

Australian research

1. Associations between lifestyle behaviours and quality of life differ based on MS phenotype

Authors: Nag, Yu, Jelinek, Simpson-Yap, Neate & Schmidt

MS presents as relapsing or progressive phenotypes; both forms present with diverse symptoms that may reduce quality of life (QoL). Adherence to healthy lifestyle behaviours has been associated with higher QoL in people with MS; whether these associations differ based on MS phenotype is unknown. This study analysed cross-sectional self-reported observational data from 1,108 iConquerMS participants. Findings revealed that diet, wellness, and physical activity, but not vitamin D or omega-3 supplement use, were associated with QoL. Specifically, certain diet types were negatively associated with QoL in relapsing remitting MS (RRMS), and positively associated in progressive MS (PMS). Participation in wellness activities had mixed associations with QoL in RRMS but was not associated in PMS. Physical activity was positively associated with QoL in RRMS and PMS. Future studies assessing timing, duration, and adherence of adopting lifestyle behaviours may better inform their role in MS management.

Read more: doi: [10.3390/jpm11111218](https://doi.org/10.3390/jpm11111218)

2. Evaluating course completion, appropriateness and burden in the understanding MS massive online course (MOOC): Cohort study

Authors: Claflin, Campbell, Doherty, Farrow, Bessing & Taylor

Many Australian and New Zealand MS Nurses, neurologists and allied health staff have recommended the Menzies and University of Tasmania MOOC to patients and their loved ones as a way of introducing them to MS and lifestyle considerations and providing MS

focused education. This study aimed to evaluate both participant engagement and measures of satisfaction, appropriateness, and burden of the MOOC entitled “Understanding Multiple Sclerosis” among a cohort of 3,518 international course participants. The researchers assessed the association of key outcomes with participant education level, MS status, caregiver status, sex, and age using summary statistics, two-tailed t tests, and chi-square tests. Findings revealed that of the 3,518 study participants, 928 (26%) were people living with MS and 862 (33%) identified as formal or informal caregivers. Results showed that the course completion rate among study participants was 67%. The course was well-received, with 97% of participants satisfied, with an appropriate pitch and low burden (a mean of 2 hours engagement per week); people living with MS were less likely than those not living with MS to complete the course; and people with a recent diagnosis of MS, caregivers, and participants without a university education were more likely to apply the material by course completion. These findings confirm that this MOOC is fit for purpose, presents information in a way that is readily understood by course participants and is relevant to their lives.

Read more: doi: [10.2196/21681](https://doi.org/10.2196/21681)

3. Utilisation of DMTs and diversity of treatment pathways in RRMS

Authors: Hillen, Ward, Slee, Stanford, Roughead, Kalisch Ellett & Pratt

The appropriate and safe use of medicines is informed by utilisation studies, of which very few exist in MS. Outcomes can inform health interventions to improve appropriate use of medicines and post marketing surveillance activities to improve safety. The aim of this study was to evaluate the utilisation and treatment patterns of DMTs for RRMS. A representative sample of the Australian pharmaceutical benefits scheme data were analysed (2006-2016) and included 20,660 patients with at least one dispensing of a DMT for RRMS during the study period (median age 41 years, 75% female). Incident and prevalent use increased by 20% and 88%, respectively. The market was responsive to 13 new listings of DMTs over the

study period. Diverse treatment pathways were found, with 278 and 93 unique sequences in 2006-2013 and 2014-2019, respectively. The researchers concluded that the availability of new DMTs has influenced both initial treatment choice and prevalence of users. Additionally, individualised treatment patterns and exposure to multiple medicines over time will challenge traditional pharmacovigilance systems. This will necessitate creative and supportive programs from MS clinicians and MS Nurses.

Read more: doi: [10.1016/j.msard.2021.103412](https://doi.org/10.1016/j.msard.2021.103412)

4. A proinflammatory diet is associated with an increased likelihood of first clinical diagnosis of CNS demyelination in women

Authors: AusImmune Investigator Group et al

While a number of studies have examined associations between dietary factors and risk of MS, little is known about intakes of inflammation-modulating foods and nutrients and risk of MS. This study tested associations between the Dietary Inflammatory Index (DII) and risk of a first clinical diagnosis (FCD) of CNS demyelination (N: 267 cases, 507 controls) using data from the Ausimmune Study. The DII is a well-recognised tool that categorises individuals' diets on a continuum from maximally anti-inflammatory to maximally pro-inflammatory, with the score calculated from dietary intake data collected using a food frequency questionnaire. Regression models were used to estimate the association between DII and FCD separately for men and women. The results demonstrated that for women, a higher DII score was associated with increased likelihood of FCD, however, there was no association between DII and FCD in men. These findings suggest that a pro-inflammatory diet is associated with an increased likelihood of FCD in women.

Read more: doi: [10.1016/j.msard.2021.103428](https://doi.org/10.1016/j.msard.2021.103428)

5. Association Between Time Spent Outdoors and Risk of Multiple Sclerosis

Authors: Sebastian...Chitnis, Waubant, Lucas & US Network of Paediatric MS centres

A ground-breaking research project, published in *Neurology*, is a collaborative project between the US Network of paediatric MS centres and Australian National University researchers. This study aimed to determine the contributions of sun exposure and ultraviolet radiation (UVR) exposure to risk of paediatric-onset MS. Children with MS and controls recruited from multiple centres in the USA were matched on sex and age.

Multivariable conditional logistic regression was used to investigate the association of time spent outdoors daily in summer, use of sun protection, and ambient summer UVR dose in the year prior to birth and the year prior to diagnosis, with MS risk, adjusting for sex, age, race, birth season, child's skin colour, mother's education, tobacco smoke exposure, being overweight, and Epstein-Barr virus (EBV) infection.

Findings revealed that during the most recent summer, spending >30 minutes outdoors daily was associated with a marked reduction in the odds of developing MS, with higher summer ambient UVR dose also protective against developing MS. Although further research needs to be done, this study suggests that, if this is a causal association, spending more time in the sun during summer (as well as residing in a sunnier location) may be strongly protective against developing paediatric MS. For families with higher risk factors for MS, this could be significant.

Read more: doi [10.1212/WNL.00000000000013045](https://doi.org/10.1212/WNL.00000000000013045)

6. Episodic foresight in MS

Authors: Manchery, Henry, Blum, Swayne, Beer, Rendell & Nangle

Episodic foresight refers to the ability to imagine future scenarios and to then use this imaginative capacity to guide future-directed behaviour. MS is associated with deficits generating the characteristics of future events (the imaginative component of episodic

foresight), but no study to date has tested whether MS is also associated with deficits using episodic foresight to appropriately *guide* future-directed behaviour. For MS Nurses and clinicians planning future care partnerships, this could be impactful. In this study, 40 people with RRMS and matched controls completed a validated measure that met strict criteria for assessing the functional application of episodic foresight, Virtual-Week Foresight. Findings showed that overall, people with RRMS did not differ significantly in how likely they were to spontaneously acquire items that would later allow a problem to be solved and were also just as likely to subsequently use these items to solve the problem. However, depressed RRMS participants were significantly impaired in foresight relative to both non-depressed RRMS participants and controls. The depressed MS subgroup also differed from the non-depressed subgroup in their ability to perform instrumental activities of daily living. This study provides further evidence for depression to be screened for and appropriately treated in MS.

Read more: doi: [10.1037/neu0000785](https://doi.org/10.1037/neu0000785)

7. Lifestyle and complementary therapies in MS guidelines: a systematic review

Authors: Weld-Blundell, Grech, Learmonth & Marck

The management of MS increasingly comprises of clinical interventions and self-management strategies including both complementary therapies and modifiable lifestyle factors, of which those with proven safety and efficacy are fundamental to best practice. However, it remains unclear to what extent MS clinical practice guidelines and consensus statements address these strategies. This systematic review assessed 31 guidelines and consensus statements which were based on these areas of practice. The review found that there was high quality literature in scope and purpose, moderate quality literature for rigour of development and low quality for applicability. Only two guidelines intended for use by people with MS, related to physical activity and exercise, mindfulness, smoking cessation, and vitamin D and polyunsaturated fatty acid supplementation, scored high in all domains. This indicates a need for more high-quality guidelines and consensus statements, and a focus on implementing resources, particularly for people living with MS.

Read more: doi: [10.1111/ane.13574](https://doi.org/10.1111/ane.13574)

8. Do dietary interventions improve health outcomes in people with MS? A Cochrane review summary with commentary

Authors: Bhasker & Khan

A broad range of complementary and alternative medicine (CAM) approaches, including dietary interventions, are currently being trialled in people with MS. Data has suggested that certain dietary interventions may improve health related outcomes for people with MS. This review aimed to assess the effectiveness of dietary interventions to improve MS-related health outcomes, from the perspective of rehabilitation. Overall, 235 randomised controlled trials, with 2,335 participants evaluated a range of dietary interventions, including polyunsaturated fatty acids, antioxidants, dietary programs and dietary supplements. The findings demonstrated methodological issues leading to unknown or high levels of potential bias. The study authors concluded that the evidence for dietary interventions in people with MS is sparse and uncertain and that there is a need for more robust studies. This is important for MS Nurses in clinical practice to be aware of for education and advice perspectives.

Read more: [10.3233/NRE-228000](#)

9. An exploratory study regarding communication facilitators and barriers reported by a cohort of multiple sclerosis (MS) community members from the international massive open online course 'Understanding MS'

Authors: Campbell, Shaw, Mainsbridge, Taylor & Claflin

Effective communication is essential for high quality MS-related healthcare, however significant knowledge and practice gaps remain in this area. The aim of this mixed methods study was to explore self-reported facilitators and barriers of communication about MS reported by members of the MS community who participated in the free international online course, created in Australia, called Understanding MS. A total of 262 responders reported facilitators for communication about MS as being honesty, kindness/empathy/compassion, openness, effective listening, clarity, and patience. Barriers to communication included encountering a lack of knowledge about MS, the invisible

symptoms of MS, uncertainty about the appropriate amount of communication, and concern about being perceived as complaining and/or burdening others. The results of this study highlight areas that should be considered when developing communication strategies for MS community members and is deserving of further exploration.

Read more: doi: [10.1016/j.msard.2021.103473](https://doi.org/10.1016/j.msard.2021.103473)

10. Epidemiological study of MS in the Illawarra region

Authors: Dal, Elphick & Fuller

This study from NSW aimed to calculate the prevalence and incidence of MS in the Illawarra region, which is located south of Sydney on the eastern coastline around Wollongong and compare this with other regions in Australia. Hospital medical records, ambulatory care unit and hospital pharmacy records were used to extrapolate data. Findings revealed an estimated MS prevalence of 116.6 per 100,000 people, with an annual incidence of 5.06 cases per 100,000. Prevalence was slanted more towards females 3:1, and relapsing remitting MS was the most common type (69.7%), followed by primary progressive MS (13%) and secondary progressive MS (11.3%). Age at diagnosis was most commonly in the 30-39 years age group for RRMS, and 30-39 and 40-49 years for primary progressive MS. Overall, the study findings showed an MS prevalence in the Illawarra region that was slightly higher than the NSW and Australian average. Further epidemiological studies are recommended to understand this phenomenon further.

Read more: doi: [10.1111/imj.15704](https://doi.org/10.1111/imj.15704)

11. Markers of Epstein-Barr virus and human herpesvirus-6 infection and MS clinical progression

Authors: Tao, Simpson-Yap, Taylor...van der Mei AusLong/AusImmune Investigators Group

Infections with Epstein-Barr virus (EBV) and human herpesvirus-6 (HHV-6) have been implicated in MS onset, but we know little about their relationships in early disease. This study evaluated associations between markers of EBV and HHV-6 infection and reactivation

with MS conversion, relapse and EDSS amongst 205 people with clinically isolated syndrome (CIS) over 5 years. Baseline measures of EBV and HHV-6 viral load were measured, along with an infectious mononucleosis history. The results showed that infectious mononucleosis demonstrates a strong positive trend with higher relapse risk but was not associated with MS conversion from CIS. Antibodies against HHV-6 also showed a strong positive trend with higher relapse rates and MS conversion rates from CIS. This study adds to the growing knowledge base about viral infections and MS.

Read more: doi: [10.1016/j.msard.2022.103561](https://doi.org/10.1016/j.msard.2022.103561)

12. A randomised controlled trial of a web-based mindfulness programme for people with MS with and without a history of recurrent depression

Authors: Sesel, Sharpe, Beadnall, Barnett, Szabo, Naismith

Evidence shows small positive effects associated with psychological treatments for people with MS including mindfulness-based interventions (MBI). This study aimed to determine whether a web delivered MBI was beneficial in MS and if a history of recurrent depression was a moderator of treatment outcome. A total of 132 participants were assessed, stratified by their history of depression, and randomised to MBI or to a waitlist. Outcomes were assessed at baseline, post-intervention, and after 3 and 6 months. Results revealed that the MBI group reported significantly improved depressive symptoms compared with the waitlist group. Those with a history of recurrent depression benefitted significantly more than those without a similar history. Additionally, there were benefits for health-related quality of life MBI group, irrespective of depression history. Pain interference was less overall in the MBI group but change over time did not differ from waitlist. There were no treatment effects reported for anxiety, pain severity or fatigue. Overall, the study revealed that the web-based MBI significantly improved depressive symptoms and health-related quality of life in people with MS. For depression, the benefits were greater for those with a history of recurrent depression. This could be an important clinical resource for MS Nurses working with patients needing psychological intervention.

Read more: doi: [10.1177/13524585211068002](https://doi.org/10.1177/13524585211068002)

International research with a focus on allied health care

13. "I'm walking into the unknown": Qualitative insights into how emotions and lived experience related to multiple sclerosis diagnosis impact on decisions to pursue disease modifying treatment

Authors: Carey, Wilson, Janssen, Chohan, Rog & Roddam

People with RRMS are increasingly included as active participants in shared decision making around their treatment options. Choosing a first DMT is a complex process that often takes place soon after a diagnosis has been given, and often required to make difficult decisions at a time when they are still coming to terms with their illness. This qualitative study investigated the views and experiences of recently diagnosed patients with RRMS when they were making their initial DMT choice in the National Health Service (NHS) setting in the UK using interpretative phenomenological analysis. Findings revealed that reactions to diagnosis were characterised by strong emotions and a feeling of despair and hopelessness. Subsequently, the DMT decision was shaped by multiple considerations around maintaining normality and restoring hope and control over one's life whilst reconciling uncertainty around efficacy. Considering the future with a DMT also elicited reflections around employment and family planning. This study gives important insights for MS Nurses and other MS clinicians to understand the lived experience of patients making DMT decisions soon after diagnosis, when engaging in shared decision making.

Read more: doi: [10.1016/j.msard.2021.103464](https://doi.org/10.1016/j.msard.2021.103464)

14. MS caregiving: a systematic scoping review to map current state of knowledge

Authors: Rajachandrakumar & Finlayson

Unpaid caregivers, typically family and friends, provide significant amounts of support to people with MS. Understanding their experiences, needs and challenges is necessary to ensure that caregivers receive the support that they require to continue in their role. The

aim of this scoping review was to map the current state of knowledge about unpaid caregivers of people with MS and identify gaps in knowledge to guide future research and practice. Studies of spousal caregivers were the most common and focused primarily on measurement of caregiver burden or other negative consequences of caregiving. Thirteen studies addressed positive consequences of caregiving. Sixteen studies reported actual tasks performed by caregivers and seven reported outcomes of caregiver support interventions. Attention to diversity issues that may influence caregiving experiences and outcomes was rare. Overall, knowledge of MS caregiving is limited, particularly with respect to tasks performed by caregivers that may contribute to negative outcomes, diversity issues and effective approaches to remediate caregiver burden. Without this knowledge, finding ways to better support MS caregivers will be difficult. MS Nurses often provide informal and formal advice and guidance for caregivers, and this review imparts significant information to assist in this role.

Read more: doi: [10.1111/hsc.13687](https://doi.org/10.1111/hsc.13687)

15. Body mass index as a predictor of MS activity and progression among participants in BENEFIT

Authors: Escobar, Cortese, Edan...Munger

There is a lack of studies on the association between obesity and conversion from CIS to MS. The aim of this study was to determine whether obesity predicts disease activity and prognosis in patients with CIS. BMI at baseline was available for 464 patients with CIS in the BENEFIT study and provided the base for this research. The BENEFIT study compared patients treated with Betaferon after the first CIS event with patients who were treated once defined as clinically definite MS. Patients were followed up for 5 years clinically and by MRI. Results revealed that obese individuals were 39% more likely to convert to McDonald criteria defined MS and had a 59% higher rate of relapse than individuals with normal weight. This provides important evidence to support MS Nurses with lifestyle education and wellness programs for patients with CIS, and more broadly for all MS patients.

Read more: doi: [10.1177/13524585211061861](https://doi.org/10.1177/13524585211061861)

16. Physical and mental health comorbidities among adults with MS

Authors: Peterson, Lin...Mahmoudi et al

This study aimed to compare the incidence of common cardiometabolic diseases, musculoskeletal disorders and psychological morbidities among adults with and without MS. Data from a national insurance claims database was used with 9,815 cases with MS and 1.4 million controls without MS. Findings included that adults with MS had a higher incidence of any cardiometabolic disease (51.6% vs 36.4%), musculoskeletal disorder (68.8% vs 47.5%) and psychological comorbidity (49.4% vs 30.8%) than adults without MS. This indicates areas where efforts need to be concentrated to facilitate screening and preventative health interventions in people with MS as a higher risk group for all three co-morbid disorders.

Read more: doi: [10.1016/j.mayocpiqo.2021.11.004](https://doi.org/10.1016/j.mayocpiqo.2021.11.004)

17. What is hidden behind the mask? Facial emotion recognition at the time of COVID-19 pandemic in cognitively normal MS patients.

Authors: Ziccardi, Crescenzo, Calabrese

The COVID-19 pandemic has forced people to wear face masks that might interfere with facial emotion recognition. Social cognition deficits have been described in people with MS, even in the absence of global cognitive impairment, affecting predominantly the ability to adequately process emotions from human faces. This study explored the ability of people with MS to recognise emotion from people wearing masks. A total of 42 people with MS and matched controls underwent a facial emotion recognition task in which they had to recognise from faces wearing or not wearing surgical masks which of the six basic emotions (happiness, anger, fear, sadness, surprise, disgust) was presented. Results showed that although face masks negatively affected emotion recognition in all participants, people with MS exhibited lower accuracy than controls. Healthcare professionals working with people with MS during COVID-19 conditions should take into consideration this effect in their

clinical practice. Implications in the everyday life of people with MS should also be discussed with them in a clinical setting.

Read more: [10.3390/diagnostics12010047](https://doi.org/10.3390/diagnostics12010047)