Patient self-management and empowerment for multiple sclerosis

The implications of dietary lifestyle management for primary care

CPD

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Background
Multiple sclerosis (MS) is a chronic neurological condition of increasing prevalence. Many people living with MS will trial various alternative therapies, including changed patterns of eating, to try to gain control over their condition. New clinical guidelines advise reducing the time between first clinical symptoms and treatment. It is the support of the healthcare team that can empower the person in their healthcare journey.

Objective
The aim of this article is to provide insights into the role of diet as an element of lifestyle management of MS and describe the implications of diet as a first-line treatment for MS.

Discussion
Many 'MS diets' have been promoted to persons diagnosed with MS, yet evidence-based advice is necessitated by an expressed need. Although health risks of short-term exploration of specific diets are not likely to cause concern, lifestyle management should be included in communication plans, with referrals to other healthcare professionals as appropriate.

THE ROLE OF DIET IS AN IMPORTANT ELEMENT of lifestyle self-management for persons living with MS (plwMS). The secondary aim is to describe the implications of diet for first-line management of MS by plwMS supported by a multidisciplinary healthcare team. The article is based on the evidence of an umbrella review conducted by the lead author[1] and a narrative of expert opinion from MS specialist clinicians contextualised to primary care.

Clinical management of multiple sclerosis

MS is a chronic demyelinating neurological condition of the central nervous system with unique case presentation.[2] The exact aetiology of MS is not yet established, although genetic and environmental factors, including the intrauterine environment, have been implicated.[2] The risk of MS is increased in people who are homozygous for the *HLA-DRB1*15* allele, but there are also more than 100 other polymorphisms.[2] Modifiable environmental risk, including vitamin D deficiency, has also been associated with risk of a first demyelinating event,[3,4] a point of contention in relation to the specificity in the updated McDonald criteria for MS diagnosis.[5]

MS care has changed over the past decade, with improved diagnostic criteria, treatment options (more than 17 are treatments currently on the Pharmaceutical Benefits Scheme for MS) and standards of monitoring disease stability (no evidence of disease activity [NEDA]-3 and NEDA-4).[6,7] The new brain health criteria recommend minimising delay to diagnosis and treatment as the gold standard of care in Australia.[8] Monitoring guidelines suggest annual magnetic resonance imaging (MRI), six-monthly specialist clinical reviews, healthy lifestyle discussions and disease-modifying therapy (DMT) efficacy safety checks within a shared decision-making platform.[9] While the initial focus is often on choice of DMT,[10] lifestyle management and management of environmental risk factors should be, and often are, included early in the treatment plans. This requires the support of a multidisciplinary team that includes the general practitioner (GP), neurologist, MS nurse specialist and allied health professionals.

Lifestyle self-management and patient empowerment

In the first years post diagnosis, plwMS often try to make sense of their diagnosis and ongoing chronic condition.[11]

A non-judgemental approach to care is needed during exploration of lifestyle management options including alternative diets. Engagement at this stage can enhance a sense of empowerment and disease acceptance,[12] as empowered patients are more likely to have a critical attitude and be willing to take control of their disease.[13]

Despite differences in patient age, ethnicity and income, empowerment is closely related to participation, control, coping, knowledge and legitimacy, suggesting a need for tailored support.[14] Continued and honest discussions of lifestyle options, including the diet, using consumer-reviewed resources build patient confidence in the relationship.[15] Motivational interviewing with plwMS during clinic visits about their knowledge of healthy lifestyle factors and how these factors affect MS and their readiness for change is required before referring to other healthcare professionals and healthcare programs.[16,17]

Wellness programs for MS have been successful in improving self-efficacy and health behaviours.[18] Programs designed as interventions related to healthy eating, physical activity and stress management[19] embedded in education and skill development have shown improvements in fatigue, fear avoidance, depression and pain symptoms for plwMS.[20] When considering wellness programs, it is vital that accurate and evidence-based information forms their basis.

To collate the evidence for lifestyle factors for MS, MS Research Australia has developed resources for health professionals and plwMS.[21] The evidence for diet is inconsistent[1] for MS disease progression. The strongest evidence is related to vitamin D and fatty acid supplementation and MS risk. However, only approximately 5–10% of vitamin D is absorbed from dietary sources,[22] and there is insufficient evidence to determine whether polyunsaturated fatty acids have any impact on MS-related outcomes.[23] The evidence for whole food or dietary pattern approaches to improve symptom management or slow disease progression is limited.[1] While the evidence related to comorbidities such as weight management and lipid levels is consistent and included in practice guidelines,[24] research specific to MS is lacking.

Dietary self-management: Implications, risks and recommendations

While DMT remains the primary focus of care, the popularity of lifestyle management sees >70% of plwMS turning toward alternative medicines, including dietary interventions.[25,26] Among Australian plwMS surveyed, 94.3% reported making changes to their diets, and 21.2% followed one or more specific diets.[27] The decision to initiate a dietary change is not only due to the range of MS symptoms, but also a desire to improve overall health.[26] However, dietary information is often obtained from potentially unreliable sources (eg the internet, family and friends) that recommend unsustainable changes to patterns of eating, including the removal of multiple food groups.[28,29]

Studies have shown that a range of 'MS diets' publicised via lifestyle programs and social media are trialled by plwMS, and only those aligned to personal experiences are deemed suitable.[30] As present, plwMS perceive certain dietary components (eg meat, fat and sugar) to have an impact on their MS, although studies have shown that the rates of exclusion – particularly for meat and dairy – are lower than previously reported.[27,28,31] Disinformation and misinformation regarding many of the dietary changes suggested for plwMS are widely supported by anecdotal stories over evidence-based principles, targeting patients with low health literacy.[29,32] A survey of plwMS found the internet (including social media) was the leading source of nutrition information used by plwMS.[33] A further audit of MS websites related to food and nutrition has exposed the low quality of the information and high rates of inaccurate content in relation to 'MS diets'. Further, other concepts, such as the microbiome, only appeared on two webpages across the three search engines used.[34] While the microbiome is of growing importance to understanding the gut–brain interactions occurring in MS, a systematic review of prebiotic and probiotic food sources related to MS has revealed that most of the published studies are in the pre-clinical stage[35] and may create consumer confusion. The importance of the microbiome is, however, acknowledged in the MS resources for health professionals,[21] though the evidence has a high heterogeneity of outcomes.

Research has identified that plwMS who sourced information about nutrition from the internet were less likely to be satisfied with their GP's and neurologist's understanding of lifestyle management for their condition.[33] The same study also found that information from these healthcare professions was highly influential for encouraging dietary change. Dietitians were a source of nutrition information for only 8% of respondents. Of the information sourced from the internet, the most common was related to the Overcoming MS program, which includes diet; this was followed by information about non–MS specific diets. Studies are ongoing for specific dietary approaches for MS, including paleo and fasting approaches, though at present the evidence is inconsistent. Naturopaths were also more likely than other health professionals to encourage elimination-style approaches to food intake.[33] Generally, MS 'diets' adhered to in the short term pose a low risk to most plwMS, although a lack of professional support can place patients at risk of dietary deficiency in the long term.

PlwMS have expressed a need for nutrition support.[30] Given limitations related to the current evidence base and a lack of nutrition practice guidelines for MS, plwMS should be encouraged to consider evidence-based behaviour change. There is a high level of consistency globally on general dietary recommendations.[36] Food-based dietary guidelines translate nutrient references and evidence for foods, diet patterns and health into actionable recommendations.[36] Such guidelines apply food-based messages to provide food choices that reflect the evidence, as people choose to eat foods, not nutrients.[37] In Australia, the Australian Dietary Guidelines (the Guidelines) are based on scientific evidence of the impact of food intakes on health outcomes.[38] The Guidelines aim to support an optimal nutritional status and reduce the risk of comorbid diseases. At present, a diet for the management of MS does not exist; therefore, MS Limited suggests that plwMS should be referred to the Guidelines, which encourage a balance of intakes from five food groups with consideration given to cultural, ethical and medical requirements. Studies underpinned by the Guidelines have also shown that improved dietary quality for plwMS results in positive outcomes, including reduced depression and pain.[27] Dietary management of MS, when supported by an Accredited Practising Dietitian, needs to be individualised to personal preferences, comorbidities, implications of disability and living situation. Ultimately, an 'MS diet' is not necessary because of the restrictive nature that is implied.

How can we support plwMS in the primary care context?

As providers of continuing and comprehensive care for plwMS, GPs have the opportunity to provide initial, evidence-based lifestyle advice. In addition, plwMS may benefit from coordinated support management of comorbidities, as hypertension, hyperlipidaemia and ischaemic heart disease are more common in plwMS than the general community,[39] and vascular comorbidities are associated with a higher risk of MS disease progression.[40] While data are lacking as to whether addressing cardiometabolic risks improves MS progression, it is important to overall health optimisation.[41] The GP has an active part to play in developing a comprehensive management plan in concordance with the goals of plwMS.[42] Where appropriate, this will include referring them to relevant allied health providers and coordinating care across their multidisciplinary team. The GP can review progress against the patient's goals and reinforce lifestyle advice as part of a team-based approach to management. Additional patient support is also available through MS Connect, MS Advisor or the service compass of the MS Limited website, which includes links to neurology and health services localised to plwMS.[43]

Conclusion

Given the clinical evidence of general lifestyle benefit to MS management, the task of the GP is that of building trust and credence through an ongoing, open, informative therapeutic clinical relationship.[44] This allows the provision of evidence-based care that is both plwMS informed and tailored to the patient's life and individual set of priorities. While no specific guidelines exist for the management of MS with diet, a growing need for credible and consistent information is expressed by plwMS. Evidence to support diet for first-line management of related comorbidities is apparent, and risks related to short-term exploration of 'MS diets' that are not based on scientific principles are generally low. An empowered and evidence-based continuity of care with a multidisciplinary healthcare team will augment lifestyle changes that are more likely to be adopted, enjoyed and sustained in the longer term.[44,45]

Key points

- Empowered patients seek control, coping skills, knowledge and legitimacy in disease management.
- Multidisciplinary care can support MS self-management with lifestyle approaches including diet.
- It is recommended that plwMS follow evidence-based recommendations in preference to an 'MS diet'.
- MS guidelines suggest minimising the time from first symptoms to commencement of treatment.
- The GP can build trust and credence with an open and informative therapeutic clinical relationship.

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