

Research paper

Effect of a residential retreat promoting lifestyle modifications on health-related quality of life in people with multiple sclerosis

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ABSTRACT

Aim To evaluate the effect of a residential retreat on promoting lifestyle modification for the health-related quality of life (HRQOL) of people with multiple sclerosis (MS).

Methods A longitudinal cohort study of adults with self-reported MS who voluntarily attended a five-day residential retreat in rural Victoria, Australia. Participants were asked to complete the MSQOL-54 questionnaire just prior to the retreat, and at one year and 2.5 years post-retreat.

Results Of 188 participants 109 (58%) completed the questionnaire. The cohort showed a significant improvement in HRQOL at one year and 2.5 year follow-up. After one year, overall quality of life (QOL) domain had increased from 73.4 to 81.7 ($P<0.001$), physical health composite from 66.2 to 76.4 ($P=0.001$) and mental health composite from

73.7 to 83.6 ($P<0.001$) in the subset of 76 with data at both time points. After 2.5 years, overall QOL had increased from 68.4 to 71.7 ($P=0.03$), physical health 59.7 to 70.0 ($P=0.01$), and mental health 66.9 to 76.6 ($P<0.01$) in the subset of 44 with data at both time points.

Conclusions HRQOL usually deteriorates over time in people with MS. Attendance at a residential retreat promoting lifestyle modification appears to have a significant short–medium term positive effect on QOL for people with MS. General practitioners caring for people with MS should consider the potential benefits of this approach in overall management.

Keywords: health-related quality of life, lifestyle modification, multiple sclerosis, MSQOL

How this fits in with quality in primary care

What do we know?

Multiple sclerosis (MS) is a lifelong, progressively disabling neurological condition, for which medications are currently only modestly effective. Various lifestyle factors have previously been shown to influence the risk of developing MS and of progression to disability.

What does this paper add

An integrative approach, combining intensive lifestyle changes, and delivered through a residential program, improves short-medium term health and quality of life in people with MS. General practitioners managing people with MS can recommend an intensive lifestyle program with the potential to significantly improve quality of life, and physical and mental health.

Introduction

Multiple sclerosis (MS) is a chronic inflammatory disorder of the central nervous system that is thought to be autoimmune and degenerative in nature. It is the most common cause of neurological disability among young adults,¹ affecting approximately 18 000 Australians and 2.5 million people worldwide. Inflammatory lesions in the brain and spinal cord cause a range of symptoms such as visual impairment, muscle weakness and spasticity and bladder dysfunction.² This incurable disabling disease affects the psychological and social wellbeing of people with MS. Among other effects, these people experience higher rates of depression and suicide.³

MS has an unpredictable clinical course that usually evolves over several decades. The frequency and severity of new lesions appears random, and they occur more often than they are detected clinically.⁴ Usually all types of MS lead to deterioration of health and permanent disability, and sometimes death.⁵ The median survival time from disease onset is around 28 years,⁶ with at least a five to ten year reduction in life expectancy.⁷

Most people with MS are treated with long-term immunomodulatory therapy including the interferons, glatiramer and more recently natalizumab. However, the effectiveness of these drugs in slowing disease progression is questionable,⁸ as is their cost-effectiveness.⁹ A systematic review of the efficacy and cost-effectiveness found some clinical benefit of these drugs, which may be counterbalanced by side effects and cost.⁹ Hence many people with MS seek non-drug therapies to manage their condition.¹⁰ Currently there is a growing need to compare pharmacological treatments to other therapies that may improve QOL.¹¹

Patients with chronic diseases often feel the need to actively gain control over their health and explore options beyond standard treatments.¹² For this reason, many people with MS have tried at least one alternative

therapy to manage the condition.¹³ Studies on therapies such as a low saturated fat diet,^{14–16} vitamin supplementation,¹⁷ exercise^{18,19} and stress management^{20–22} have suggested a benefit. There has been a call for these modalities to be considered in the primary care management of people with MS.²³

Previous studies have explored the outcome of combined intervention programmes for people with MS, delivered through weekly sessions.^{24,25} A review of the literature found no studies on residential educational and experiential programmes encouraging lifestyle modifications for people with MS.

Since April 2002, we have conducted five-day residential retreats for people with MS in conjunction with the Gawler Foundation, Victoria. This private organisation is a registered charity funded by donations and course fees. It is situated in the Yarra Valley, Victoria, and has accommodation for 36 participants, on-site catering facilities and large meeting and meditation areas. It offers programmes for people with cancer and multiple sclerosis, as well as wellness programmes. The MS programme is based on detailed literature reviews of the potential benefit of lifestyle and medication interventions in MS.^{26–28} The recommendations are summarised in Box 1.

This longitudinal cohort study aimed to monitor the ongoing health-related quality of life of a cohort of people with MS after attending these retreats.

Methods

Design and procedure

Participants of the MS retreats held between April 2002 and March 2008 at the Gawler Foundation were approached with regard to participating in the study. These MS retreats were advertised through some MS societies in Australia, local newspapers, a book²⁷ and

Box 1 Lifestyle and therapy recommendations

Diet and supplements

A plant-based wholefood diet plus fish, with no saturated fat, as far as is practical

Omega-3 fatty acid supplements: 20g (20mls or 20 capsules) a day (of flaxseed oil or fish oil, or the equivalent amount in fish)

Optional B group vitamins or B12 supplement if needed

Vitamin D

Sunlight 15 minutes daily three to five times a week, as close to all over as is practical

Vitamin D3 supplement of 5000 IU daily in winter or if no sun exposure

Aim to keep blood level of vitamin D around 150nmol/l

Meditation

30 minutes daily

Exercise

30 minutes around five times a week, preferably outdoors

Medication

One of the disease-modifying drugs, beginning as early in the illness as possible, if required

Steroids for any acute relapse that is distressing

One of the more potent drugs, such as mitoxantrone, if the disease is rapidly progressive

an associated website (www.takingcontrolofmultiple sclerosis.org). People attending the retreats self-reported having MS diagnosed by a neurologist, although a small number of people with other neurological conditions were accepted onto the courses.

Programme registrants were requested to complete the MSQOL-54 questionnaire²⁹ just prior to attending a retreat. Completed questionnaires were collected when the participant attended. Participants were advised that they would be contacted and asked to complete follow-up questionnaires by post at intervals of one and 2.5 years after attending the retreat. Pre-paid addressed envelopes were provided for the return of consent forms and completed questionnaires.

Intervention

The five-day residential programme was educational and experiential, based on incorporating the best available evidence about lifestyle factors such as diet, sun exposure and vitamin D supplementation, meditation, exercise and stress reduction. These modalities were able to be undertaken by participants on an ongoing basis without the need for medical prescription. Some participants were also taking standard disease-modifying therapies for MS. Between 13 and 34 people with MS attended each of these retreats, which are held two or three times a year.

Patients were provided a plant-based wholefood diet consistent with Swank's dietary recommendations.³⁰ Flaxseed oil was also incorporated into meals to ensure participants had adequate intake of essential fatty acids.

The five-day programme consisted of educational sessions about the evidence and practical issues surrounding changes in diet, essential fatty acid supplementation, sun exposure, stress management and exercise. These sessions were presented by two of the authors (GAJ and IG). There were daily meditation sessions, group counselling and sessions of Qigong or gentle Hatha yoga exercises, with a focus on promoting healthy emotions and meditation to balance the effects of stress. These sessions were presented by counsellors from the Gawler Foundation. Patients were introduced to techniques such as progressive muscle relaxation meditation,²² guided imagery and dyadic focus groups. Massage and one-to-one counselling sessions were also offered to participants.

Assessment

The programmes were evaluated by administering the MSQOL-54 questionnaire. Since the instrument first appeared in 1995,²⁹ it has been extensively validated in people with MS worldwide,^{31,32} and used in assessing the impact of fatigue,^{33,34} depression³⁵ and exercise,³⁶ as well as a number of medical therapies.³⁷

The MSQOL-54 uses the well-validated RAND 36-item Health Survey (SF-36) as a generic core measure.²⁹ To make it more MS specific, the SF-36 is supplemented with 18 additional items comprising of health distress, sexual function, satisfaction with sexual function, overall QOL, cognitive function, energy, pain and social function. Scores of individual items are recorded on a Likert scale. Physical health and mental health composite scores for the MSQOL-54 are determined from the weighted sum

of selected scale scores. Both scale and composite scores range from 0 (poor health) to 100 (optimal health) (Table 1).

Statistical analysis

Descriptive statistics (mean, 95% confidence interval for the mean, median, interquartile ranges, numbers and percentages) were used to describe sample characteristics. The results for participants who completed baseline questionnaires and one other time point were assessed separately, as most people did not complete questionnaires at all three time-points.

Comparisons between the baseline and follow-up time-point scale item and composite scores were made by using the Wilcoxon Signed Ranks test. Correlations between baseline items, domain scores and health composites were assessed using the Spearman correlation coefficient.

All analyses were conducted with SPSS version 15.0 for Windows.

Results

A total of 257 people attended the MS retreats held between March 2002 and March 2008. Of these, 210 completed a baseline questionnaire, and we had contact details for 195 of them. Three had died and four had attended the retreats with neurological conditions different from MS. All people in the sample attended the full five days of the retreat.

Of 188 eligible subjects, 109 (58%) consented to participate in this ongoing study. Many had missing data at time points other than baseline (Table 2). Complete data across all time-points were obtained from 11 participants, all women; 65 participants only completed baseline and one-year follow-up questionnaires, and 33 participants only completed baseline and 2.5 years follow-up questionnaires.

There were 94 females out of the 109 participants (86.2%). As there were so few male participants, gender differences were not assessed.

Ten out of the 14 QOL domains improved over one year. Table 3 shows the baseline and one year MSQOL-54 scale and composite scores. The role limitations due to physical problems domain had the greatest improvement (41.7 points), whereas the cognitive

Table 1 Domains of the MSQOL-54 that comprise the physical health and mental health composite score

Domains	Physical health composite	Mental health composite
Physical function	Overall QOL	
	Health perceptions	Emotional wellbeing
	Energy	Cognitive function
	Role limitation due to physical problems	Role limitation due to emotional problems
	Pain	Health distress
	Social function	
	Sexual function	
	Health distress	

Table 2 Number of participants at each completed time point (total $n=109$)

Completed time points	Number of participants	Females	Males
Baseline – 1 year	76 (70%)	69	7
Baseline – 2.5 years	44 (40%)	36	8
Baseline – 1; 2.5 years	11 (10%)	11	0

function domain improved the least (5.0 points). The median for role limitations due to emotional problems after one year remained unchanged, but a significant increase ($Z = -2.639$, $P=0.008$) was still detected by the Wilcoxon Signed Ranks test. The changes across one year among the scores for physical health, pain, sexual and social function were statistically insignificant.

Figure 1 illustrates the significant improvement found at one year follow-up in overall QOL (10.2 points), mental health composite score (9.9 points) and physical health composite score (8.3 points).

Similar improvements were seen between the baseline and 2.5 years follow-up group (Figure 2). Overall QOL increased by 3.3 points. Six of the QOL domains and the two composite scores significantly improved after 2.5 years (Table 4). The health distress domain

improved by 20 points, double the improvement found at the one year follow-up.

Compared to the results at one year follow-up, at 2.5 years there were no significant changes in role limitations due to physical problems, role limitations due to emotional problems, cognitive function, change in health and satisfaction with sexual function domains. However, at the 2.5 year follow-up there was an improvement in sexual function.

Using the baseline questionnaire raw scores, many of the questions strongly correlated with each other according to criteria found in Cohen.³⁸ Table 5 summarises the baseline QOL domains and composite scores that strongly correlated with overall QOL, physical health composite score and mental health composite. Overall QOL strongly and positively correlated with a number of health domains, including

Table 3 Comparison of MSQOL-54 domain and composite scores at baseline and one year

Domain	<i>n</i>	Baseline	One year	Z score	P-value
		Median (IQR)	Median (IQR)		
Physical health	75	75 (45–90)	72.2 (45–95)	–0.093	0.926
Role limitations due to physical problems	75	33.3 (0–100)	75 (25–100)	–3.695	<0.001
Role limitations due to emotional problems	75	100 (33.3–100)	100 (66.7–100)	–2.639	0.008
Pain	75	85 (76.7–85)	93.3 (70–93.3)	–1.047	0.295
Emotional wellbeing	76	72 (64–84)	82 (68–92)	–3.354	0.001
Energy	76	56 (40–64)	64 (40–76)	–3.444	0.001
Health perceptions	75	65 (50–80)	75 (50–85)	–2.341	0.019
Social function	71	83.3 (66.7–91.7)	83.3 (66.7–100)	–0.737	0.461
Cognitive function	76	80 (60–94.6)	85 (70–98.8)	–2.859	0.004
Health distress	74	70 (45–85)	80 (68.8–90)	–5.116	<0.001
Sexual function	62	83.3 (66.7–91.7)	83.3 (45.8–83.4)	–0.918	0.359
Change in health	74	50 (25–56.3)	75 (50–75)	–4.513	<0.001
Satisfaction with sexual function	62	50 (25–75)	75 (50–100)	–2.518	0.012
Overall QOL	76	73.4 (60–81.7)	81.7 (65.8–91.2)	–3.786	<0.001
Physical health composite score	55	66.2 (54.0–78.1)	76.4 (55.2–88.2)	–3.335	0.001
Mental health composite score	73	73.7 (58.1–85.5)	83.6 (71.9–83.6)	–4.725	<0.001

IQR = interquartile range

n = number of participants

Differences assessed by Wilcoxon Signed Rank test

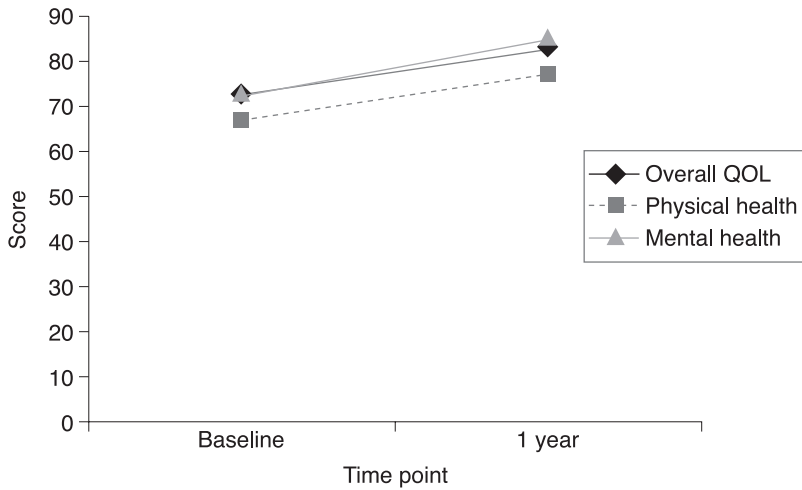


Figure 1 Medians of overall QOL and composite scores at baseline and one year

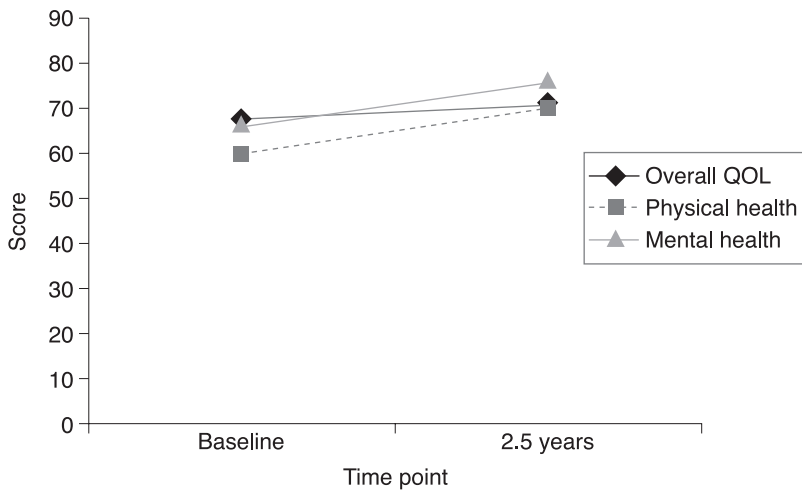


Figure 2 Medians of the overall QOL and composite scores at baseline and 2.5 years

emotional wellbeing and energy, and also the mental and physical health composite score of the MSQOL-54.

Among the baseline questionnaires, 22 questions had a missing response. Five questions had greater than 2% of responses missing.

Discussion

Our study provides evidence of a continuing improvement in HRQOL in people with MS after attendance at a five-day residential retreat. Almost all the QOL domains assessed by the MSQOL-54 significantly improved or remained the same at one year and 2.5 years after subjects had attended the retreat. After 2.5 years, participants who attended the retreat made significant improvements in the overall QOL domain, physical health composite and mental health composite scores. None of the domains revealed any deterioration at either time point. This is quite unusual

for a group of people with this chronic progressively disabling condition.

Our strong impression was that participants were greatly empowered by the programme; many arrived feeling hopeless and disempowered, with no sense of being able to help themselves in managing the illness. Many participants, in written feedback for course evaluation, commented that they felt inspired to take control of the illness, and that the course was life changing. The intervention was devised to be essentially self-administered with periodic input from the participant's general practitioner to provide ongoing support and to monitor, for instance, vitamin D and B12 levels, medications and quality of life; participants felt this to be a more holistic approach to their health compared with periodic specialist appointments focused largely on medications.

The presenters did not find the programme difficult to implement, although it is not really suitable for larger groups as there are often many questions from participants to be answered during the sessions, and

Table 4 Comparison of MSQOL-54 domain and composite scores at baseline and 2.5 years

Domain	<i>n</i>	Baseline	2.5 Years	Z score	<i>P</i> -value
		Median (IQR)	Median (IQR)		
Physical health	44	62.5 (26.3–90)	77.5 (25–95)	–0.750	0.453
Role limitations due to physical problems	43	25 (0–75)	50 (0–100)	–1.249	0.212
Role limitations due to emotional problems	43	100 (0–100)	100 (33.3–100)	–1.787	0.074
Pain	44	89.2 (70.4–100)	29.6 (35.8–93.3)	–0.518	0.604
Emotional wellbeing	44	68 (52–83)	76 (64–87)	–2.437	0.015
Energy	44	44 (29–59)	50 (33–68)	–2.019	0.044
Health perceptions	44	65 (40–75)	70 (46.3–85)	–2.476	0.013
Social function	42	75 (50–91.7)	75 (66.7–91.7)	–1.249	0.212
Cognitive function	44	80 (60–90)	85 (66.25–93.8)	–1.504	0.133
Health distress	44	57.5 (36.3–78.8)	77.5 (56.3–95)	–3.316	0.001
Sexual function	38	75 (54.1–85.4)	79.2 (56.2–93.8)	–2.106	0.035
Change in health	43	50 (25–50)	50 (25–75)	–1.394	0.163
Satisfaction with sexual function	38	50 (50–75)	62.5 (50–75)	–0.721	0.471
Overall QOL	43	68.4 (50–81.7)	71.7 (60–86.7)	–2.157	0.031
Physical health composite score	36	59.7 (46.2–76.6)	70.0 (52.5–87.8)	–2.476	0.014
Mental health composite score	42	66.9 (43.1–84.2)	76.6 (62.0–76.6)	–2.657	0.008

IQR = interquartile range

n = number of participants

Differences assessed by Wilcoxon Signed Rank test

this would be unwieldy with groups greater than about 35. The programme appears to be relatively transportable; a similar programme has been offered (by GAJ) annually since 2007 in the Coromandel in New Zealand, in conjunction with the MS Society of Auckland and the North Shore Inc.

The MSQOL-54

Measures of treatment effectiveness in MS have traditionally been based on an evaluation of a patient's level of impairment or disability using measures such as the Expanded Disability Status Scale. Clearly measuring quality of life is also critically important, and some would suggest a more important outcome than clinical outcome.³⁹ HRQOL is a broader measure of

disease impact that conceptualises aspects of life quality or function influenced by health status.⁴⁰ A recent study has shown that the MSQOL-54 is better than generic measures in detecting treatment effects.⁴¹ Measures of HRQOL can be used with a wide variety of populations and interventions, allowing comparison between them. MS-specific HRQOL instruments are used to evaluate the clinical effectiveness of interventions because they acknowledge that health status in MS is influenced by factors other than relapse rate and level of impairment.⁴² Currently the MSQOL-54 questionnaire is the most commonly used evaluation tool for patients with MS.⁴²

The reasonably high survey response rate of 58% was consistent with those found in other studies surveying MS populations.^{43–45} It suggests that people

Table 5 MSQOL-54 domains and composites that strongly correlated ($r>0.5$) with overall QOL, physical health composite and mental health composite at baseline

Domain	Domain	<i>r</i>	<i>n</i>
Overall QOL	Emotional wellbeing	0.621	108
	Energy	0.618	108
	Health perceptions	0.507	107
	Health distress	0.548	106
	Physical health composite	0.660	88
	Mental health composite	0.643	106
Physical health composite	Physical health	0.700	89
	Role limitations due to physical problems	0.790	89
	Pain	0.508	89
	Emotional wellbeing	0.563	89
	Energy	0.763	89
	Health perceptions	0.552	89
	Social function	0.693	89
	Health distress	0.638	89
	Mental health composite	0.624	88
Mental health composite	Role limitations due to emotional problems	0.817	106
	Emotional wellbeing	0.894	106
	Energy	0.588	106
	Social function	0.571	105
	Cognitive function	0.596	106
	Health distress	0.713	106

n = number of participants

r = Spearman's rank correlation co-efficient

$P<0.001$

with MS have a favourable attitude towards mailed surveys, and may in this study also reflect their positivity following the retreat, and an eagerness to contribute towards MS research.

QOL comparisons

Studies assessing QOL of people with MS over more than two years are scarce. However, in general they suggest a natural decline in most HRQOL domains over time in keeping with the known physical deterioration. The improvements found in our study differ for example from the findings of an Italian prospective study of 251 people with MS which showed that five years after the initial MSQOL-54 was completed, MS patients significantly worsened in the domains of change in health ($P<0.0001$), physical function ($P<0.002$) and health perceptions ($P=0.01$).

Surprisingly, despite MS being a chronic disease that gradually causes neurological impairment over time, there was a marginal but significant improvement in the MSQOL-54 cognitive function domain after one year. This is similar to the physical health

domain, which was also expected to gradually worsen over time, but instead improved at 2.5 years follow up.

Our findings are consistent with the results of the UK 'OPTIMISE' programme, where the health promotion programme had significant positive effects on physical function, mental (emotional well-being) health and general health (health perceptions) domains. However, unlike our study, the OPTIMISE programme found no significant improvement in the pain, physical, emotional, social function and fatigue domains of QOL.²⁵ Similarly, in a wellness intervention for women with MS, only pain and mental health (emotional well-being) QOL domains improved significantly.²⁴

QOL improvements

Overall QOL positively correlated with emotional wellbeing, energy, health perceptions and health distress QOL domains, and physical health and mental health composites. Interestingly, three out of the four mental health composite subscales correlated with overall QOL, and six of eight physical health composite subscales were associated with overall QOL. It

appears that the perceived QOL of our MS participants was influenced by both mental health and physical health. These results contrast with those reported in another longitudinal study which evaluated the determinants of QOL among people with secondary progressive MS.⁴⁶ It was proposed that interventions which improve the mental health of people with MS consequently improve perceived QOL. Our results suggest that both mental and physical health were equally important in contributing to perceived QOL.

Our study participants showed less optimistic self-reported QOL at baseline than was reported in a previous cross-sectional study.⁴⁷ In contrast to our study, where 65.7% of participants reported a favourable QOL, the Canadian study reported 77% of their participants being mostly satisfied or delighted with QOL. It could be argued that due to the self-selected nature of our study, the retreat appeals to people who are dissatisfied with their QOL, as it is less likely that someone who is satisfied would actively seek to improve QOL further.

Although missing data suggest that the sexual function scales may not be representative of sexual problems in our sample, it is crucial to investigate the impact of sexual dysfunction among the MS population. A high proportion of people with MS experience at least one symptom of sexual dysfunction⁴⁸ which influences all aspects of QOL. Consequently, future studies on HRQOL of the MS population should consider modifying the sexual function and sexual satisfaction scales of the MSQOL-54 or use an additional instrument to measure sexual dysfunction.

There are a limited number of longitudinal cohort studies monitoring the HRQOL of people with MS for more than two years. MS is so variable in clinical course and effect that it is important to assess the HRQOL of participants over a long period of time. More research needs to be done in this area so that the natural course and effect of interventions on HRQOL of people with MS can be assessed. Our study is continuing to enrol patients and we aim to report our findings at the five-year time point when we have enough participants.

Limitations

Ideally studies evaluating the effect of interventions in MS should include a control group. The documented improvement from baseline to subsequent years of the survey may have been an artefact of maturation, that is, people with MS learned to cope over time and their changes in attitudes and adjusting to life with MS had nothing to do with the intervention. However, this is very unlikely as previous studies of people with MS over time have shown steady deterioration in quality of life.

Longitudinal cohort studies are particularly valuable in monitoring populations with chronic diseases that are variable in their progression, particularly those evaluating non-drug therapies as ours has. However, sample size can be a problem in such long-term studies due to the waning enthusiasm of participants to be involved; this was a limitation of the current study, in particular the small number of participants completing all three (baseline, one year, and 2.5 years) time points.

A measure of adherence would have been useful in this study to allow an assessment of the relative contributions made by the different parts of the intervention. Although the response rate in our study was quite high, the validation and use of an online version of the MSQOL-54 may increase the participation rate further, and this will be trialled in ongoing studies.

Our study relied on self-report for the diagnosis of MS and we did not require proof of diagnosis from participants. Hence it is possible that some of our participants may not have had MS but a similar neurological condition, although we did exclude all participants (four) who declared an alternative neurological diagnosis. The type of MS among the study population was also unknown, and we can draw no conclusions about this.

Our results may not be representative of the MS population. A high proportion of our study participants were female, which is not reflective of the estimated female–male ratio of MS incidence of 3:1.⁴⁹ The female preponderance in our study might be explained by women's greater willingness to talk about their difficulties and to attend self-help programmes.

Conclusions

Longitudinal cohort studies can be useful in monitoring the progress of people with MS. This study showed ongoing improvements in HRQOL after an intensive lifestyle modification course. This could potentially make a significant difference to the lives of many people with this condition. Further controlled studies are warranted to examine the long-term effects of such interventions on QOL.

Our findings contribute to the growing body of evidence that health promotion programmes and non-drug therapies for MS patients have a beneficial effect. General practitioners may find this holistic approach useful in managing people with MS.

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ETHICAL APPROVAL

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PEER REVIEW

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CONFLICTS OF INTEREST

Professor Jelinek was diagnosed with MS in 1999; he has been remunerated by the Gawler Foundation since 2007 for leading the residential retreats; he has published a book about the management of MS entitled *Overcoming Multiple Sclerosis: An Evidence-Based Guide to Recovery* released by Allen and Unwin in 2010. Drs Gawler and Dye were remunerated by the Gawler Foundation.

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