

Research Roundup- Spring 2021

Every 3 months, the Research Team at MS Australia will bring you the latest in social and applied science research performed by MS Australia funded researchers, as well as significant other Australian and international research in this field. Of particular interest to us is research that supports translation to the MS community, so that people living with MS can have the opportunity for an enhanced quality of life. The article citation is included, and digital object identifier (doi) or unique link to the article at the end of the citation, for those that wish to view the full article and delve a little deeper.

This edition we cover:

Australian social and applied research

1. Hunter, A., Grech, L. B., Borland, R., das Nair, R., White, S. L., & Marck, C. H. (2021). Barriers and motivators for tobacco smoking cessation in people with multiple sclerosis. *Multiple Sclerosis and Related Disorders*, 54, 103085–103085.

<https://doi.org/10.1016/j.msard.2021.103085>

Smoking is a key modifiable risk factor for people with MS, yet little evidence exists on whether the needs of people who continue to smoke are met. For this study, 25 current and recent smokers were interviewed about their beliefs, attitudes and knowledge about smoking and quitting support needs. The study revealed that many people with MS have little knowledge of the risks of smoking on MS progression. It was noted that MS healthcare professionals asked about smoking, but often did not follow up with resources and referrals to quitting support services. This study has been the first to demonstrate that the smoking cessation needs of Australian people with MS are not being met. Based on the study findings, the researchers have provided recommendations for MS clinicians to provide access to information and smoking cessation services for both the short and the longer term. These recommendations include resource development for guidance and training for MS clinicians, evidence-based resources to provide information on smoking and MS disease progression and links to smoking cessation tools and resources and cross-referral pathways between smoking cessation services and MS services. This study was funded by MS Australia.

2. Yeh, W. Z., Widyastuti, P. A., Walt, A. V. der...Jokubaitis, V. (2021). Pregnancy-related relapse in natalizumab, fingolimod and dimethyl fumarate-treated women with multiple sclerosis. *BMJ Neurology Open*, 3(Suppl 1), A2–A2.
<https://doi.org/10.1136/bmjno-2021-ANZAN.4>

Using data from the MS Base registry, Dr Vilija Jokubaitis, Dr Wei Yeh and their research team (comprising many Australian MS neurologists) have explored pregnancy-related MS disease activity and some of the disease modifying therapies (DMTs) used in relapsing-remitting MS. Over 1600 pregnancies were investigated over an 8-year period. Many of the DMTs for MS are not used in pregnancy due to concerns over the foetus and current government advice (from the Therapeutic Goods Administration [TGA]) for use in pregnancy. The researchers were able to identify those women using natalizumab (Tysabri) and fingolimod (Gilenya) pre-pregnancy experienced a slightly higher relapse rate during pregnancy. In those women who continued with Tysabri during pregnancy, relapse rates were reduced; and those commencing Tysabri again after delivery also experienced reduced postpartum relapses. In this study, breastfeeding women were also noted to be less likely to relapse. This information is helpful for MS neurologists to provide individualised advice to women under their care who are planning a pregnancy, to optimise their condition and protect against relapses, especially in the postpartum period where relapses are more likely. This study was funded by MS Australia.

3. Rath, L., Bui, M. V., Ellis, J... & van der Walt, A. (2021). Fast and safe: Optimising multiple sclerosis infusions during COVID-19 pandemic. *Multiple Sclerosis and Related Disorders*, 47, 102642–102642.
<https://doi.org/10.1016/j.msard.2020.102642>

The COVID-19 pandemic required fast action and planning to ensure that people with MS were able to continue with their infusible treatments. Researchers from Melbourne set out to be innovative and explore if reducing time in clinical settings, by reducing infusion times, could benefit both staff and patients who were feeling vulnerable with possible exposure to the COVID-19 virus. The researchers analysed the effects of administering the MS treatment infusions natalizumab (Tysabri) and ocrelizumab (Ocrevus) at a faster rate than was currently recommended (called “rapid infusion method”) to see if this led to a safe, but more efficient use of time in the infusion unit. Patients who had prior exposure to the medications were enrolled into the study and a total of 369 infusions assessed. All infusion reactions experienced

(10 in total) were mild to moderate and did not require infusion discontinuation. The study concluded that the frequency or severity of infusion reactions using the rapid infusion method were no different to usual practice and could potentially save hospital resources during the COVID-19 pandemic. This is an excellent example of translating research quickly to practice for improving MS quality of life and management.

4. Marck, C., Hunter, A., Heritage, B... & Learmonth, Y. (2021). The effect of the Australian bushfires and the COVID-19 pandemic on health behaviours in people with multiple sclerosis. *Multiple Sclerosis and Related Disorders*, 53, 103042–103042. <https://doi.org/10.1016/j.msard.2021.103042>

In a study funded by the Melbourne Disability Institute and MS Australia, researchers Dr Claudia Marck and Dr Yvonne Learmonth, together with their research teams, have explored the impact of these back-to-back crises on the health behaviours of people with MS. They investigated behaviours such as physical activity, unhealthy eating habits, sleeping patterns, alcohol consumption, medication adherence and smoking using an online survey and interviews for a more in-depth exploration. Findings indicated that both the bushfire crisis and COVID-19 pandemic have added further challenges to healthy behaviours of people living with MS, with greater physical inactivity, unhealthy eating and increased alcohol consumption reported. Although these are in line with findings in the general population, it is arguably of higher importance in people with MS, who may need additional support to maintain positive health. The researchers are advocating for MS healthcare professionals and people with MS to be aware of this tendency during times of adversity, and to actively promote the uptake of more healthy behaviours such as maintaining physical activity, healthy eating and sleeping patterns, and adhering to recommended alcohol consumption guidelines. This will ensure the best quality of life in the future for people living with MS.

5. Bessing, B., Hussain, M. A., Claflin, S. B., Chen, J., Blizzard, L., van Dijk, P., Kirk-Brown, A., Taylor, B. V., & van der Mei, I. (2021). Work productivity trajectories of Australians living with multiple sclerosis: A group-based modelling approach. *Multiple Sclerosis and Related Disorders*, 54, 103131–103131. <https://doi.org/10.1016/j.msard.2021.103131>

Previous studies have documented reduced work capacity and work productivity loss in MS, but little is known about the longitudinal trajectories of work productivity in MS. A total of 2121 employed participants of the Australian MS Longitudinal Study (AMSLS), an MS Australia-supported research platform, were followed over 4 years with at least two repeated measures. Researchers identified three distinct work productivity trajectory groups over this time; the more severely affected 'moderately reduced' (17.0% of participants), the 'mildly reduced' (46.7%) and 'full' (36.3%) where the employment trajectory showed no reduction. Researchers noted that higher education level, higher disability, and higher MS symptom severity were associated with increased probability of being in a worse work productivity trajectory. The severity of MS symptoms, particularly the clusters 'fatigue and cognitive symptoms', and 'pain and sensory symptoms' were associated with the lower work productivity groups and clinical care, self-care, and interventions focused on minimising the impact of MS symptoms could benefit individuals at risk of work productivity loss.

6. Parkinson A, Drew J, Hall Dykgraaf S, Fanning V, Chisholm K, Elisha M, Lueck C, Phillips C, Desborough J. (2021). 'They're getting a taste of our world': A qualitative study of people with multiple sclerosis' experiences of accessing health care during the COVID-19 pandemic in the Australian Capital Territory. *Health Expect*. Online ahead of print. <https://doi.org/10.1111/hex.13284>.

People living with MS need complex care and often engage with a variety of healthcare professionals (HCPs) to manage their health and well-being. The pandemic brought specific challenges for people living with MS in accessing their usual care and treatments. These concepts were explored in this qualitative research study from Dr Anne Parkinson and Dr Jane Desborough, together with their team from the Australian National University (ANU) and in partnership with the Our Health In Our Hands (OHIOH) project. The researchers explored the experiences of people living with MS in accessing healthcare, including via telehealth, during the COVID-19 pandemic in Australia. Findings revealed that telehealth has been a valuable tool in managing both MS and general health, providing improved access, convenience, and a contact-free consultation. During the pandemic, the contact-free option added a degree of protection in the vulnerability felt by people living with MS in encountering the COVID-19 virus. Additionally, fatigue and transport issues were greatly relieved by avoiding long trips, often complicated by long days, waiting times and parking concerns. Researchers noted that people living with MS found that video telehealth was more personal than phone telehealth as they were able

to feel more personal connection over video, with the added benefit of a modified physical examination with their HCP, which is important in assessing symptoms of MS. Researchers also noted that telehealth was perhaps better suited to already established relationships with HCPs, where people with MS have already developed trust and confidence with their HCPs. The study also found that there are some knowledge and capacity gaps for HCPs when conducting telehealth and that they may benefit from education to help them communicate effectively using this platform with their patients and clients. This study shows that careful planning and appropriate use of telehealth has a place in future care for people living with MS, beyond the COVID-19 pandemic.

International social and applied research of interest:

7. Fleming, K. M., Herring, M. P., Coote, S. B., & Tindall, D. (2021). Participant experiences of eight weeks of supervised or home-based Pilates among people with multiple sclerosis: a qualitative analysis. *Disability and Rehabilitation*, 1–8. <https://doi.org/10.1080/09638288.2021.1939446>

This exploratory qualitative study investigated participants' experiences of supervised and home-based Pilates. Researchers reported that home-based Pilates was a safe, intensity appropriate exercise method to improve mental health outcomes among persons with mild symptoms of MS, with home-based Pilates reducing both exercise participation and accessibility barriers commonly experienced by PwMS. The researchers recommended larger studies to further explore these concepts.

8. Gromisch, E. S., Neto, L. O., Sloan, J., Tyry, T., & Foley, F. W. (2021). Using the multiple sclerosis resiliency scale to identify psychological distress in persons with multiple sclerosis. *Multiple Sclerosis and Related Disorders*, 53, 103079–103079. <https://doi.org/10.1016/j.msard.2021.103079>

The Multiple Sclerosis Resiliency Scale (MSRS) is the first resilience measure that is specific to multiple sclerosis (MS)-related challenges. This study aimed to examine the MSRS' ability to identify persons with MS experiencing depression or anxiety symptoms, using data from 884 participants in the North American Research Committee on MS (NARCOMS) registry. Findings revealed that the MSRS total score's classification accuracy was high, ranging between 86.2% and 92.2% for depression, and between 78.1% and 82.8% for anxiety. This indicates that the MSRS can be used to identify persons with MS experiencing mental health difficulties with relatively good classification accuracy, which may help MS care clinicians to triage who needs additional assistance or support. Translating this to clinical

practice means that people with MS needing mental health support may be picked up and that paths to mental health wellness, and improved quality of life can begin sooner.

9. Valentine, T. R., Alschuler, K. N., Ehde, D. M., & Kratz, A. L. (2021). Prevalence, co-occurrence, and trajectories of pain, fatigue, depression, and anxiety in the year following multiple sclerosis diagnosis. *Multiple Sclerosis*, 135245852110233–13524585211023352. <https://doi.org/10.1177/13524585211023352>

Pain, fatigue, depression, and anxiety are common in MS, but little is known about the presence, co-occurrence, and trajectories of these symptoms in the year after MS diagnosis. For this study, during the post-diagnosis year, rates of pain, fatigue, depression, and anxiety were examined, along with rates of symptom co-occurrence; and stability/change in symptom severity. Findings demonstrated that in the first year post-diagnosis, participants experienced clinically significant symptoms at some point; with 50.9% for pain, 62.6% for fatigue, 47.4% for depression, and 38.7% for anxiety. Additionally, most patients exhibited co-occurring symptom; 21.3% with two, 19.1% with three, and 17.4% with four. The proportions of patients with clinically significant symptoms were generally stable over time; however, rates of symptom development/recovery revealed fluctuations at the individual level. This research reiterates the need for frequent screening of newly diagnosed patients to commence interventions as early as possible and preserve quality of life. Clinically, this research reminds MS healthcare professionals to look deeper into these invisible symptoms in that first year of diagnosis in order to help set-up better long-term outcomes.

10. Massano, C., Lima, M., Monteiro, I., Machado, R., Correia, I., Nunes, C. C., Macário, C., Sousa, L., Santana, I., & Batista, S. (2021). Outcomes on Social and Classic Cognition in adults with Pediatric-onset Multiple Sclerosis. *Multiple Sclerosis and Related Disorders*, 53, 103071–103071. <https://doi.org/10.1016/j.msard.2021.103071>

Little is known about cognitive outcomes in adults who have their first MS relapses as children. This research compared cognitive performance in classic and social domains between two groups of 30 patients each, one group with paediatric-onset MS and the other with adult-onset MS. This study has shown that paediatric-onset MS patients are more likely to have cognitive impairment as adults than

adult-onset MS patients, and that information-processing speed and visual memory domains may be more severely affected. It is thought that the interference of MS during critical neurodevelopmental periods of childhood may explain this difference. Awareness of this tendency in children by MS healthcare teams can lead to consistent and early assessment and intervention of cognition in children, to maintain and improve quality of life, especially as they move into adulthood, relationships, and employment.

11. Reyes, S., Cunningham, A. L., Kalincik, T., Havrdová, E. K., Isobe, N., Pakpoor, J., Airas, L., Bunyan, R. F., van der Walt, A., Oh, J., Mathews, J., Mateen, F. J., & Giovannoni, G. (2021). Update on the management of multiple sclerosis during the COVID-19 pandemic and post pandemic: An international consensus statement. *Journal of Neuroimmunology*, 357, 577627–577627.

<https://doi.org/10.1016/j.jneuroim.2021.577627>

This consensus statement, from both Australian and international MS experts, provides updated recommendations on MS management during the COVID-19 crisis and the post-pandemic period applicable to neurology services around the world. The statements/recommendations give advice regarding implementation of telemedicine; use of disease modifying therapies and management of MS relapses; management of people with MS at highest risk from COVID-19; management of radiological monitoring; use of remote pharmacovigilance; impact on MS research; implications for lowest income settings, and other key issues. These guidelines will be periodically updated and should be considered in line with local regional and country circumstances, evolving all over the world.