementary and conventional HCPs will have better insight in the current use of CAMs in MS management.

## Methods

A questionnaire was mailed to 1230 recipients of the SA MS Society newsletter. The MS Society of SA/NT is the key state-based non-Government organisation providing infor-mation and services to individuals with MS. MS Society clients are either self-referred and/or encouraged to join by their MS specialist following diagnosis. Individuals with a MS diagnosis were eligible to respond. The following information on demographics and health-related factors was collected: type of MS diagnosis, time since diagnosis, condition severity, age, gender, place of residence, household income and education level. A modified qualitative disease severity rating scale developed by Shinto et al.[8] was used in substitution for Kurtzke's extended disability status scale (EDSS). The questionnaire included a descriptive explanation of each severity category as used previously[8] to help participants classify their disease severity. Minor modifications to wording were made for the Australian setting. For the statistical analysis, the six severity categories were collapsed into three: 'none/minimal or mild', 'moderate or some support needed' and 'severe MS symptoms (requiring a walker/crutch or unable to walk)'. The type of MS diagnosis relied on participants' self-report and included an 'unsure' category. CAMs surveyed included minerals, vitamins, essential fatty acids (EFAs), herbals, homeopathics, flower remedies and other supplements. Dietary interventions included the 'Swank', organic, gluten-free, allergen-free and low-fat diets.

The questionnaire was designed to investigate the types of CAMs/dietary interventions used by individuals with MS, patterns of use, reasons for using/not using these interventions, sources of information, monthly expenditure and perceptions of efficacy.

The questionnaire was developed using information from earlier studies[5–8,12,16,17] in consultation with a multidisciplinary panel from the SA/NT MS Society and a consumer with MS. The survey was piloted with a small number of individuals with MS and amended as necessary.

Ethics approval was provided by the Human Research Ethics Committee, Division of Health Sciences, University of South Australia. Administration of the questionnaire was also approved by the SA/NT MS Society.

## Statistical analyses

Questionnaire responses were analysed using the Statistical Package for the Social Sciences (SPSS) version 15.0 (SPSS Inc, Chicago, IL, USA). Frequency, percentage and other descriptive statistics were used to describe and summarise data. Exact chi-square tests were used to examine relationships between participants' demographics/health-related factors and use of CAMs/dietary interventions, with a *p* value < 0.05 considered significant. A post-hoc analysis was conducted examining the standardised residuals to determine in which categories the differences existed. A standardised residual of 2 or greater (absolute size) indicated significance in that cell.

# Results

## Response rate

A total of 428 surveys were returned (response rate 34.8%). Twelve surveys were excluded due to respondents giving responses unable to be interpreted. This included questionnaires where the respondent stated that they did not use CAMs/dietary interventions but filled out some of the section about specific CAMs or diets used. It was unclear whether these respondents had understood the survey. Others were excluded because responses were indecipherable and/or contradictory. These surveys were excluded by consensus of three authors. Thus 416 surveys were analysed.

## Frequency of CAMs/dietary intervention use and association with demographic and health-related factors

Overall, 64.7% of respondents ($n = 269$) reported current/previous use of CAMs/diets. Respondents could indicate duration of 'current' or 'previous' use (not shown). Nearly all these respondents ($n = 263$) had used at least one CAM product with 6 participants implementing dietary interventions only.

The association between demographic and health-related factors and use of CAMs/dietary interventions is summarised in Table 1. The frequency of males reporting CAMs/diet use (60.3%) was slightly lower than females (66.3%); however, this was not significant. There was a trend for respondents with a diagnosis of relapsing—remitting MS and secondary progressive MS to be more likely to use CAMs/dietary interventions, however differences only reached significance when the 'unsure of type' category was considered.

A lower frequency of CAMs/diet use was reported with greater disease severity. Of respondents unable to walk, 53.8% reported CAMs/dietary intervention usage while 50.9% of respondents relying on a walker/crutch to walk reported usage. A higher frequency of CAM usage was reported in those with mild (72.3%) or moderate (73.0%) severity MS and those needing some support to walk (72.9%). When severity categories were collapsed from six into three ('none/minimal or mild', 'moderate or some support needed' and 'severe MS symptoms'), there was a significant difference in CAMs/diet usage between the categories ($\chi^2 = 12.172$, 2 df, $p = 0.002$). An analysis of the standardised residuals to establish where this significance occurred indicated that subjects with a more severe condition (requiring a walker/crutch or unable to walk) tended to use CAMs/diets less than would be expected if there had been independence.

There was no significant difference between the rate of usage of CAMs/diets with time since MS diagnosis. There was a higher percentage of use amongst respondents living in rural areas compared to those living in city/metropolitan areas (i.e. 70.4% vs 65.3%). However, there were no significant differences between the various categories for place of residence. Analysis of standardised residuals revealed no differences.

There was a similar frequency of use reported over the household income brackets. The frequency of respondents using CAMs/diets was significantly higher amongst those who had completed tertiary education ($\chi^2 = 12.168$; 2 df; $p = 0.002$).

## Types of CAMs/dietary interventions used and perceptions about efficacy

Amongst respondents using CAMs/diets, a median number of 6.0 CAM products were used/person (range 0—31). For 72.1% of those using CAMs/diets, use was concurrent with conventional treatment. The median number of dietary interventions used was 1.0 (range 0—11).

Amongst those reporting current/previous use of CAMs, vitamins, EFAs and minerals were the most commonly used product categories, with a total use of 81.8%, 80.7% and 62.5%, respectively. A range of herbals were used including *Ginkgo biloba* (18.2%), valerian (16.4%), ginseng (10.4%) and St. John's Wort (9.7%). The most commonly implemented dietary interventions were low fat (39.8%), sugar-free/low sugar (23.8%) and wheat or gluten-free (16.4%). The MS-specific 'Swank diet' was implemented by 11.1% of CAMs/diet users.

The frequency of use and perceptions of efficacy of various commonly used CAMs are shown in Table 2. Less than half of users perceived the CAMs they used/had used (other than cranberry, glucosamine/chondroitin, magnesium, B group vitamins and vitamin D) to be effective.

## Reasons for using and not using CAMs/dietary interventions in MS

CAM/diet use targeted a broad range of MS-specific symptoms as well as more general symptoms and well-being (Fig. 1). A number of other reasons were stated including prevention of attacks/relapses of MS, aiding sleep, treating restless legs, neuralgia and detoxification.

Reasons cited by 147 non-users for not employing any form of CAMs/diets included: never considered using them (43.5%); satisfied with conventional treatment (29.3%); did not believe they worked (19.7%); cost (12.9%); and doctor advised against using (7.5%).

## Information sources

A broad range of sources were consulted for information on CAMs/diets with conventional HCPs and family/friends/caregivers being the most common (Fig. 2). Of the 118 respondents who sought CAM information from conventional HCPs, most obtained it from doctors (71.2%). Other information sources included radio, product manufacturers and other associations.

## Monthly expenditure

Monthly expenditure was most frequently AUD$20 to $49 as reported by 27.9% of CAMs/diet users. Monthly expenditure was AUD$100 or more for 23.0% of CAM/diet users.

**Table 1** Respondents' health-related and demographic factors and use of CAM/dietary interventions.

| | Users of CAM/dietary interventions, n (%) | Non-users of CAM/dietary interventions, n (%) | Statistical significance (Chi-square) |
|---|---|---|---|
| All respondents (n = 416) | 269 (64.7) | 147 (35.3) | |
| *Health-related factors* | | | |
| Type of diagnosis | | | |
| Benign | 10 (62.5) | 6 (37.5) | $\chi^2$ = 11.872; 5 df; |
| Relapsing—remitting | 161 (70.6) | 67 (29.4) | p = 0.035 |
| Primary progressive | 21 (55.3) | 17 (44.7) | |
| Secondary progressive | 26 (72.2) | 10 (27.8) | |
| Progressive-relapsing | 11 (68.8) | 5 (31.2) | |
| Unsure of type | 31 (50.0) | 31 (50.0) | |
| No response | 9 (45.0) | 11 (55.0) | |
| Time since MS diagnosis (in years) | | | |
| 0—9.9 | 118 (64.8) | 64 (35.2) | $\chi^2$ = 54.78; 5 df; |
| 10—19.9 | 92 (65.7) | 48 (34.3) | p = 0.443 |
| 20—29.9 | 42 (66.7) | 21 (33.3) | |
| 30—39.9 | 14 (63.6) | 8 (36.4) | |
| 40—49.9 | 1 (25.0) | 3 (75.0) | |
| 50—50.9 | 0 (0.0) | 1 (100.0) | |
| No response | 2 (50.0) | 2 (50.0) | |
| Condition severity | | | |
| None/minimal or mild | 108 (67.1) | 53 (32.9) | $\chi^2$ = 12.172, 2 df, |
| Moderate or some support needed | 97 (72.9) | 36 (27.1) | p = 0.002 |
| Severe MS symptoms (walk with walker/crutch or unable to walk) | 63 (52.5) | 57 (47.5) | |
| No response | 1 (50.0) | 1 (50.0) | |
| *Demographic factors* | | | |
| Gender | | | |
| Male | 73 (60.3) | 48 (39.7) | $\chi^2$ = 1.341; 1 df; |
| Female | 193 (66.3) | 98 (33.7) | p = 0.260 |
| No response | 3 (75.0) | 1 (25.0) | |
| Place of residence | | | |
| City/metropolitan | 190 (65.3) | 101 (34.7) | $\chi^2$ = 5.225; 3 df; |
| Rural | 57 (70.4) | 24 (29.6) | p = 0.156 |
| Remote area | 18 (51.4) | 17 (48.6) | |
| Regional centre | 2 (40.0) | 3 (60.0) | |
| No response | 2 (50.0) | 2 (50.0) | |
| Household income | | | |
| Less than AUD$20,000 | 72 (61.5) | 45 (38.5) | $\chi^2$ = 2.335; 3df; |
| Between AUD$20,000 and $49,999 | 91 (62.8) | 54 (37.2) | p = 0.506 |
| Between AUD$50,000 and $100,000 | 79 (69.9) | 34 (30.1) | |
| More than AUD$100,000 | 16 (69.6) | 7 (30.4) | |
| No response | 11 (61.1) | 7 (38.9) | |
| Level of education | | | |
| Primary | 4 (36.4) | 7 (63.6) | $\chi^2$ = 12.168; 2 df; |
| Secondary | 138 (60.0) | 92 (40.0) | p = 0.002 |
| Tertiary | 126 (73.7) | 45 (26.3) | |
| No response | 1 (25) | 3 (75) | |

## Discussion

Similar to previous studies, we found a high prevalence of CAMs/dietary interventions use in SA people with MS.[5–8,10–12,14] However, these other studies included physical and behavioural approaches and did not report the use of specific CAM products or special diets as separate categories.

**Table 2** Frequency of use and perception of efficacy for CAM products amongst users of CAMs and dietary interventions (n = 269).

| CAM products | Current use, n (%) | Previous use, n (%) | Perceived to be effective[a] |
|---|---|---|---|
| **Minerals** | | | |
| Calcium | 97 (36.1) | 43 (16.0) | 58 (46.0%) |
| Magnesium | 93 (34.6) | 51 (19.0) | 71 (54.2%) |
| Zinc | 63 (23.4) | 39 (14.5) | 36 (39.6%) |
| Iron | 38 (14.1) | 29 (10.8) | 24 (35.3%) |
| Selenium | 33 (12.3) | 38 (14.1) | 23 (31.5%) |
| **Vitamins** | | | |
| Multivitamins | 34 (12.6) | 8 (3.0) | 21 (47.7%) |
| Vitamin A | 28 (10.4) | 22 (8.2) | 21 (39.6%) |
| Vitamin B 1,2 and/or 6 | 103 (38.3) | 40 (14.9) | 70 (54.3%) |
| Vitamin C | 76 (28.3) | 38 (14.1) | 51 (47.2%) |
| Vitamin E | 64 (23.8) | 30 (11.2) | 39 (43.8%) |
| Vitamin B12 | 111 (41.3) | 45 (16.7) | 80 (55.6%) |
| Vitamin D | 80 (29.7) | 25 (9.3) | 49 (50.5%) |
| Folic acid | 54 (20.1) | 26 (9.7) | 25 (31.3%) |
| **Plant/herbal supplements** | | | |
| Cranberry | 22 (8.2) | 2 (0.7) | 16 (66.7%) |
| Grape seed/pine bark extract | 9 (3.3) | 16 (5.9) | 9 (37.5%) |
| *Ginkgo biloba* | 32 (11.9) | 21 (7.8) | 21 (42.9%) |
| Ginseng | 12 (4.5) | 18 (6.7) | 8 (28.6%) |
| St. John's Wort | 8 (3.0) | 18 (6.7) | 9 (34.6%) |
| Valerian | 17 (6.3) | 28 (10.4) | 18 (40.9%) |
| **Essential fatty acids** | | | |
| Fish oil | 168 (62.5) | 53 (19.7) | 94 (47.0%) |
| Evening primrose oil | 62 (23.0) | 61 (22.7) | 37 (32.5%) |
| Flaxseed oil | 13 (4.8) | 3 (1.1) | 7 (41.2%) |
| Cod liver oil | 3 (1.1) | 1 (0.4) | 1 (20.0%) |
| Alpha lipoic acid | 9 (3.3) | 7 (2.6) | 6 (35.3%) |
| **Miscellaneous supplements** | | | |
| Coenzyme Q10 | 21 (7.8) | 26 (9.7) | 12 (28.6%) |
| Chelation therapy | 4 (1.5) | 8 (3.0) | 2 (13.3%) |
| Cerebrosides/glyconutrients | 11 (4.1) | 5 (1.9) | 8 (42.1%) |
| Carnitine | 3 (1.1) | 6 (2.2) | 1 (9.1%) |
| Glucosamine/chondroitin | 12 (4.5) | 1 (0.4) | 10 (76.9%) |
| Melatonin | 5 (1.9) | 8 (3.0) | 5 (35.7%) |
| **Homeopathic products** | 15 (5.6) | 28 (10.4) | 14 (35.9%) |
| **Flower remedies** | 7 (2.6) | 16 (5.9) | 6 (24.0%) |

[a] Denominator is the subset of respondents using the specific CAM product, some respondents reported using the product both currently and previously.

It is notable that there was a high prevalence of use despite a limited evidence-base for the use of CAMs/diets in MS.[9,18,19] The following CAMs were the most frequently used 'currently' by CAM users: fish oil (62.5%), vitamin B12 (41.3%), vitamin B1, 2 and/or 6 (38.3%), magnesium (34.6%), vitamin D (29.7%) and evening primrose oil (EPO) (23.0%). The most common diet used 'currently' was the low fat diet (39.8%). The only Australian published study examining CAM use by people with MS (n = 40) also found a high usage of EPO (50%).[14] This study also reported that half of the participants used an oral vitamin supplement, although vitamin types were not detailed.[14] Nayak et al.'s large US study[6] found herbal medicines (used by 27% of participants) and vitamins (used by 45%) were commonly used. In the same study, the 'Swank' diet (used by 16% of participants) and general dietary modifications including a low-fat diet (used by 10%) were common. Another large US study[20] found vitamin C, vitamin E, B complex, B12 and EFAs were frequently used. Similar to our study, *Ginkgo* was the most popular herbal medicine.[20]

There is growing interest in supplements rich in omega-3 and 6 EFAs in MS,[21] which may offer anti-inflammatory and immunosuppressive benefits.[9] Although EFAs confer other health benefits, their usage has not been shown to reduce the number of MS relapses and severity of exacerbations.[21,22]

Low vitamin B12 has been linked to MS, as B12 is a prerequisite for myelin synthesis[23–25] and deficiency somewhat resembles MS clinically.[23–25] Although large, controlled stud-
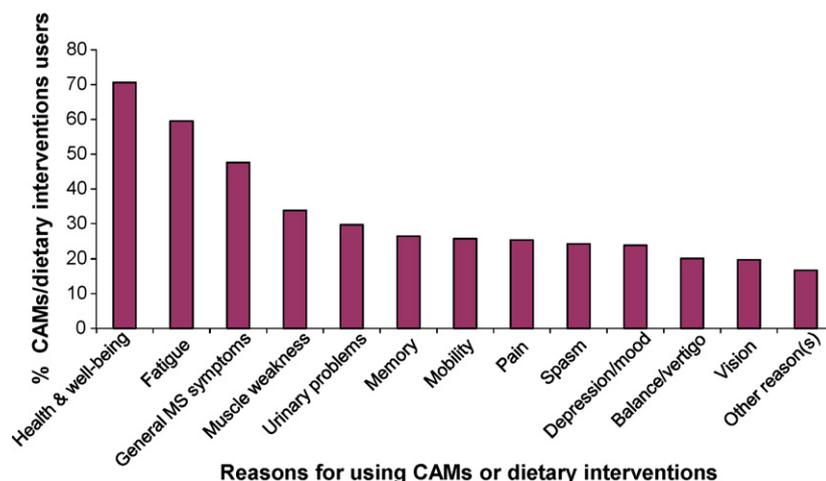
**Figure 1**   Reasons for using CAMs or dietary interventions in MS ($n = 269$). *Note*: Percentages add up to more than 100% because more than one target symptom could be chosen.

ies with vitamin B12 in MS have not been conducted, it is plausible that B12 may have a role in MS. There is currently insufficient evidence to recommend B12 supplementation other than for deficiency. Similarly, evidence for other B-vitamin supplementation is scant, although low levels of vitamins B1, 2 and 6 have been reported.[23,26]

The frequent usage of magnesium reported here may be attributed to claims it can reduce muscle weakness/cramps in MS. However, there is currently inadequate data supporting such a role.[9]

A relationship between the geographic distribution of MS, exposure to sunlight, and vitamin D metabolism has long been considered. In the US-American Nurses' Health Study, women who took additional vitamin D supplements had a 40% lower risk of MS.[27] To date, there has not been sufficient evidence to routinely recommend vitamin D therapy for MS. However, people with MS should routinely have their vitamin D levels measured and vitamin D prescribed if deficient, being mindful of hypercalcaemia as a possible side effect.

The frequent implementation of the low fat diet in the SA MS population may be attributed to awareness that, theoretically, increased dietary intake of saturated fatty acids may disrupt myelin stability, leading to increased susceptibility to demyelination.[9,21,28] Although unproven, it seems plausible to advocate a low-fat diet as other health benefits can result. The low-fat 'Swank diet' has also been suggested for delaying MS progression.[9]

An international review examining relationships between demographics and health factors with general CAM use found a tendency for users to be middle-aged, highly educated and female.[29] A 2004 SA study found that the greatest CAM use amongst the general population was by women aged 25—34, with higher income and education.[16] Our study suggested tertiary education, but not gender and income, influenced CAM use in MS.

In this study, the gender response rate (2.4:1.0; female:male) most likely reflects the gender ratio of the condition. Reported female:male ratios in MS vary geographically (e.g. between 1.1:1 and 3.4:1 within Europe[30] and over
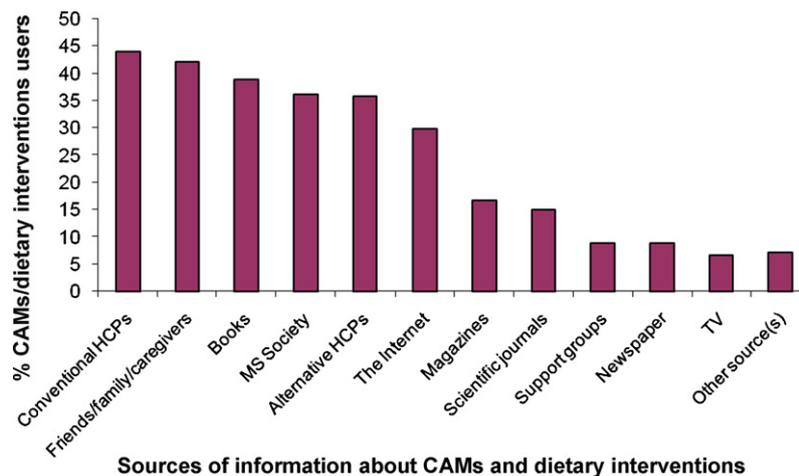


**Figure 2**   Sources of information about CAMs and dietary interventions ($n = 269$). *Note*: Percentages add up to more than 100% because more than one source could be chosen. HCPs = health care practitioners.

time (e.g. from 1.5:1 in 1961 to 2.6:1 in 1996 in Newcastle, Australia[31]).

Regarding the relationship between level of education and CAM use in MS, results from our study were congruent with two studies which showed that tertiary education was associated with CAM use.[6,10] However, these findings contrasted to those of Sastre-Garriga et al. who found no relationship with education level.[12]

We found that those reporting a more severe condition had a lower frequency of CAM use than those reporting mild to moderate disease. This is in contrast to two US studies[6,10] who found that disease severity had no influence on CAM use in MS and to a further two studies[5,11] where it was found that those with more severe disease had higher usage.

Our questionnaire also examined reasons for not using CAMs/diets based on a question developed previously for a US study of CAM use in MS.[6] The most frequent responses from 'non-user' respondents in our study were: never considered using these interventions (43.5%), satisfied with conventional treatment (29.3%) and did not believe that CAM interventions work (19.7%). The most frequent reasons cited by 'non-users' in Nayak et al.'s study[6] were: never considering CAMs as a health care option (26.8%), cost (25.1%) and satisfaction with conventional treatment (21.7%).

Considerable 'out-of-pocket' expenditure is associated with CAMs/diets for individuals with MS in managing their condition. As CAMs have a limited evidence-base to support usage in MS,[9,18,19] they are not subsidised by the Australian government. The monthly expenditure on CAMs in our study is consistent with the general SA population which was reported as AUD$21.23 in 2006.[16]

Conventional HCPs, friends, family and caregivers were the most frequently reported CAM information sources in our study. There is a need for non-biased, evidence-based materials regarding the use of CAMs/diets in MS that meet the needs of those with MS and others involved in their care. Access to information such as the evidence-base, safety and rationale of various CAM products will equip all stakeholders with knowledge and skills to make informed decisions about CAM use in MS.

As CAMs/diets are widely used in MS, it is important that conventional HCPs develop an open therapeutic relationship with MS patients. They should determine whether people are implementing CAMs/diets to manage MS and be prepared to seek and interpret information as appropriate. Having access to a patient's comprehensive medication history will minimise the occurrence of interactions with other medicines and facilitate detection of adverse effects.

To ascertain the representativeness of the study sample, comparisons were made with a national report including data from the Australian Multiple Sclerosis Longitudinal Study.[32] This report estimated that 61% of people with MS in Australia live in major cities (metropolitan) suggesting our study sample was slightly over-representative for people living in the city/metropolitan setting. The report also estimated that 33%, 46% and 21% of people with MS have a mild, moderate and severe condition, respectively. Our study's condition severity distribution differed somewhat, with 39%, 32% and 29% of respondents reporting a mild, moderate and severe condition, respectively. When the representativeness of the female:male ratio of respondents was considered, the gender ratio of respondents was 2.4:1 which matches the reported MS gender distribution in SA.[33] In addition, the type of MS diagnosis reported by respondents reflects international data on distribution. Globally, it is reported that approximately 15% of people with MS have primary-progressive/progressive-relapsing disease, while 85% have relapsing—remitting/secondary progressive disease.[34]

Potential limitations of this study include the retrospective nature of data collection and response and/or recall bias. Additionally, evaluation of disease severity may be limited as respondents self-assessed condition severity. As different studies use different scales, direct comparisons with other studies should be interpreted with caution. The SA/NT MS Society does not provide members with information on MS diagnosis; therefore this study relied on respondent self-report which may be subject to error. A somewhat low response rate of 34.8% was achieved and no reminders were sent. However, this response rate was similar to some earlier studies.[6,8]

## Conclusions

This study revealed that 64.7% of the SA MS population used CAMs/dietary interventions. Usage of these interventions was higher in those with tertiary education and less severe disease. There is a lack of good quality clinical evidence supporting use of CAMs/diets frequently implemented in MS. More randomised controlled studies are needed to improve their evidence-base. This study can inform HCPs of the patterns and frequency of usage of CAMs/diets by people with MS in SA.

## Acknowledgements

## References

1. Pender MP. Multiple sclerosis: early diagnosis and comprehensive management. *Medicine Today* 2006;**7**:14—21.
2. Porth C. *Essentials of pathophysiology: Concepts of altered health states*. 2nd edn. Philadelphia, PA: Lippincott Williams & Wilkins; 2007.
3. Flachenecker P. Epidemiology of neuroimmunological diseases. *Journal of Neurology* 2006;**253**(Suppl. 5). V/2—V/8.
4. Calabresi PA. Diagnosis and management of multiple sclerosis. *American Family Physician* 2004;**70**:1935—44.
5. Apel A, Greim B, Zettl UK. How frequently do patients with multiple sclerosis use complementary and alternative medicine? *Complementary Therapies in Medicine* 2005;**13**:258—63.
6. Nayak S, Matheis RJ, Schoenberger NE, Shiflett SC. Use of unconventional therapies by individuals with multiple sclerosis. *Clinical Rehabilitation* 2003;**17**:181—91.
7. Pucci E, Cartechini E, Taus C, Giuliani G. Why physicians need to look more closely at the use of complementary and alternative medicine by multiple sclerosis patients. *European Journal of Neurology* 2004;**11**:263—7.

8. Shinto L, Yadav V, Morris C, Lapidus JA, Senders A, Bourdette D. The perceived benefit and satisfaction from conventional and complementary and alternative medicine (CAM) in people with multiple sclerosis. *Complementary Therapies in Medicine* 2005;**13**:264—72.

9. Schwarz S, Leweling H. Multiple sclerosis and nutrition. *Multiple Sclerosis* 2005;**11**:24—32.

10. Berkman CS, Pignotti MG, Cavallo PF, Holland NJ. Use of alternative treatments by people with multiple sclerosis. *Neurorehabilitation and Neural Repair* 1999;**13**: 243—54.

11. Marrie RA, Hadjimichael O, Vollmer T. Predictors of alternative medicine use by multiple sclerosis patients. *Multiple Sclerosis* 2003;**9**:461—6.

12. Sastre-Garriga J, Munteis E, Rio J, Pericot I, Tintore M, Montalban X. Unconventional therapy in multiple sclerosis. *Multiple Sclerosis* 2003;**9**:320—2.

13. Apel A, Greim B, Konig N, Zettl UK. Frequency of current utilisation of complementary and alternative medicine by patients with multiple sclerosis. *Journal of Neurology* 2006;**253**:1331—6.

14. Hooper K, Pender M, Webb P, McCombe P. Use of traditional and complementary medical care by patients with multiple sclerosis in South-East Queensland. *International Journal of MS Care* 2001;**3**:3—13.

15. 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. *Multiple Sclerosis* 2006;**12**:94—100.

16. MacLennan AH, Myers SP, Taylor AW. The continuing use of complementary and alternative medicine in South Australia: costs and beliefs in 2004. *Medical Journal of Australia* 2006;**184**:27—31.

17. Stankiewicz M, Smith C, Alvino H, Norman R. The use of complementary medicine and therapies by patients attending a reproductive medicine unit in South Australia: a prospective survey. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 2007;**47**:145—9.

18. Bowling A. *Alternative medicine and multiple sclerosis*. New York: Demos Medical Publishing; 2001.

19. Huntley A. A review of the evidence for efficacy of complementary and alternative medicines in MS. *International MS Journal* 2006;**13**(4):5—12.

20. Yadav V, Shinto L, Morris C, Senders A, Baldauf-Wagner S, Bourdette D. Use and self-reported benefit of complementary and alternative medicine among multiple sclerosis patients. *International Journal of MS Care* 2006;**8**:5—10.

21. Farinotti M, Simi S, Di Pietrantonj C, et al. Dietary interventions for multiple sclerosis. *Cochrane of Database Systematic Reviews* 2007;(1). CD004192.

22. Payne A. Nutrition and diet in the clinical management of multiple sclerosis. *Journal of Human Nutrition & Dietetics* 2001;**14**:349—57.

23. Miller A, Korem M, Almog R, Galboiz Y. Vitamin B12, demyelination, remyelination and repair in multiple sclerosis. *Journal of Neurological Sciences* 2005;**233**:93—7.

24. Sandyk R, Awerbuch GI. Vitamin B12 and its relationship to age of onset of multiple sclerosis. *International Journal of Neuroscience* 1993;**71**:93—9.

25. Goodkin DE, Jacobsen DW, Galvez N, Daughtry M, Secic M, Green R. Serum cobalamin deficiency is uncommon in multiple sclerosis. *Archives of Neurology* 1994;**51**:1110—4.

26. Johnson S. The possible role of gradual accumulation of copper, cadmium, lead and iron and gradual depletion of zinc, magnesium, selenium, vitamins B2, B6, D, and E and essential fatty acids in multiple sclerosis. *Medical Hypotheses* 2000;**55**:239—41.

27. Munger KL, Zhang SM, O'Reilly E, et al. Vitamin D intake and incidence of multiple sclerosis. *Neurology* 2004;**62**:60—5.

28. Weinstock-Guttman B, Baier M, Park Y, et al. Low fat dietary intervention with omega-3 fatty acid supplementation in multiple sclerosis patients. *Prostaglandins Leukotrienes % Essential Fatty Acids* 2005;**73**:397—404.

[29]. Bishop FL, Lewith GT. Who uses CAM? A narrative review of demographic characteristics and health factors associated with CAM use. *eCAM* 2008, doi:10.1093/ecam/nen023.

30. Pugliatti M, Rosati G, Carton H, et al. The epidemiology of multiple sclerosis in Europe. *European Journal of Neurology* 2006;**13**:700—22.

31. Barnett MH, Williams DB, Day S, Macaskill P, McLeod JG. Progressive increase in incidence and prevalence of multiple sclerosis in Newcastle, Australia: a 35-year study. *Journal of the Neurological Sciences* 2003;**213**:1—6.

32. *Access economics. Acting positively: strategic implications of the economic costs of multiple sclerosis in Australia.* Canberra, ACT, MS Australia. <http://www.accesseconomics.com.au/publicationsreports/showreport.php?id=7&searchfor=2005&searchby=year>; 2005 [accessed 24.11.08].

33. McLeod JG, Hammond SR, Hallpike JF. Epidemiology of multiple sclerosis in Australia: with NSW and SA survey results. *Medical Journal of Australia* 1994;**160**:117—9, 121.

34. Vollmer T. The natural history of relapses in multiple sclerosis. *Journal of the Neurological Sciences* 2007;**256** (Suppl. 1):S5—13.