

AMSLS NEWS



Australian MS Longitudinal Study (AMSLS)

October 2021

It's been another challenging year of uncertainty and lockdowns in Australia, but our AMSLS participants have never faltered in contributing important information to help improve the lives of everyone with MS. Some high impact and common issues have been tackled recently, including sleep, pain, how MS treatments are resourced, how the MS Nurses impact the health of those with MS, and the effects of the lockdowns on people's quality of life. We once again thank you wholeheartedly as we share the highlights of these studies and AMSLS plans for 2022.

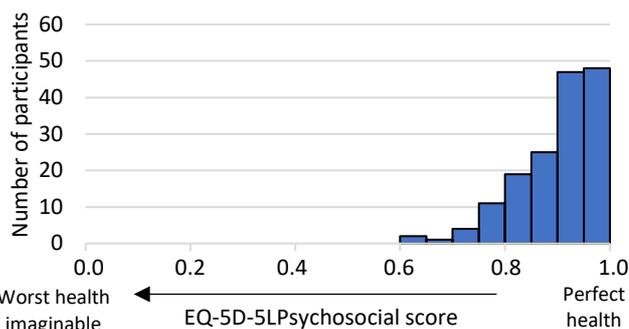
Improving healthcare resourcing decisions

Decisions on which treatments receive government funding are based on each treatment's ability to improve the lives of those who need it. The assessment of quality of life for these decisions, however, are often based on instruments that do not adequately measure the health impacts for those with MS, and consequently, some good treatments may not receive the funding they deserve.

Our *2020 Quality of Life Survey*, led by Dr Julie Campbell, was designed specifically to address this issue and provide recommendations on the most efficient instrument that also accurately reflects quality of life. We had a remarkable response rate close to 70% for this very important survey, which provides a comprehensive base for our internationally significant and ongoing quality of life research – thank you!

Preliminary results established that one of the most common instruments used in the majority of health economics and quality of life studies, the EQ-5D-5L, may not be an appropriate survey instrument for people living with MS as it does not ask enough questions about psychosocial health factors such as sleep, energy levels, relationships and

Changes to scores of participants with 'perfect health' on the EQ-5D-5L when including 4 extra psychosocial questions



feeling connected to the community.

The adjacent figure shows that those who scored themselves as having 'perfect health' (an "HSU" value of 1) on the EQ-5D-5L consequently scored much lower health levels on another instrument called the EQ-5D-5L Psychosocial, that asks just 4 more questions about some of these psychosocial health factors.

Final analysis and recommendations will follow in 2022, with the results vital in the quest to ensure the best treatment options receive the funding they deserve.



Do you know someone with MS who is not part of the AMSLS family?

We are always accepting new participants. To join, download the information sheet and consent forms from:

www.MSRA.org.au/AMSLS

Need to contact us?

AMSLS.info@utas.edu.au

(03) 6226 4739

We're always happy to hear from you!

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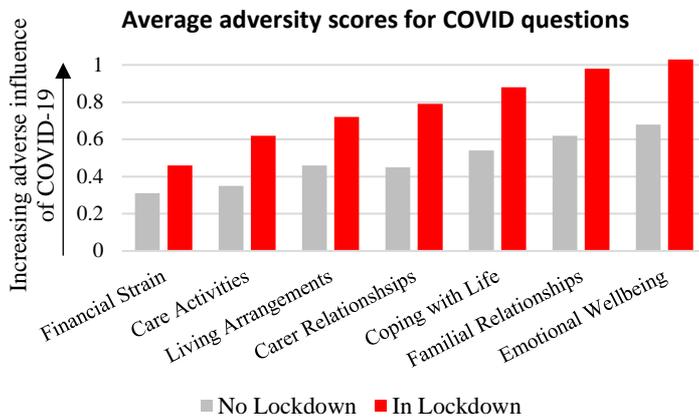
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Institute for Medical Research

The impact of the COVID-19 lockdowns on quality of life

When the *2020 Quality of Life Survey* was sent out in late July 2020, participants in greater Melbourne and Mitchell Shire had been in COVID-19 lockdowns for 4 weeks. They would remain in lockdown beyond the close of the survey, and up until 26 October. During the same period, most other participants nationwide were not in lockdowns.

With the *Quality of Life Survey* containing some specific COVID-19 related questions, we could therefore directly investigate how lockdowns impacted the quality of life of people living with MS.



Analysis of the data indisputably shows that participants in lockdown, especially those with high disability severity, are most impacted by the ongoing pandemic. The work has also shown that the pandemic affects emotional wellbeing more than other dimensions of health; however, every aspect of life was negatively impacted across the board for those living in lockdown, as shown in the adjacent figure.

Qualitative analysis is currently being done on the descriptions participants provided about how their physical and emotional circumstances were impacted by the COVID-19 pandemic. This will supplement the statistical results, with recommendations based on the overall findings to include a focus on maintaining emotional wellbeing, as well as supporting access to care and financial security during lockdowns.

Due to the timing and incredible support of participants for the *2020 Quality of Life Survey*, the survey will continue to provide some vital information around the impact of the pandemic, and we look forward to keeping AMSLS participants up to date with information as it becomes available.

MS and employment

With the 8th instalment of the *National MS Employment Survey* this year, the AMSLS continues its ongoing mission to support those with MS in the workforce. PhD candidate Barnabas Bessing has been instrumental in deciphering the long-term impacts of MS symptoms on work capacity, and subsequently ensuring this information gets translated into real-world recommendations in the *MS WorkSmart* program. His high-quality, practical results have resulted in multiple prizes and an invitation to speak at the MS Nurses conference. His latest research is summarised below.

Estimating the impact of work environment factors on MS-related work productivity of Australians – We looked at how work environment factors such as work self-efficacy (belief in ability to manage daily work tasks), work psychological safety (description of safe and supportive work environment) and work difficulties (general cognitive difficulties, prospective memory difficulties, low self-esteem, interpersonal difficulties, non-supportive workplace and fatigue) are associated with MS-related work productivity loss in AMSLS participants.

The key variables that were associated with MS-related work productivity loss were self-efficacy, low self-esteem, and interpersonal difficulties.

These findings suggest interventions targeted at increasing people's belief in their ability to manage their daily tasks, improving self-esteem and strategies to resolve interpersonal challenges for people with MS might help improve productivity in the workplace and keep people in their jobs.



Estimating the impact of MS symptom severity on key employment decisions of Australians with MS – Examining the impact of MS symptom severity on key employment decisions showed physical MS symptoms, such as fatigue, walking difficulties, difficulty with balance and spasticity, were all associated with the need to change work role and work environment as well as the disclosure of a person's MS status.

While other variables, such as demographics, MS symptom severity and other clinical variables were not associated with a decision to leave a job by choice, the invisible MS symptoms, such as feelings of anxiety and depression, were associated with both an intention to voluntarily quit a job within 12 months, and feelings that people would be forced to leave a job not by choice.

These findings suggest that those with physical MS symptoms are more likely to stay at work and ask for change in their roles and working environment, but those with invisible MS symptoms are more likely to quit their jobs. This highlights the need for more proactive intervention to address those issues of anxiety and depression for those with MS who wish to be employed.

Sleep matters - the impact of MS on sleep and overall quality of life

It is well known that sleep is very important for good health. Dr Laura Laslett is using data from the *2020 MS Nurses and Sleep Survey* to take a closer look at sleep in people with MS in Australia, looking for associations between poor sleep, other symptoms of MS and overall quality of life.

Poor sleep is very common in the community, but was found to be even more common in people with MS, with 68% of AMSLS participants recording poor sleep quality on the Pittsburgh Sleep Quality Index. When reporting on the month preceding the survey, 33% of AMSLS participants reported that they felt that their sleep had interfered with activities of daily life, and 45% with social functioning.

Older people and those with a university degree were less likely to have poor sleep quality. Conversely, being overweight related to poor sleep quality, as did MS factors including greater MS disability, and having had an MS relapse in the last 12 months. Having more severe MS symptoms was also associated with worse sleep quality, particularly fatigue and cognitive symptoms, anxiety and depression, and pain and sensory symptoms.

Similarly, having more severe symptoms of MS (sexual dysfunction, balance/walking/spasticity problems, sensory symptoms and pain, anxiety and depression, and cognitive symptoms and fatigue) combined with poorer sleep related measures (daytime sleepiness, symptoms of restless legs syndrome and poor sleep quality) and obesity were all associated with poorer quality of life. The symptoms with the greatest impact on quality of life were anxiety and depression.

Overall, this tells us that both MS symptoms and sleep-related measures are important for quality of life in people living with MS. We plan to build on this work in the upcoming *2022 Sleep Survey*. This will tell us if/how sleep patterns change in people with MS, and will allow us to investigate what the predictors of change in sleep are over time. This information can assist in planning clinical trials to test whether treatments for poor sleep are effective for people with MS. Based on the findings from the 2020 data, this will need to target both symptoms and sleep if we are to improve quality of life for people living with MS.

The links between diet and health outcomes

Studies of people with MS have shown that diet may play a role in reducing inflammation and neurodegeneration, which is central to MS. While healthy eating has general health benefits, most of the studies of people with MS are observational in design and are not able to prove that there is a cause effect relationship between the specific pattern of eating or diet, and the varied MS outcomes. Despite this lack of evidence, dietary advice and specific dietary approaches (MS diets) have been developed with the aim to reduce MS activity or symptoms through nutrition.

Dr Claudia Marck looked at the links between MS symptoms and types of eating patterns from the *2016 Lifestyle and Environment Survey* and did find relationships between a healthier diet score and better health outcomes, particularly for overall quality of life, feelings of depression, and vision, bowel and pain symptoms. Higher intake of fruit, vegetables and fibre, and, to a lesser extent, healthy fats were all linked to a better overall quality of life, lower pain, lower feelings of depression and anxiety and fewer bowel symptoms.

While these results highlight some interesting findings, further research is required to determine whether making changes to a healthier diet can translate to improvements in the associated symptoms and if so, how can we best support people in making such changes for the better. An extension of this research is especially important, as the current data provides a link between diet and some MS symptoms, but on its own cannot determine to what extent symptoms may be eased by a healthier diet, or whether having better health provides more motivation and an ability to consume a healthy diet in the first place (that is, associations do not prove cause effect).

From other studies, we know that a healthy diet, including a balance of all of the 5 food groups alongside regular physical activity, can contribute to better health. If you are interested in more information, please refer to the Modifiable Lifestyle guide available on the Multiple Sclerosis Research Australia website. If you would like to make changes to your diet to improve your health, please consult an Accredited Practising Dietitian for evidence-based advice.

Diet – key statistics

- **94.3% of AMSLS participants make an effort to eat healthily.**
- **21.2% of participants follow one or more specific diets (vegetarian, sugar-free, low fat), of which 7.7% follow an 'MS diet' (e.g. Swank Diet, Overcoming MS Diet or the Wahls Diet). Of those who follow an MS-specific diet, 53% said they do not follow it strictly.**
- **A healthier overall diet, as well as higher fruit, vegetable, fibre and healthy fat intake was related to some better health outcomes, particularly quality of life and depression.**
- **Most dietary variables were not associated with level of mobility disability, fatigue, walking, balance, bladder, sexual, sensory, and spasticity symptoms.**
- **Some participants reported they eliminated meat (8%), dairy (8%) or both (4%) from their diet. There was no strong evidence that meat and/or dairy consumption was associated with health outcomes.**

AMSLS Focus for 2022

| Topic | Details | Supporting Survey(s) |
|--|--|--|
| Sleep – in collaboration with Dr Cynthia Honan (University of Tasmania) | The data that we collected on sleep in 2020 has been very useful (see ‘Sleep matters’ on page 3). To build on this work, we will now look at how sleep changes over time, people’s confidence in their ability to make changes to improve sleep, any diagnosed sleep conditions and treatments / medications used to get to sleep. | <i>2022 Sleep Survey</i> <i>2019 MS Nurses and Sleep Survey</i> |
| Concept of self – led by Dr Cynthia Honan and Holly Emery (University of Tasmania) | The perception that people have of themselves, also called self-concept, is likely to change as a result of an impactful event such as the diagnosis of MS. We will investigate how MS impacts on changes to self-concept and other factors that may contribute to this change, e.g. changes in level of social support and employment. | <i>2022 Self-concept Survey</i> |
| Pain | The <i>2021 Pain Survey</i> aimed to provide deeper insights into the types of pain that people with MS experience, the impact of pain on daily activities and experiences with the management of pain. In 2022, this data will be analysed. | <i>2021 Pain Survey</i> |
| Quality of life instrument – led by Dr Julie Campbell, Menzies Institute | Decisions on government funding for many treatments are supported by quality of life instruments. This work will assess the best type of quality of life questionnaire to use for making informed healthcare decisions. As the survey was conducted during COVID-19 lockdowns, we are also examining the impact of lockdowns on quality of life. | <i>2020 Quality of Life Survey</i> |
| Crisis resilience – led by Dr Yvonne Learmonth, Murdoch University, and Dr Claudia Marck, University of Melbourne | This work will examine the impact of COVID-19 on health behaviours and medical care and how to minimise the impact of a crisis. | <i>2020 Lifestyle and Environment Survey</i> |

Pilot study of a cohort of people who care for or support AMSLS participants

MS has a profound impact on the lives of those who care for or support people with MS. However, we do not have a good understanding of the support roles and needs of these people, the factors that are associated with support burden, and how roles and burden change throughout the disease course of the person with MS. Once we understand this, we can start supporting the support people.

We are keen to obtain funding to set up a cohort of people who care for and support an AMSLS participant. To increase the chance of obtaining funding for this longitudinal study that will run alongside the AMSLS, it is important to demonstrate that it is feasible to run such a study. This includes showing that we are able to recruit sufficient support people, and demonstrating that the measures on support roles and burden are working well for this group. We will therefore conduct a pilot study. We aim to recruit support people via 100 randomly chosen AMSLS participants and test a Support Survey that we will develop. If you are selected to be part of this pilot study, we hope you are willing to participate.



AMSLS Administration and Communications Survey*

Top 5 barriers to completing AMSLS surveys

1. Forgetting to complete the surveys
2. Life getting in the way of completing surveys (other commitments or health)
3. I find it hard to pick from the answers as they don't quite fit my situation
4. I find it hard to choose an answer as I can't distinguish between what is MS related and what is something else
5. I don't feel I'm contributing much to the study

Survey preferences

| Time to complete surveys: | | Surveys per year: | |
|---------------------------|------|-------------------|------|
| 10 minutes or less: | 13 % | 2: | 14 % |
| 10-20 minutes: | 37 % | 3: | 26 % |
| 20-30 minutes: | 27 % | 4: | 31 % |
| 30-40 minutes: | 10 % | 5: | 4 % |
| 40-50 minutes: | 2 % | 6: | 24 % |
| 50+ minutes: | 10 % | (unanswered): | 1 % |
| (unanswered): | 1 % | | |

*Online responses only to 30 September 2021

The AMSLS team thanks you for your ongoing support. Together we can make a difference.