RESEARCH ROUNDUP FOR WINTER: June 2022

This quarter, as we see the coldest start to winter for some time, let's warm you up with a selection of key Australian research findings that have direct applications in the MS clinic and the community. There are also a couple of international studies that deal with areas that we know little about, such as transgender care in MS and links between pain and constipation in other demyelinating disorders.

Whilst all of the studies mentioned here have significant impacts in MS nursing, my favourites this quarter include article number 3 on vaccine hesitancy in the MS population and how healthcare professionals can make a significant difference on this front, as well as number 6 from Tasmania, where we have new MS incidence and prevalence data to inform our planning and service provision. Of the international research articles, number 10, exploring transgender MS patients really hit home for me. I remember (like it was yesterday) looking after a transgender patient quite early in my MS career who was really struggling on multiple fronts, with me feeling absolutely powerless to know how to help this person manage both MS and life. Of course, kindness and compassion are always our "go-tos" in these situations, but there is so much more that could have been done, including education and supporting the wider healthcare team working with me in best practice in challenging cases.

Australian Social and Applied Research

1. Evaluating the impact of the Understanding Multiple Sclerosis online course on participant MS knowledge, health literacy, resilience, self-efficacy, quality of life, and MS symptom severity

Authors: Bessing, van der Mei, Taylor, Honan, Blizzard & Claflin

Many MS Nurses will be familiar with the massive open online course (MOOC) about MS, referring patients and families to the website. This study targeted people who completed the course and aimed to estimate the impact of this MOOC on MS-related knowledge, health literacy, self-efficacy, resilience, quality of life, and MS symptom severity. Examining a group of 560 people using regression and modelling methods, the researchers found significant increases in MS-related knowledge for both people living with MS (PwMS) and those without MS, with larger effect sizes for those with higher educational levels. Among PwMS, there were also significant increases in self-efficacy, but no increase in resilience, MS symptoms severity or quality of life. Although there was a significant increase in MS-related knowledge, which was unrelated to the changes in the other study outcomes, both for PwMS and for those not living with MS, outcome-specific health educational interventions may be needed to effect change in other health outcomes. This study adds to our knowledge of the health impact of online health education for the MS community.

Read more: doi: 10.1016/j.msard.2022.103717

2. Gait stability reflects motor tracts damage at early stages of MS

Authors: Cofre-Lizama, Strik, Van der Walt, Kilpatrick, Kolbe & Galea

Gait in PwMS is affected even when no changes can be observed on clinical examination. A sensitive measure of gait deterioration is stability; however, its correlation with motor tract damage has not yet been established. This study aimed to compare stability between PwMS and healthy controls (HCs) and determine associations between stability and diffusion magnetic resonance image (MRI) measures of axonal damage. N=25 PwMS (Expanded Disability Status Scale (EDSS) < 2.5) and 15 HCs walked on a treadmill and various measurements were assessed and compared on stability. Results demonstrated that stability was significantly different between the groups. Poorer gait stability is associated with corticospinal tract (CST) axonal loss in PwMS with no-to-low disability and is a sensitive indicator of neurodegeneration. Clinically there could be impacts for assessments down the track when larger studies confirm these findings.

Read more: doi: 10.1177/13524585221094464

3. Implementing education: Personal communication with a healthcare professional is a critical step to address vaccine hesitancy for people with multiple sclerosis

Authors: Panniset, Kilpatrick, Cofre-Lizama & Galea

People with MS (PwMS) were first able to access COVID-19 vaccines in Australia in March 2021. At this stage, vaccine hesitancy was high (up to 43% in the general population). This study used an online survey to examine factors influencing COVID-19 vaccination willingness among PwMS in Australia. A total of 149 participants with MS completed the online survey during 2021, examining demographic, environmental and clinical factors with respect to vaccine willingness, including attitudes towards COVID-19 illness and vaccines. The majority of participants were on high efficacy disease-modifying therapies (DMTs) (64.9%), while 19.9% were on no DMTs. Only 53.3% of people on DMTs were vaccinated, compared to 75% of those who were not on DMTs. People on ocrelizumab therapy (n = 35) had a lower vaccination rate (39%) than those on other medications (n = 86, 59%). Vaccine willingness in the unvaccinated was most highly correlated with knowledge regarding the vaccine. Almost two-thirds of participants had read MS-specific information about COVID-19 vaccinations and found it easy to understand (67.6%) and applicable to their situation (53.6%). However, less than half (47.8%) reported the information helped them make a personal vaccination decision. Over two-thirds (64.9%) had discussed vaccinations with their healthcare professional and 31.1% had not. Of those who had not, they were significantly less informed about the interactions of the vaccine with MS medications and had a significantly lower intention of vaccine uptake than those who had discussed this with their healthcare professional.

This study highlights that vaccination efforts should be delivered by healthcare professionals. This should focus on educating those who are managed with DMTs, and include individual recommendations related to specific DMTs, how the vaccines work, expectations regarding potential side effects, potential exacerbation of MS symptoms, likelihood of recovery from any exacerbation, and the relative risks of side effects versus COVID-19 infection. This is very likely to fall to the MS Nurse and neurologist in clinic settings, and the article provides specific recommendations to assist in this education.

Read more: doi: 10.1016/j.msard.2022.103933

4. Multiple Sclerosis incidence: A systematic review of change over time by geographical region.

Authors: Lane, Ng, Poyser, Lucas & Tremlett

The incidence of MS has reportedly increased over time; however, change in MS incidence has not been rigorously assessed globally. This systematic review aimed to report on the change in MS incidence rate according to geographical location from publications between 1985 and 2020. The researchers identified over 60 papers across 24 countries, with the highest output of studies from Italy, Norway and Canada. Findings reported that MS incidence rates significantly increased in 38 studies, significantly decreased in 13 studies and remained stable in 11 studies. Specifically looking at paediatric cases of MS, two studies showed an increase in incidence, and one a decrease. Unfortunately, many of the studies focused on a small region of a country, rather than the entire country incidence. The review was also influenced by inconsistent case definitions in some areas. In summary, although by number of studies, the predominant global pattern was increasing MS incidence, in studies where a consistent case definition was used across the duration of the study and with high population coverage, no predominant pattern of MS incidence was evident. Further studies are needed, following consistent case definitions and in wider geographical areas.

Read more: doi: 10.1016/j.msard.2022.103932

5. Physical activity participation in Australians with multiple sclerosis: associations with geographical remoteness

Authors: Learmonth, Heritage, Marck, Chen & van der Mei

Physical activity (PA) participation offers many benefits for persons with MS, who are significantly less active than the general population. However, little is known about the association between geographical remoteness and PA participation in persons with MS. This study aimed to identify PA levels in the rural Australian MS population. The Australian MS Longitudinal Study (AMSLS) was used to conduct a survey of 1,260 respondents. Findings showed that 24% of respondents did not participate in any form of PA. Furthermore, the study found that remoteness was not associated with PA participation, and that those performing any PA living in more remote areas, had, on average, higher levels of PA overall. Healthcare professionals are encouraged to include promotion of PA as part of MS management. Many MS Nurses and clinics already educate this aspect of patient care as a component of Brain Health, and on modifying lifestyle factors for the best outcomes in MS. This study suggests that PA promotion does not need to differ based on geographical location.

Read more: doi: 10.1080/09638288.2022.2082564

6. Increasing incidence and prevalence of multiple sclerosis in the Greater Hobart cohort of Tasmania, Australia

Authors: Simpson-Yap, Atyars, Blizzard, van der Mei & Taylor

The Greater Hobart region of Tasmania has consistently had the highest recorded prevalence and incidence rates of MS in Australia. The study researchers aimed to reassess the MS epidemiology in 2009-2019 and assess longitudinal changes. To do this, cases were recruited from clinics as well as multiple other data sources. A total of 436 MS cases resident on prevalence day in 2019 were identified, and of these cases, 130 experienced symptom onset within the key incidence period of 2009-2019. Prevalence was estimated to be 197 per 100 000 of population, which represented a 36% increase since 2001 and more than 3-fold increase since 1961. The incidence rate during 2009-2019 was estimated to be 5.9/100 000 person-years, which represented a 2.8-fold increase since 1951-1961 and 65% increase since 2001-2009. The mortality rate during 2009-2019 was estimated to be 1.5/100 000 person-years, which was comparable to 2001-2009 (1.0/100 000) but reduced by 61% from 1951 to 1959 (2.1/100 000). The female to male prevalence sex ratio was 2.8, comparable to the 2009 value of 2.6. Comparisons with Newcastle, Australia, which is located further north in NSW, demonstrate a near complete elimination of the latitudinal gradients for prevalence and incidence, which was attributed by the researchers to changing local Hobart demography.

The study concluded that prevalence and incidence of MS continue to increase significantly in Hobart, alongside marked reductions in mortality and increased case longevity. The marked increase in incidence is of particular note and may reflect longstanding changes in MS risk behaviours including changing sun exposure, obesity rates, and smoking behaviours, particularly in females. Falling mortality contributes to increased longevity and prevalence, likely reflecting improved overall MS healthcare and implementation of disease-modifying therapy. This information is integral for MS service planning provision and for understanding wider effects of modern-day MS care.

Read more: doi: 10.1136/jnnp-2022-328932

7. Vitamin D fortification of milk would increase Vitamin D intakes in the Australian population, but a more comprehensive strategy is required

Authors: Dunlop, James, Black et al

Low vitamin D status is prevalent in Australia, ranging between 15% and 32% in the adolescent and adult populations, and additionally, there is low vitamin D intake across the population. This strongly suggests that data-driven nutrition policy is needed to increase vitamin D intake and improve status in the Australian population. Food fortification is a potential strategy.

This article explored vitamin D food composition data and nationally representative food and supplement consumption data to model a fortification scenario of adding vitamin D for fluid dairy milks and alternatives. Modelling showed that fortification of fluid milks/alternatives with vitamin D at the current permitted level would produce a meaningful increase in vitamin D intake, which could be of potential benefit to those with a low vitamin D status. However, this initial step would be insufficient to ensure that most of the population achieves the North American recommendations for vitamin D intake. This approach could be included as an effective component of a more comprehensive strategy that includes vitamin D fortification of a range of foods. Something interesting to watch out for in the future in providing clinical advice and modification of dietary lifestyle factors for PwMS.

Read more: doi: 10.3390/foods11091369

8. Long-term trajectories of employment status, workhours and disability support pension status, after a first episode of CNS demyelination

Authors: Zarghami, Taylor et al and the AusLong Investigator Group

People with MS face significant employment-related challenges, with little known of the drivers of these outcomes. This study examined prospective trajectories of employment-related outcomes up to 11 years following a first episode of central nervous system demyelination (FCD). Outcomes were employment status (full-time, part-time and unemployed), average workhours per week and disability support pension (DSP; receiving/not receiving). Group-based trajectory modelling was used to identify groups with common trajectories.

Findings revealed distinct trajectories for employment, workhours and DSP. Compared with stable full-time, the female sex was strongly associated with being in the stable part-time trajectory. This could be due to other factors than MS, such as family responsibilities. A greater level of disability at 5-year review and having more than two comorbidities at baseline) were associated with being in early and late deteriorated employment trajectories, respectively. Compared with the increased part-time trajectory, every additional relapse during the 5 years post-FCD was associated with a 10% increased risk of being in the reduced part-time employment group. For every additional EDSS point at 5-year review, the risk of being in the DSP trajectory increased.

These trajectories indicate the complex impact of MS on employment from its earliest timepoints. Understanding these trends could enable better targeting of interventions to facilitate workforce retention, particularly for females, those with a higher number of comorbidities, more frequent relapses and greater rate of disability accrual. Providing meaningful advice in clinic to improve employment outcomes long term could significantly improve overall outcomes and quality of life for PwMS.

Read more: doi: 10.1177/13524585221089900

International Social & Applied Research

9. Experiences of receiving a diagnosis of multiple sclerosis: a meta-synthesis of qualitative studies

Authors: Topcu, das Nair et al

This meta-synthesis aimed to explore qualitative evidence on experiences of people with MS in receiving a diagnosis, to derive an understanding of adjustment. A total of 37 papers and 874 people with MS were analysed. Findings revealed that around the time of an MS diagnosis, people experienced considerable emotional upheaval and difficulties such as a lengthy diagnostic process, which limited their ability to make sense of their diagnosis and adjust (this will be no surprise to MS Nurses). However, support resources (from clinicians) and adaptive coping strategies (such as acceptance) facilitated the adjustment process. Additionally, several unmet support needs such as the need for personalised information and tailored emotional support, were identified that, if addressed, could improve adjustment to an MS diagnosis. These are key areas where MS Nurses can make a significant impact.

Read more: doi: 10.1080/09638288.2022.2046187

10. Recommendations to address the unique clinical and psychological needs of transgender persons living with Multiple Sclerosis

Authors: Sullivan, Kane, Valentic & Rensel

People living with MS face challenges coping with chronic illness and transgender (TGD) persons living with MS may experience additional challenges and barriers to care. Medical biases toward TGD people are widely reported, and best practices in TGD MS care have not yet been identified. This article explored a case report of a TGD person living with MS to assist healthcare professionals in understanding the unique aspects of their clinical and psychological care needs. Additionally, the researchers conducted a systematic review of the literature for relevant topics related to the unique care needs of TGD persons living with MS. Findings revealed the importance of providing an inclusive environment, comprehensive care, mental health screening, domestic violence screening, and case coordination for TGD persons living with MS. This is significantly aligned with goals of MS nursing care. It is highly recommended that MS Nurses caring for TGD persons read this full article to explore the ways in which they can holistically care for TGD patients and clients.

Read more: doi: 10.7224/1537-2073.2021-066

11. Women with female infertility seeking medically assisted reproduction are not at increased risk of developing multiple sclerosis

Authors: Kopp, Pinborg, Glazer & Magyari

The aim of this study was to explore if female infertility amongst women seeking medically assisted reproduction (MAR) was associated with prevalence or incidence of MS. The study authors provided an overview of what is already known about infertility and MS, including that women with MS have fewer children compared to women without MS. PwMS more often have other coexisting autoimmune disorders including hypothyroidism compared with the general population. Thyroid dysfunction is associated with ovarian cause of infertility, miscarriage, and ovarian failure. Conversely, women with endometriosis, that is highly associated with infertility, also more often have other coexisting autoimmune diseases including MS and hypothyroidism, when compared with the general population.

However, whether the low fertility rate among women with MS is due to a genetic predisposition to other autoimmune and endocrine disorders that lead to reduced fertility, or an active choice of the woman, disease-related pathology or treatment-specific effect on endocrine and/or ovarian function, is not completely understood. The study examined a register-based cohort study of a total of 310,357 women from 1996 to 2018. Findings revealed that women with a history of infertility did not have an increased risk of developing MS compared with apparent fertile women. However, the prevalence of MS was slightly higher among women undergoing MAR compared with women who had a child without

MAR, but this was not related to origin of infertility (male versus female factor infertility). The findings also suggested that women with MS may undergo MAR treatment more often than women without MS due to more awareness about the possibility of MAR treatments, sexual dysfunction related to MS disease, but also need for timing of the pregnancy to avoid an unnecessary long period without DMTs (especially high efficacy DMTs) and hence a wish to conceive quickly. These findings are important for MS Nurses and neurologists counselling with women with MS of childbearing age.

Read more: doi: 10.1093/humrep/deac041

12. Is there a link between neuropathic pain and constipation in NMOSD and MOGAD? Results from an online patient survey and possible clinical implications

Authors: Lotan, Romanow, Levy & Kister

Neuropathic pain and constipation are common among people with neuromyelitis optica spectrum disorder (NMOSD) and myelin oligodendrocyte glycoprotein antibody disease (MOGAD) and can have a negative impact on quality-of-life measures. The study aimed to explore a possible association between the two symptoms. A total of 317 participants with either NMOSD (approximately two-thirds) or MOGAD (approximately one-third) completed a survey, with 206 participants of the sample reporting neuropathic pain. Of these people, 137 participants also experienced constipation. Both symptoms were significantly more common among patients with a history of myelitis. Among patients with neuropathic pain and constipation, 47 participants (34%) thought there was a relationship between the two conditions, with the majority reporting increased severity of pain when constipation severity was increased and, conversely, alleviation of pain when constipation lessened. The possible association opens a possibility of a new approach to managing neuropathic pain, which tends to be poorly responsive to symptomatic therapies and is associated with worse quality of life in NMOSD and MOGAD. Of course, further studies are warranted to confirm the results, but it may provide a clinical pearl for MS Nurses in the meantime to help alleviate both distressing symptoms.

Read more: doi: 10.1016/j.msard.2022.103825