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RESEARCH PAPER



Understanding barriers, enablers, and long-term adherence to a health behavior intervention in people with multiple sclerosis

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ABSTRACT

Background: The optimal management strategy for multiple sclerosis (MS), and many other chronic diseases, likely involves health behavior modification. Multimodal behavioral interventions may be most effective, but little is known about long-term adherence in people with MS.

Methods: This qualitative study assessed barriers and enablers to long-term adherence by people with MS who self-selected for a 5-day health behavior intervention 3–5 years prior. Thirteen women and five men participated in semi-structured phone interviews, which were transcribed and thematically analyzed.

Results: The experience was described as useful for information gathering, decision making, and practical strategies regarding health behaviors. The majority still followed supplementation and dietary recommendations most of the time, although consuming non-recommended food while eating out was common. Support at home, ability and enjoyment in food preparation, and ability to resist unhealthy foods were both barriers and enablers. Adherence to “time-consuming” exercise and meditation recommendations were less common and episodic. Many reported competing interests on time from work and family; and barriers including injuries and symptoms, weather, financial or geographical barriers, and lack of person-centred support and motivation. Increased fitness and mobility, weight loss, and a sense of accomplishment and control were advantages and motivators. Practical and attitudinal strategies employed included planning, tailoring activities to ability and preference, and self-monitoring.

Conclusion: While most people attempted to engage with all components of the intervention initially, only some still engaged with all components, and none to the recommended levels. These data can inform future quantitative studies and health behavior interventions.

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► IMPLICATIONS FOR REHABILITATION


- A multimodal group lifestyle intervention may be useful to assist people with multiple sclerosis in information gathering, decision making, attitudinal changes, and practical strategies regarding health behaviors; as well as providing a sense of hope for the future and control over wellbeing.
- While participants are unlikely to engage with all components of a multimodal intervention to the recommended level, they are likely to make improvements to one or more health behaviors.
- Experiential learning, including going through recipes and ingredient lists, and practicing meditation and physical exercises, is helpful to instigate behavior change.
- The initiation and maintenance of behavior change was assisted by support from family, friends, and health practitioners; and practical strategies employed by participants, including planning, self-monitoring, and tailoring activities to ability and preference


Introduction

Multiple sclerosis (MS) is the most common progressive neurological disorder affecting young adults [1]. Hallmark symptoms include progressive gait instability, weakness, numbness and fatigue, with depression and anxiety being common comorbidities. The etiology is not fully understood. While there are some genetic risk factors [2], lifestyle and environmental factors such as Epstein–Barr virus infection, cigarette smoking, low levels of vitamin D, and increased body mass index, are key contributors [3,4]. Recent evidence indicates that eliminating these known risk

factors could prevent over 60% of MS cases [5]. Evidence is building that these and other health behaviors play a pivotal role in MS symptoms, disability worsening and progression [6], inflammatory processes [7], and comorbidities [8].

Current treatment options for MS focus mainly on pharmaceutical interventions. First-line immune modulating drugs have demonstrated a modest reduction in relapse rates but there remain concerns regarding cost-effectiveness, both short and long-term side effects and the potential for serious adverse events [9]. Despite ongoing efforts to find new strategies and improve the management of MS, many people with MS still develop

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 Supplemental data for this article can be accessed [here](#).

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substantial disability and most encounter mental health problems, comorbidities, and decreased quality of life (QOL). The optimal management strategy for MS, as with many other chronic diseases, is likely to involve a combination of modern medication and lifestyle risk-factor modification [6].

The modification of health behaviors, such as smoking, diet, and physical activity, is well established in the management of other chronic diseases such as cardiovascular disease and type-2 diabetes. Although most people with MS want and actively seek lifestyle advice [10,11], there are currently few guidelines or mainstream management strategies that incorporate education or support to modify lifestyle risk-factors. This is despite mounting evidence that low levels of vitamin D, smoking, stress, sedentary behavior, adverse lipid blood levels, high levels of alcohol use, and obesity are significant risk factors for disease progression, fatigue, and poor mental and physical health-related QOL [6,12–15]. Importantly, there are no known disadvantages or risks involved with modifying these health behaviors. Providing people with MS with information and tools to minimize these risk factors likely has additional benefits, as the degree to which people with MS engage with their healthcare is associated with improved self-efficacy, QOL [16], and decreased risk for comorbidities [17].

Intervention trials in MS targeting a single health behavior such as exercise or meditation are increasingly common. By contrast, multimodal intervention studies are scarce, even though they may be most effective [18], and effects may be multiplicative. In addition, as many trials lack longitudinal follow-up [19], an international multidisciplinary working group has called for more research in this area [20]. Lifestyle intervention trials can be difficult to design and conduct [21], but such evidence is needed to enable a shift in MS management towards a more holistic approach [22]. We have previously published results of a multimodal lifestyle intervention for people with MS, showing significant improvements of QOL at 1, 3, and 5 years compared to baseline [23–25]. These data showed varying degrees of adherence to the recommendations of the intervention, in particular for physical activity, which on a group level did not change at 1 and 3 years after the intervention [25]. Understanding long-term adherence to health behavior interventions is instrumental when designing future primary or secondary chronic disease interventions.

This qualitative study aimed to better understand barriers and enablers to adherence to health behavior recommendations in people with MS who attended a lifestyle intervention.

Methods

Here, we report the methods using the Consolidated criteria for reporting qualitative research (COREQ) [26] guidelines. The study was approved by the Health Sciences Human Ethics subcommittee of the University of Melbourne (1647111).

MS health behavior intervention

The intervention, advertised as the Overcoming MS (OMS) lifestyle retreat, took place in rural Victoria, Australia over five consecutive days. The intervention was advertised online and through social media, and participants were able to self-enroll online. The venue consisted of individual and shared accommodation and was wheelchair accessible. Attendance fees varied depending on the level of accommodation chosen, and also covered all meals. There were five intervention facilitators (two with MS), including a medical professor, a psychiatrist and three experienced counselors, all with extensive knowledge of MS. Table 1 lists the OMS

Table 1. Overcoming multiple sclerosis (OMS) lifestyle intervention recommendations.

Lifestyle factor	Recommendation
Diet	A plant-based wholefood diet plus seafood, with very low saturated fat (<20 g/day)
Dietary supplementation	No dairy, meat, palm or coconut oil, no fried foods Omega-3 fatty acid supplements: 20–40 ml of fish or flaxseed oil daily; can be omitted on days when oily fish is eaten Optional B group vitamins or B12 supplement if needed
Physical activity	20–30 minutes around five times a week, preferably vigorous and outdoors
Smoking	No tobacco smoking and avoid passive smoking
Vitamin D	Sunlight 15 minutes daily 3–5 times a week as close to all over body exposure as practical Vitamin D3 supplement of at least 5000 IU daily, adjusted to blood level Aim to keep blood level of vitamin D high, between 150–225 nmol/L (may require up to 10,000 IU daily)
Meditation or other stress reduction activity	30 minutes daily

lifestyle recommendations promoted during the intervention (intervention and retreat used interchangeably hereafter).

The facilitators delivered information and practical advice on incorporating these recommendations into daily life in a face-to-face group setting during the 32 h of formal contact and additional informal contact over meal and tea breaks. The instruction was delivered in a manner that focused on maintaining a positive outlook, well-being, and empowerment. The food provided was in line with the recommendations, and facilitators modeled the lifestyle behaviors with regular meditation and exercise sessions. Any difficulties or emotions attendees experienced were encouraged to be freely shared. Groups of up to 35 attendees consisted of mostly people with MS with some partners or family members, and almost all attendees participated in all sessions. Attendees were provided with take-home information and online support groups were created for those wishing to participate. No adverse events were reported.

Study design

The research methodology employed was pragmatic [27]. This study is a qualitative component of a larger quantitative project, and a pragmatic approach allows for the subjective experiences and understandings of participants to be captured in a manner that does not conflict methodologically with the broader study design. As we were interested in the understandings and experiences of the barriers and enablers to long-term adherence of lifestyle modifications, qualitative interviews were chosen as the most appropriate method of data collection.

Study participants and procedures

Participants were eligible for the study if they had attended one of seven consecutive retreats conducted between March 2012 and May 2013, and were aged 18 years or older. A random number generator was used to sequence invitations to eligible participants ($n = 165$). Invitations were sent in groups of 5 to avoid over-recruitment as recruitment would be halted when themes were saturated. An email invitation was sent with participant information and a consent form attached, followed by up to two reminder emails.

Participants provided verbal consent before the start of the interview. The interviews were semi-structured, with the questions developed by the research team (supplementary material).

Table 2. Participant characteristics.

Participant	Sex	Age at time of interview	Disease duration at time of interview	PDDS (time of assessment) ^a
1.1	M	37	9	0 (Nov 2016)
1.2	F	65	42	3 (Nov 2016)
2.1	F	32	8	0 (Mar 2017)
2.2	F	41	5	1 (Mar 2015)
3.1	F	57	6	7 (July 2015)
3.2	F	57	4	1 (July 2015)
3.3	F	52	14	6 (Mar 2012)
3.4	F	68	7	6 (July 2015)
4.1	M	62	4	4 (July 2015)
4.2	M	46	4	1 (July 2015)
5.1	F	55	18	6 (Sept 2015)
5.2	M	44	5	2 (Sept 2015)
5.3	F	63	12	5 (Sept 2015)
6.1	F	55	5	1 (Mar 2016)
6.2	F	49	4	1 (Mar 2016)
6.3	F	39	6	1 (Mar 2016)
6.4	F	33	4	1 (Mar 2016)
7.1	M	51	12	2 (May 2016)

^aPatient determined disease steps was not assessed at time of interview, but as part of ongoing quantitative study. We report the PDDS score available that was collected closest to the interview time.

Interviews were conducted in English, were audio recorded and transcribed verbatim by an external professional transcription agency. Transcripts were checked for completeness and accuracy by the authors. Recruitment was halted when saturation of themes was accomplished. Purposive sampling was undertaken towards the end of the recruitment phase in an attempt to include more people who were current or recent smokers.

Demographics

Of the 61 people invited to participate, 5 men and 13 women agreed to be interviewed for the study. At the time of the interview, they were aged between 32 and 68 (median 51) years and were diagnosed with MS between 4 and 42 (median 6) years ago, with 13 out of 18 within 10 years of diagnosis. Time between intervention and interview was between 3 and 4.5 years. Participant characteristics can be found in Table 2. Within the quotes we report the age and level of disability of the participant who provided the quote.

Research team and reflexivity

The interviewers CB (Master of Public Health, research assistant) and CM (PhD, Research Fellow) had no formal qualitative research training, but both had several years of experience with conducting qualitative interviews and analyses for research. CB and CM each conducted half of the interviews via phone or Skype from a private office. They had no prior relationship with any of the participants. One of the authors (GJ) had involvement in the intervention as designer and facilitator; the retreats are currently still running. To minimize bias, this researcher had no involvement in recruitment, interviewing or data analysis. Participants may have been aware that this researcher headed a research team (including CM, CB, and TW), the focus of which was to examine the effect of healthy lifestyle for people with MS. To increase recruitment of those who did not follow the recommendations for the lifestyle interventions, the information sheet that accompanied the invitation stated that: "... regardless of whether or not you are currently following the recommended lifestyle. We are looking for both people who have, and have not, followed some and all of the recommendations ..."

Data analysis

The interview transcripts were analyzed using thematic analysis. This approach produces provisional hypotheses and common themes from the data [28]. The data were organized into a system of coded patterns and themes, using the six-step framework advocated by Braun and Clarke [29]. The coding was performed in NVivo Pro by EB (BA, MPH, highly experienced qualitative researcher). This coding was checked across the transcripts by CB, TW, and CM to establish consensus about the coding structure and to ensure validity.

Results

We report the participant number with age (e.g. 35 years) and level of disability: Mild (mild disability; PDDS score 0–2) Mod (moderate disability; PDDS score 3–5), or Sev (severe disability; PDDS score 6–8).

The retreat

To begin each interview, participants were asked the question: "How has the retreat affected your life?", before being asked specifically about resultant behavior changes for each recommended lifestyle modification. Overwhelmingly, participants responded positively to this question: *"I've reflected on the retreat many a time. It's been a very positive experience for me"* (P4.1, 62 y, mod).

Participants described the retreat as being important for four main reasons. Firstly, the retreat was a valued source of information that raised awareness of lifestyle modifications for the management of MS. Participants recounted how they were either made aware, or reminded, of the potential changes they could make to support a healthier lifestyle with MS: *"... the information that was provided was definitely a big factor. Because we were well informed, the research, all the findings, it was a lot of good information."* (P1.1, 37Y, mild). Following this, participants communicated the importance of the retreat in helping them to shift their attitude about living with and managing MS. The retreat was described as a space that "inspired hope" and "provided direction and clarity": *"It's a turning point really. Before it was – I think I was a bit of a mess and then [the retreat] guided me to the correct path."* (P2.2, 41 y, mild). Participants then spoke about the retreat as it impacted their decision-making. It "reinforced" and "cemented" their decision to commit to lifestyle modification and made them more "serious", "determined", and "conscientious" about behavior change: *"I feel like even if I haven't taken up all of these strategies ... [the retreat] has given me a sense that there are things that I can do and I think that's very powerful."* (P5.1, 55, sev). Finally, participants recalled the experiential nature of the event. Practical examples of how to make the recommended modifications including cooking, food preparation, and stress-reduction techniques were learned with a group of people with a shared experience: *"I really enjoyed tasting all the food that they had there. I loved the instruction in meditation."* (P3.2, 57, mild). Here, participants also related the importance of seeing other people with MS: *"so I think for me, the retreat, seeing other people, young people who had been diagnosed and all of that was good for me."* (P6.3, 39 y, mild).

All participants reported the retreat as being an affirming experience for them (and would recommend the retreat to others). This was despite participants having different levels of exposure to the OMS program prior to going on the retreat, varying time of retreat attendance from diagnosis, and different levels

of disease progression since retreat attendance, among a group of randomly selected past attendees.

While most people attempted to engage with all components of the intervention initially, at the time of the interviews, only a couple of participants engaged with all aspects of the intervention still, and none to the recommended level. However, every participant engaged with at least one of the components: *"I suppose the diet is the only one (of the lifestyle recommendations) that's hung around. Because I'm so disabled I'm so reliant on my providers. Yes, that makes it really difficult to adhere to everything."* (P3.3, 52y, sev). Many felt that there was a contrast between the conventional MS management focused on symptoms and illness, versus this intervention which focused on health: *"It's very easy to feel like your health and your future is in the lap of the gods and in the lap of the doctors and the drugs. That's a really bad feeling; whereas this is - it's all really positive stuff that I'm doing for myself that I wholeheartedly believe is doing good for me"* (P6.3, 39y, mild). Some said that it gave them a sense of control: *"I thought the one thing I can take control of - and I guess that's the thing; control. Take control of your situation, take control of this thing."* (P6.1, 55y, mild); especially if there was no other management strategy: *"So I had to take responsibility and actually take on something ... Otherwise, with there being no medication, I would feel as if I was losing - that I didn't have control of what I was doing."* (P5.3, 63y, mod).

Lifestyle factors

Diet

Participants had the most to say about the dietary recommendations, far above the other recommended lifestyle modifications. This may reflect the emphasis the intervention placed on the importance of healthy diet.

Making the change in diet

Learning about and experiencing eating according to the dietary recommendations during the 5-day retreat provided an opportunity for participants to conceptualize how the low saturated fat, plant-based diet would work in the context of their own lives and *"learn how to make [the diet] a habit"* (P2.1, 32y, mild). While the diet seemed restrictive to some, others were pleasantly surprised by some of the food they were served: *"There was some chocolate chia pudding thing and I'm like, that cannot be on my diet."* (P6.1, 55y, mild). The retreat was also a supportive environment for partners of people with MS to learn about the diet.

Some participants, described adopting a plant-based plus seafood diet as a "dramatic" change where the diet *"had its moments"* (P1.2, 65y, mod). One participant said: *"At first the idea of forever was really difficult for me"* (P6.3, 39y, mild), whereas making a change was easier for others: *"Easiest thing I've ever done!"* (P6.1, 55y, mild); *"I probably enjoy my food more than I ever did"* (P3.2, 57y, mild). One participant dedicated three months over the summer period to transition into the diet fully. Making the change was easier for the self-described "foodies": *"I love cooking, and so I threw myself into the diet quite easily"* (P6.4, 33y, mild). By contrast, those who did not possess an aptitude for cooking found the diet more difficult to implement: *"I guess I might be pretty lazy in the kitchen as well. That might make a difference."* (P3.4, 68y, sev). Having simple rules such as no dairy or meat made them easy to follow whereas as one participant stated: *"the gray zones is a bit more difficult because then it's really - well I can do it; not too much"* (P2.2, 41y, mild).

Adherence to diet

Participants estimated they were still following the OMS dietary recommendations between 70 and 100% of the time. One participant ceased the diet when they underwent medical treatment overseas, but would consider taking up the diet again in the future. Some participants had no difficulties adhering to the diet: *"The diet I've been on for sure. That's not on and off"* (P2.2, 41y, mild). Maintaining the regimen closely for main meals cooked at home was commonly reported, but less so for snacking and eating outside the home. A change in attitude to adherence over time was common amongst participants. Participants recounted being very disciplined with the recommendations after the retreat, as one stated: *"I spent several years being really difficult to go out to eat with ... I just figure [now] the occasional lapse really isn't going to matter. It's a small issue, not a big one."* (P3.2, 57y, mild). Several participants described their attitude to adhering over time similarly, and not worrying so much about small deviations: *There might have been a bit of chocolate here or cake and things like that. You'd say oh god this couldn't hurt and that sort of drifted in a bit."* (P3.4, 68y, sev).

Diet in the social context

Many spoke about the importance of support from family, friends and healthcare professionals. Support from clinicians was uncommon: *"it's difficult to get the support - the medical support in the UK. So my neurologist only looks at medication ... That's the only thing he would do."* (P5.2, 44y, mild). Some keep searching until they find a specialist who is supportive of the OMS recommendations: *"she (the neurologist) was very interested in the program and she asked for the details. I was so impressed because - not once have any of the other GPs or neurologists that I've seen have paid any attention to it"* (P6.3, 39y, mild). Following the diet in the context of family and social life was present across all interviews. Those participants who were single when they adopted the diet commented that the change would have been more difficult for them had they been partnered. Partners and families affected the ease with which participants could adapt to a new way of eating. When partners were willing to adopt the dietary recommendations (even in part), participants indicated that this was helpful for them, as it made transitioning easier: *"It does make it easier when she's [eating the same] food ... you're sort of in it together"* (P1.1, 37y, mild). It also worked in the other direction, having to cook two or more meals to satisfy different family members was more difficult for participants: *"Trying to get the kids on board. That was an uphill battle."* (P3.3, 52y, sev). Participants recognized that adopting the diet had the capacity to impact others in the family, and this was especially the case where meals were primarily prepared by a partner: *"I'm not the main preparer of meals in our household so I know it's an added burden"* (P4.2, 46y, mild). This extended to participants with functional decline: *"Once I got to the point where I couldn't cook anymore my husband had to take over doing the cooking, he found it difficult because the kids didn't want to do it and he wasn't keen on [the diet]"* (P3.1, 57y, sev).

Eating outside of home

Participants also spoke about adhering to the diet in social contexts outside the immediate family unit: *"When I'm doing [the diet] by myself it's no problem, but in the social context then it's a bit harder"* (P2.2, 41y, mild). Having to explain or communicate dietary requirements to others was described as being somewhat difficult *"sometimes you're trapped, you're at someone else's house and you're hungry and you have to eat what they've got, you just do your best. But in general, in my life, I am strict"* (P1.2, 65y, mod).

Furthermore, participants did not want to inconvenience others who were preparing food for them, fearing being perceived as fussy or being too restrictive: *"I try to balance that with being fanatical, you don't want other people to perceive you like that. I guess from the outside to other people looking in they think 'Oh my gosh – how can you do that?'"* (P6.2, 49y, mild). A few participants who travelled for work or were required to eat out in the context of their employment recounted that this could also be difficult: *"... when you do business lunches, your menu options are always very restricted or you need to have something tailored."* (P4.2, 46y, mild). Often participants described minor difficulties with consuming "unseen ingredients" such as added oils in food not cooked at home: *"sometimes I just suck it up and have something that I know has probably been cooked in vegetable oil and that kind of thing."* (P5.1, 55y, sev). By contrast they reported that meat or dairy were more obviously detected and therefore easy to avoid: *"when I go out to eat I don't necessarily follow the diet. I do as much as I can. I definitely avoid dairy and red meat."* (P6.2, 49, mild).

Adherence strategies for diet

Strategies that were developed over time fell into two (sometimes blended) categories; practical and attitudinal. Practical strategies to help with food preparation and cooking included online grocery shopping (where this was possible), and bulk cooking and freezing meals. Participants described making up for small lapses by carefully monitoring and more closely following recommendations for a short while after. Some participants kept a food diary when they started the diet to help them track what they ate. Another participant recounted how she had some business cards with the diet printed on that she would hand out at restaurants. This facilitated communication with restaurant and kitchen staff about her needs when eating out. Others described eating around certain foods when eating out: *"If there's a salad with cheese on it or something, I will just give away the cheese and the egg yolk or whatever and that makes it – it's not too bad"* (P5.3, 63y, mod).

Some strategies were both attitudinal and practical. Soon after transitioning to the OMS diet, one participant described how: *"Every three months I used to have a 'blow-out day' and let myself eat whatever I wanted. I found that was like a bit of carrot to get through the preceding three months..."* (P6.3, 39y, mild).

Participants spoke about employing willpower and decisiveness in their approach to the diet: *"The diet, food-wise, that was just being strict and not, I don't know, a lot of willpower there, just like, no, I'm not having anything and that's a decision I made."* (P1.1, 37, mild); *"Day-to-day I'm very strict. I've got really good willpower [laughs]"*. (P6.3, 39y, mild). Other attitudinal strategies included framing the diet as a challenge. This was described as being empowering, and left participants less prone to feeling overwhelmed by it. This extended to making adjustments in the way people approached going to restaurants by focusing on the social aspects of eating out: *"The mindset has to be different that it's the people you're going with and the occasion, rather than the food."* (P5.2, 44y, mild).

Advantages and disadvantages

Overall participants had positive feelings towards the diet: *"I feel like why not eat this way? Why doesn't everybody do it?"* (P5.1, 55y, sev). There was also a sense from participants that the diet was beneficial for reducing risk factors associated with other conditions: *"Well there's the – typically espoused advantages, you've got a lower risk of cancer, a lower risk of diabetes, all of those things."* (P3.2, 57y, mild). One participant said: *"I think the advantages of the diet outweigh the disadvantages"* (P4.2, 46y, mild), attributing a

lack of illness progression to the diet. The disadvantages participants described often had less to do with the diet itself, than with frustrations with meal preparation, cooking, and eating with others. A number of participants experienced significant weight loss which was mostly seen as beneficial: *"I was overweight at the time of diagnosis, quite a lot overweight and I've lost weight, over 40 kilos, just because of the diet"* (P6.1, 55y, mild). Some participants worried that they had lost too much weight and re-introduced certain food groups such as meat or dairy to gain weight: *"I've lost a heap of weight to the point where I'm probably a bit underweight. So I've actually introduced chicken back into my diet"* (P4.2, 46y, mild). Similarly, some described occasionally deviating from the recommendations to include lean meat for extra iron and protein or nonfat yoghurt for extra calcium: *"So maybe just a spot of cheese now and again or really kick my heels up and have one very low-fat steak once a week."* (P3.4, 68y, sev).

Omega-3 fatty acid supplementation

Omega-3 supplementation was not perceived to be challenging, although three participants were not supplementing at the time of the interview. Nearly all participants focused on incorporating flaxseed oil into their dietary and cooking practices, which was encouraged during the retreat: *"I don't look at it as another tablet or pill I have to take... it's really part of my cooking."* (P5.2, 44y, mild). This focus on supplementation as part of an overall approach to diet encouraged adherence to this recommendation: *"taking the flaxseed oil... that's an easy thing... I just put it into my morning smoothie and that's it. It's easy."* (P6.1, 55y, mild). The main difficulty participants described with adhering to omega-3 supplementation was accessing a good quality flaxseed oil in some rural areas and outside of Australia, and some did not like the taste.

Sun exposure

Outdoor work, hobbies such as gardening, and exercise provided opportunities for participants to obtain natural sun exposure. Two main barriers existed in terms of achieving the recommended levels of vitamin D; firstly, getting regular sun exposure was not practical for some people who worked indoors and could not manage to spend enough time outside during daylight hours. This was a further challenge for participants experiencing disease progression or functional decline: *"Well I was out in the sun a lot before I was diagnosed... as I got worse I just couldn't do that. I couldn't get outside."* (P3.1, 57y, sev). The second barrier participants described was not knowing what their vitamin D levels were and getting their levels tested. The time and effort required to get a blood test was off-putting for some participants, and this was exacerbated when participants encountered a lack of medical support for supplementation and/or testing from treating physicians, which was not uncommon: *"he (neurologist) didn't believe in that, so he said well it's not scientifically proven. So he didn't want to measure my blood level at that time, so I didn't have that. My GP (general practitioner) only wanted to follow what the neurologist was saying so he didn't want to do it either"* (P5.2, 44y, mild).

Vitamin D supplementation

Participants unanimously reported being able to supplement without difficulty, particularly because this recommendation does not require the same potential time commitments or household adjustments of the other recommendations. One participant spoke of her frustration with a friend with MS who did not supplement and regularly had very low vitamin D levels: *"[It] is the one thing that's so easy and it's such a preventative thing and I just*

feel like shaking her!” (P6.3, 39y, mild). The way participants supplemented varied depending both on the time of the year and on their geographic location, as recommended at the retreat. For example, it was common for participants to report supplementing with 10000 IU of vitamin D every day during the winter months, then reducing this to either 10000 IU 3 times per week or 5000 IU each day during summer. Some participants supplemented over winter then relied on natural sun exposure during the warmer months to maintain the recommended vitamin D levels, as recommended. However, many did so without knowing whether this strategy was effective in maintaining an adequate level of vitamin D.

Exercise

Participants understood and accepted the recommendation of exercise as important: “After the retreat [I was] more aware that you’ve got to do this thing [exercise] for you.” (P1.2, 65y, mod), and for some participants the retreat acted as a catalyst for exercise: “I do more exercise now than I would, had I not gone [to the retreat]” (P5.3, 63y, mod). “[Before the retreat] I was just a blimp, a couch potato.” (P3.2, 57y, mild). Especially for one who initially thought exercise should be avoided: “I remember when I got diagnosed that in particular I was like: do not run, do not exert any physical exertion or strain yourself at all because your body is so fragile.” (P6.4, 33y, mild).

Adherence to exercise recommendations

Most participants had incorporated or increased their levels of incidental exercise (incidental walking, dog walking/training, gardening, playing with children) and/or gentle exercise (walking, yoga) since the intervention. Participants described the “busyness” of their day-to-day routines—working, running errands, looking after children and family, and consequently feeling as if they were leading very active lives. But while most participants reported engaging in some form of exercise, they largely did not meet the recommended lifestyle intervention guideline of 20–30 min of vigorous exercise 5 times/week. One participant compared adhering to the different recommendations and said: “So I think (the diet) is easier because we have to eat, and with the exercise and the other things there, you think, well... yeah, I know I’m a bit complacent with the exercise and meditation” (P1.1, 37y, mild).

Barriers to regular exercise

Participants with functional decline or fear of falls reported having difficulty with finding a safe way of doing vigorous exercise: “I was doing aqua aerobics and chair-based yoga as well, but I had to stop because I deteriorated” (P3.1, 57y, sev); “I have trouble with one of my legs... Walking is just not doing it, but I don’t think I could run without falling over.” (P6.1, 55y, mild). “Going to the gym was just too hard and too treacherous. Too many opportunities to trip and fall.” (P5.1, 55y, sev). Others said that despite understanding the recommendations, incidental exercise was the best they could do: “I probably fall short of [the recommendation] because it is meant to be vigorous. I wouldn’t do three times a week of vigorous exercise but I get plenty of incidental exercise.” (P6.3, 39y, mild).

Most participants reported an episodic pattern of exercise, with a range of barriers and competing interests that prevented a regular regimen, and similarly a range of strategies to get back on track, often not specific to the context of MS. Inclement weather was noted as impacting on motivation, with weather-

dependant activities more likely to be paused or discontinued during winter months, especially in colder climates. Conversely, participants described being more active during periods of good or warmer weather. Geographical distance from facilities was another barrier to exercise: “I could go to a gym, which would be a 25-kilometre drive – well, I suppose I could, but I just don’t.” (P7.1, 51y, mild). Conversely, one participants stated: “the exercise one is getting easier as we go along, especially since I moved into the retirement village and the facilities are there for me to use” (P5.3, 63y, mod). Participants did note that maintaining regular exercise could be resource-intensive. Classes, gym and pool passes, exercise equipment, and professional and/or clinical consultation were noted to all incur a cost. One participant stated: “You need to have a bit of finances.” (P6.2, 49y, mild) about the resources required for swimming (squad) training. The participants engaging in episodic exercise also described having experienced injuries, MS related symptoms, or illness.

By far, the perceived time commitment required to fulfill the recommendation was the most difficult obstacle to regular, vigorous exercise. Competing interests on time were mentioned by almost all participants. Participants who were employed (especially in full-time employment) and/or had family and caring commitments talked about needing to find or make the time in their day to exercise, and often this was not possible: “I think ideally I would like to be doing [exercise] all the time, but I’m realistic in that at the age and phase of my life... I don’t have a lot of that time I can put into exercise and meditating or whatever else because it’s just not available to me. I want to do it, it’s just juggling life, getting that life balance.” (P4.2, 46y, mild). On the other hand, participants who were retired or working part-time were more easily able to incorporate exercise into their schedules: “I find that most days [exercise] fits into place. I’m fortunate, because I’m retired and I haven’t got any working commitments or anything like that.” (P1.2, 65y, mod). Others said fatigue played a role too: “It was all a bit much, working full-time, dealing with the house. I don’t like to say fatigue, but I would get tired and there just didn’t seem to be enough hours in the day to do everything” (P6.1, 55y, mild).

Exercising for pleasure contrasted sharply with “having” to exercise. Some had not found a type of exercise that was enjoyable despite trying different things, or their preferences changed over time: “I don’t like gyms.” (P3.2, 57y, mild); “I don’t like sports in general.” (P5.2, 44, mild), “I suppose I’ve tried different forms of exercise... At the time I was doing swimming; I’ve done yoga as well. Yoga I really enjoyed but I’m not doing much of it at the moment... So I have experimented a bit with exercise to find the right thing.” (P6.3, 39y, mild).

Strategies and advantages for regular exercise

Participants described a number of deliberate strategies they employed to try to increase and maintain exercise. Again, these strategies were not specific to the context of MS. Participants prioritized and scheduled exercise, exercised in small increments, focused on exercise they enjoyed doing, employed self-monitoring techniques using apps and devices, made a commitment to exercise (such as buying a dog that had to be walked), and where necessary, made modifications to their regimens in order to maintain some level of exercise. For example, participants related scaling exercise to cope with injury and recovery (chair yoga/yoga, recumbent cycling/cycling).

Participants spoke at length about the physical feedback that exercise provides. Exercise feels good and this provides

motivation: *"I enjoy feeling fitter" (P6.3, 39y, mild); "... Exercise is getting easier as [I] go. I think the more you do, the more – is it the [endorphins]? ... The more exercise you do, the more you want to do" (P5.3, 63, mod).* Establishing and maintaining an exercise routine can also have positive effects psychologically, by creating a sense of control: *"When you get back on track with the exercise you feel yourself walking better so you think oh good that's working ..." (P3.4, 68y, sev).* While for some fatigue was a barrier, others turned this into a motivation: *"The same ones that most people find the reasons not to exercise is – I know that it creates energy for me so if I'm tired I know I need to exercise" (P3.2, 57y, mild).*

Motivating factors participants described were also not specific to the context of MS. For some participants, the social connections they made participating in exercise, such as team sports, group exercise classes, and swimming squads, were motivating factors for exercise: *"I've made great friends doing pilates." (P1.2, 65y, mod).* Participants spoke of having a sense of accomplishment having completed challenging or endurance activities: *"I feel so proud of myself after I've done a long bike ride." (P3.2, 57y, mild).* The financial outlay involved with some forms of exercise was a motivating factor *"I've paid the money so I may as well do it." (P6.1, 55y, mild).* Another motivating factor participants described was consultation with knowledgeable practitioners, both in clinical and coaching contexts. Person-centred and specific instruction was seen as helpful: *"She [pilates instructor] knows what I can do and what I'm capable of and when [my body] is tired one week she'll be able to tell me that as I walk in." (P5.3, 63y, mod),* and as complimentary to the information provided by neurologists: *"There's been a lot of other little things that the physiotherapist and [podiatrist]... keeping on top of my symptoms. I think you need that – you need that specialist knowledge ... you're not going to get lifestyle things from your neurologist." (P5.1, 55y, sev).*

Stress reduction (meditation)

Participants were asked about how they fared at maintaining the lifestyle recommendation of performing 30 min of a stress-reduction activity per day, such as meditation. The type of stress reduction was not prescribed, and participants recounted practicing variations of meditation, relaxation, mindfulness, prayer, as well as yoga practice to achieve 30 min of a daily stress reduction practice. Almost universally, participants described the daily stress reduction practice as being the most difficult lifestyle modification to maintain: *"it's when the workload has been less I have meditated more which should be the opposite" (P2.2, 41y, mild).* This was despite participants' understanding of reducing stress as a trigger for MS symptoms and making changes in other parts of life to reduce stress: *"Stress management, meditation, building your life around trying to keep well, because stress is such a huge trigger for MS relapses." (P2.1, 32y, mild).*

For some participants the retreat was their first experience of facilitated meditation. When adopting a regular practice at home after the retreat, some participants described being unsure about whether they were "doing it correctly". Some found it became easier over time with practice: *"I've found it becoming easier over time because I think at the start it feels like a long time and it's hard to stop your brain from being too active" (P6.3, 39y, mild).* Participants did not see any disadvantages to their chosen stress reduction practices, and often described feeling better physically when actively meditating, and feeling the physical effects of being relaxed: *"I think the meditation's been the primary one in my job, which has – previously been pretty full on, pretty stressful. I find*

that if I have a difficult, busy day, I'm not quite so wrung out as I would have been. I put that down to meditation." (P4.1, 62y, mod), *"Or if I come home and I've been feeling stressed or tired or just whatever, I just meditate. I just feel how much better it made me feel, so I just kept on doing it." (P2.1, 32y, mild).* Although one participant said: *"I don't seem to be able to get the routine going. Perhaps I haven't seen the – any advantages to it. I know that people who do meditation religiously really do feel that it makes a difference, but I haven't felt that myself." (P5.3, 63y, mod).*

Long-term adherence to meditation

Having limited time and a lack of motivation were described as being the main barriers to maintaining a dedicated stress reduction practice. Participants described finding enough "alone" time hard, and fitted in stress reduction practices for less time than the recommended 30 min if that was all they could manage. Once a regular practice had been established, participants described employing self-monitoring strategies to help maintain their practice. For example, when regular practice slipped they would use a phone app, or join a class to try to recultivate their practice: *"I just did (a course) and that was good because it got me at least doing some mindfulness at sporadic times of the day. I'm not doing a formal sit down 20 min of meditation, I was doing it for a while but it's fallen away." (P6.2, 49y, mild).* Structured practice, such as meditating first thing in the morning, or using apps for reminders and motivation were noted as being helpful strategies. For some participants making the time for regular practice, then getting out of the habit was a cycle that occurred frequently: *"I'm a bit hit and miss with my meditation. I am a little bit of a stress person and stress does set my symptoms off. So I really try. I was for a while doing it religiously and then just, I don't know, again life just got too busy and that's a thing that just got dropped with the exercise" (P6.1, 55y, mild).* Making time "to do nothing" was clearly difficult for people with busy lives with competing demands and responsibilities. For participants with families and children, finding alone time was often difficult, but made easier with supportive partners: *"There was an eagerness (from my husband) to support me with the meditation (P6.1, 55y, mild).* Some said that they choose to prioritize other health behaviors such as exercise in the limited spare time they had available: *"I find it difficult just to sit still. It's my personality really." (P6.2, 49y, mild).*

Smoking

Despite purposive sampling toward the end of the study, no participants were included who smoked within 2 years before the time of the intervention, or at any time after.

Discussion

While it is clear that healthy lifestyle is associated with better health outcomes in people with MS, little is known about long-term adherence to behavior change interventions for people with MS [20]. We aimed to assess barriers and enablers to long-term adherence in people with MS who self-enrolled in a healthy lifestyle intervention. Participants overall reported they had improved their health behaviors after participating in the intervention 3–5 years prior.

The majority of participants followed the diet recommendations most of the time, but very few follow these all of the time. Most take omega-3 supplements daily. All participants took vitamin D (varying doses) and most got some sun exposure

depending on time of year. Exercise and meditation was episodic for almost all participants; only two participants meditated daily, and similarly only two participants managed to do the recommended level and frequency of exercise.

Multimodal interventions

While no one engaged with all the components of the multimodal intervention to the recommended levels at the time of this study; everyone still engaged with at least one, and often more than one component. Particularly, the time involved to meet the stress reduction and/or exercise recommendations was a significant barrier and depending on personal preference and circumstances, most people chose one over the other. Overall, the experience was described as useful and “transformative” for information gathering, decision making, and practical strategies regarding health behaviors, as well as providing a sense of hope for the future, comradery, and control over wellbeing.

Compared to targeting a single behavior, a multimodal lifestyle intervention may be most effective in improving health behaviors and health outcomes. The health behaviors targeted by the intervention are often clustered [30], and changing one may affect another. Dolan et al. [31] have postulated that one health behavior, such as physical activity, may either have a “promoting spillover effect”, e.g., *I should keep up the good work and eat healthily*, or a “permitting spillover effect”, e.g., *after exercising, I now deserve a piece of cake*. Whether a promoting versus permitting spillover effect occurs depends on numerous factors including (but not limited to) whether the underlying motive of the first behavior is more intrinsic rather than coerced or financially rewarded, having a stricter rule-based versus a more flexible outcome-based mindset, and lower perceived costs and effort [31]. While an strict “all or nothing” rule, such as no dairy or meat, was helpful for people when making decisions around food, “the gray zones” around consuming fats were more difficult to navigate. If there were no healthy options available (e.g., at work or social functions) or they had little control over food preparation (e.g., while traveling or if physical ability prohibited) they would sometimes choose to consume the unhealthy food and balance it with a period of more closely following recommendations afterwards. Other recommendations, such as those around stress reduction through meditation and exercise were perceived to be more flexible, and most participants reported doing the best they could by doing short mindfulness moments, or incidental exercise. Others reported they did not enjoy exercising or meditation and could not motivate themselves to do so. Supplementing with vitamin D and omega 3 fatty acids were seen as the easiest recommendations to adhere to, as they were the least effortful, time-consuming, and had no impact on social or family life. Other than the general recommendations, individual goal-setting was rarely used and many simply tried the best they could towards meeting the recommendations.

While very few studies have examined multimodal lifestyle interventions in MS, Plow et al., assessed barriers and facilitators to healthy eating, exercise and sleep. They reported that participants of a multimodal lifestyle intervention [32] found benefit in the provision of evidence of benefits of healthy behaviors, and in developing an action plan taking into account personal preferences and health problems. Similarly, participants in our study reported that the evidence around benefits to healthy behaviors was useful and increased their motivation for initiating and maintaining health behaviors. While our intervention provided general recommendations, many participants deviated from those over

time and developed health behaviors that were tailored to their personal preferences and abilities, and fitted in with their family and work lives. In line with the patterns of healthy lifestyle behaviors we found in our data, Audulv et al. [33] reported that self-management for people diagnosed with a range of chronic diseases including MS followed different patterns over time. Similar to our data, consistent self-management was more often observed for medication and to a lesser extent for eating healthily, while episodic self-management was more often observed for physical activity which depended often on factors such as symptoms, the weather and time [33]. Audulv et al. also described on-demand self-management to manage acute symptoms, such as decreasing stressful activities during a flare-up. Participants in our study also reported increasing their stress-reduction activities when they felt it was needed or following the diet recommendations more closely when symptoms increased. Finally, they described that a transitional self-management pattern was seen in people who were slowly adapting to their symptoms over time and making arrangements in their daily activities to manage fatigue or pain [33]. Similarly, participants in our study found creative ways to adapt to mobility limitations or symptoms over time. A back-up plan for exercise activities when symptoms or relapse prevented usual activities ensured that they could remain active.

Diet and omega-3 supplementation

Eating according to the recommendations most of the time was common. Many reported eating some meat, dairy or processed foods (which are not recommended), often while out for meals at restaurants, with work, or visiting friends and family. Similarly, data from a trial where people with MS were randomized to a low fat (15%) diet with omega-3 supplementation for one year reported a 70% adherence [34]. Another similar trial found that after accounting for drop-out, approximately 70% adhered to the recommendations (20% or less of calories from fat at least 80% of the time) during the 1 year study [35]. Plow et al. [36] interviewed eight people with MS who had mobility impairment to assess barriers to nutritional behaviors. Similar to our findings, they reported that fatigue and mobility impairments were common barriers, and that family members at home played a large role in food selection and preparation, characterizing them “gatekeepers”. While lack of time was often reported as a major barrier to some of the other “time-consuming” lifestyle recommendations, this was not as much a problem for the diet recommendations in our study, with one participant stating “that’s easier because we have to eat”. It was clear that those who enjoyed cooking, and/or viewed the recommendations as a positive challenge had far less trouble adjusting than those who did not enjoy cooking, or those who were not physically able to prepare food. A supportive environment at home seemed to be an important enabler for adhering to the recommendations, and this was facilitated when the partner, family and/or friends were supportive. Family members cooking, or requesting, meals that did not fit within the recommendations, and having to eat at work or social functions were reported to be major barriers.

Vitamin D and sun exposure

Similar to our findings, adherence to vitamin D supplementation on recommendation has previously been reported to be high with median adherence at 97% [37]. While the act of supplementing was not difficult, some participants did express difficulty

raising their vitamin D through sun exposure citing work, time and disability barriers. Others reported difficulty determining their vitamin D levels due to lack of medical support, or time, for testing. In Australia, vitamin D tests were the fastest growing Medicare item in recent times and testing has increased rapidly over the past 15–20 years, prompting concerns of over-testing [38]. Despite considerable research in MS suggesting that high normal vitamin D serum levels may be beneficial [39], a recent meta-analysis found no significant benefit for disease progression compared to placebo [19], potentially due to a paucity of suitably robust clinical trials. There are numerous large randomized trials investigating the efficacy of high dose vitamin D supplementation in people with MS due to release results soon, which may assist in elucidating the potential benefits of vitamin D supplementation for people with MS.

Physical activity

Unsurprisingly, a sizeable body of research has accumulated regarding the perceived barriers and facilitators of exercise for people with MS. While regular physical activity is well recognized as having an important role in managing some of the deleterious effects of MS [14], people with MS engage in physical activity to a lesser extent than the general population [8]. Our results were in line with previous research on barriers to exercise in people with MS, where fatigue or physical exertion, physical impairment, costs, inadequate transportation, lack of family or professional support, accessibility barriers, fears associated with program participation (e.g. safety), and lack of time and/or motivation were reported [40–44]. Further, another qualitative study of 33 people with MS before, during, and after a personally tailored 12-week program to promote long-term maintenance of self-directed exercise showed that people with MS reported exercise barriers to be lack of confidence and exercise knowledge, together with negative perceptions of their physical capabilities [45]. One participant in our study acknowledged that she had avoided exercising after being diagnosed with MS as she thought this would negatively affect her “fragile body” but had now taken up high intensity exercise after learning of the benefits. Another study found that the decision to take part in physical activity emerged from an interaction between beliefs about physical activity (e.g., “fine line between benefit and harm; activity as a waste of time; Use it or lose it”), emotional responses to past or future activity (e.g., “what ifs”), and fatigue [46]. This decision-making process, dependent on many competing factors and barriers which change day to day (weather, injuries, fatigue), may explain why episodic patterns of physical activity were common in our study.

Facilitators of participation that emerged from our study were also similar to those reported previously including having a knowledgeable instructor and experiencing physical and psychosocial benefits from the program [44], physical performance and personal accomplishment [43], perceived postural and mood improvements, opportunities for social interaction, and an improved ability to deal with daily difficulties [45]. A further study reported that among highly active people with MS the benefits of exercise were found to be enhanced life satisfaction, an overall positive outlook on life, feelings of accomplishment and competence and greater perceived independence and autonomy [47]. In our study, those with high levels of physical activity had often established these regimens before they were diagnosed with MS and enjoyed exercising. Similarly, a study looking at self-management in people with chronic disease including MS reported that those with a consistent diet or exercise regimen often already

had established these routines and habits long before their diagnosis [33].

Stress reduction

Several studies have assessed the effect of meditation or mindfulness interventions on health outcomes in MS, but to our knowledge, none have reported on barriers or enablers to long term adherence of the practice beyond the intervention period. Similar to our study, two mindfulness based stress reduction trials reported that shortly after the intervention finished participants found it difficult to keep up the practice, but those that were able to keep practicing reported feeling an increased sense of control and positive outlook [48,49].

Smoking

One survey has reported on barriers to smoking cessation in MS, which included unpleasant withdrawal symptoms and expensive treatment for tobacco dependence, and perceived benefits from smoking on boredom and coping [50]. One smoking cessation trial protocol has been published, but the trial was halted due to recruitment difficulties [51]. Similarly, we were not able to recruit current or recent smokers into our study; very few smokers attend these retreats, reflecting the high level of engagement with positive health behaviors of this group.

Intervention facilitator

Finally, a strong personal relationship with the designer and main facilitator of the intervention (GJ) was identified in our study, similar to the Oslo study, a Norwegian study promoting healthy diet and smoking cessation among people at risk for cardiovascular disease [52]. Participants reported their relationship with the principal investigator of the Oslo Study as friendly and supportive; a role model. Participants in our study also reported they saw the main facilitator as a role model and aspired to live according to his recommendations. Furthermore, the family-based approach and the impact of spouses was emphasized by the participants of the Oslo study, which in our study was also the case for those who were accompanied by a support person. Participants of the Oslo study reported a process of empowerment and personal control as an important element of sustainable change [52]. In our study this was also reported by those who adhered more closely to the recommendations.

Limitations

There was no theoretical framework of behavior change underlying this study, therefore, the retrospective use of a behavior change taxonomy was difficult. Further, although the lead facilitator did not change through the period of the studied retreats, fidelity of the delivery of the intervention was not measured and may have varied over time. The relationship between the participants and main intervention facilitator played an important role, and as previously reported by others, this may not be easily reproducible [52]. The eligible sample included mostly highly educated and motivated people with MS who self-funded and self-selected to participate in a health intervention. Furthermore, the response rate for this sub-study was less than 30% (18/61), and those with better adherence and healthier lifestyles may have been more likely to participate. Therefore, the generalisability of this study to all people with MS may be limited. In the interest of

time, transcripts were not sent back to participants, but instead checked by the authors against the audio files. Finally, people may have given socially acceptable responses, and thus over-reporting adherence to recommendations. Therefore, adherence as reported in this study may be overestimated.

Conclusion

Study participants reported still adhering to one or more (but not all) of the recommendations 3–5 years after the lifestyle intervention, although in varying degrees and often in an episodic manner. Main barriers were lack of time due to competing demands such as family life and employment, support and motivation, injuries, MS symptoms such as mental or physical fatigue, and disability. Changing existing habits (e.g. diet) was reported by participants to be easier than initiating new habits if these were time consuming (e.g. exercise and meditation). Enablers for healthy lifestyle included support for lifestyle change and maintenance, tailoring activities to the individual's ability and preference, self-monitoring, and assistance with practical solutions to overcome barriers. Advantages such as increased fitness and mobility, sense of control and accomplishment, and weight loss were reported. These findings may help refine current and other multimodal lifestyle interventions for people with MS.

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GJ receives royalties from his book: *Overcoming MS*. He is also the founder of the charity *Overcoming MS* and has received remuneration for facilitating the intervention this study relates to, and associated activities. None of the other authors declare a conflict of interest.

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