

Crisis Resilience In people with Multiple Sclerosis (C-RIMS)

Brief preliminary report – 18th June 2020



A Investigators

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B Project Aim and method

AIM: To identify issues raised and experienced by people with MS and their carers during the COVID-19 pandemic

To achieve the above aims we are inviting the MS community (e.g., people with MS, carers, healthcare providers and representatives from MS advocacy groups) to complete an online survey and to participate in semi-structured interviews. We also performed a scoping review of relevant social media and online forums related to MS and the COVID-19 pandemic.

C Recruitment to date

- Ethical approval Murdoch University (HREC 2020/039), University of Melbourne (HERC 2056720).
- Research assistant appointed (Dr Assunta Hunter, UoM).
- Ongoing recruitment via disability advocacy groups (e.g., MS Research Australia, MS Australia, MDI), carer support groups (e.g., Carers Australia), healthcare provider groups (e.g., MS Nurses Australasia, Australian Physiotherapy Association), and neurologists and MS clinics across Australia, recruitment numbers indicated below
- Scoping review of social media and websites.

	Recruited Survey participants	Completed interview participants
Persons with MS	107	15
Carers	4	2
Healthcare providers	35	2
MS advocacy staff	14	4
Total	160	23

as of 18/6/20

D Findings to date

D1 Survey

Survey participants with MS include representatives who have a range of disability levels symptoms and associated healthcare needs. Our participants indicated:

- Concern regarding access to exercise activities, social activities, medical tests (e.g., MRI appointments and/or drug infusions), physiotherapy and their general practitioner were particularly high.
- Over 80% reported health behaviour changes including reduced physical activity participation (52%), changed sleeping pattern (42%), increased physical activity (30%), increased alcohol consumption (35%), and unhealthy eating (40%)
- participants indicated a want for simple, timely and accurate healthcare information, some indicated a need for an information hotline and some indicated online information may be preferred.

Survey data from our carers, healthcare providers and MS advocacy staff** indicate:

- People with MS have been concerned about access to healthcare, in particular; medical tests (e.g., MRI appointment and/or drug infusions), neurologist and physiotherapy and exercise activities during the pandemic.
- The healthcare providers and MS advocacy staff reported overall increased workload during the pandemic and provided examples as to what impact this has had on healthcare provision.

- A need for MS specific information during the pandemic and MS specific support services (e.g., to access groceries).

D2 Interviews

People with MS

Interviewed participants with MS raised the following points from their experiences:

- Increased anxiety reported leading to some symptom worsening. Social isolation was a concern for many. Some worried that the pandemic might cause a MS relapse.
- Information access: easy access to specific MS related to medication and co-morbidities information wanted, hotline or online information preferred.
- Access to medical treatment: preparations were in place early in pandemic to ensure access, concerns raised over access to hospital visits.
- Access to MS specialists: access to MS nurses and GPs was limited, in particular for people newly diagnosed access to MS specialist care was limited
- Access to general healthcare: NDIS support and reviews were limited, access to psychologist, physiotherapist and exercise physiologist was limited, negatively affecting symptom management
- Telehealth: considered acceptable yet a notable decreased quality of care
- Health behaviours: decreased exercise participation, and increased alcohol and unhealthy eating noted.
- Access to groceries: limited during times of isolation, many not aware of systems to improve access.
- Employment: disclosure of personal health information was necessary, and participant took leave or unpaid leave, to facilitate isolation

Future support needs

- Better access to MS healthcare providers and a central telephone help line for individualised responses to specific queries, and to dispel misinformation
- Proactive services (e.g. MS employment service, MS nurse/society) to regularly check in with people
- More centralized information sources with MS specific information, including for families and carers
- Information for employers and co-workers about MS and MS medications, and better and quicker provision for people with MS to work from home, better access to MS Employment Service

MS nurse and MS Advocates:**

Interviewed healthcare providers and MS advocates raised the following points from their experiences:

- **Health system organisation:** Workload increase resulting in unpaid/out of hours preparation. Patients unable to access routine care (i.e., MRI, reviews, physiotherapy). Tele-consultations utilised however not deemed effective replacements to routine interactions. Newly diagnosed patients not receiving continuity of care
- **Information provision:** Want for a “Single Source of Truth” (webpage or phone number with an informative referral service), specific for Australia, and state directives.
- **Access to services:** Availability and access to healthcare professionals caused high concern
- **Employment:** Clarification over government support (e.g., jobseeker/job keeper), concerns over disclosing personal health information to employer and safe return to work

Future support needs

- Nationally coordinated response with helpline with trained people with focus on consistent messaging.
- MS recognised as a disease that can impact on the immune system and as a chronic disease
- Better promotion of and extension of who has access to on-line shopping for people with MS currently some access is only those on NDIS (i.e. early shopping/priority shopping using Centrelink cards, pension cards and MS ID cards), and to organisations providing delivery services of medication and other goods.
- Better explanations of self-isolation and who was most at risk (in the beginning of the pandemic)
- More access to affordable Mental Health services. Mental Health Care Plans not enough.
- Creation of disaster preparedness plan and policies
- Stock of PPE, cleaners and sanitiser available to carers.
- More consistency between hospital policies (e.g. ensure MS nurses are included in tele-consults)
- A register of MS clinicians to pro-actively share information

Carers

Interviewed carers raised the following points from their experiences:

- Access to services: Notable delay in NDIS plan approvals and medical management, and concerns over access to PPE equipment “A small world became smaller” lack of access to family, restaurants, or ability to leave the region.

Future support needs

- Better communications between hospitals, neurologists and GPs and patients.
- Easier communication for patients with the MS nurse.

D3 Scoping review of social media and websites

Review of Facebook posts associated with Australian MS support group reviewed (1/02/2020 – 5/06/2020), much information is similar to our results in section D2, and D3 above.

- Concerns on access to healthcare, medications and groceries
- Discussion and increased comments followed when updated information was posted by MS Australia in particular webinars with neurologists, advice on neurologists, financial assistance and delivery of medicines.

New information, not yet discussed in our survey or interviews

- Access to carer support (e.g., COVID19 testing)

**analysis as of 10/6/20

E Next steps

E1 Survey

Our survey remains open for another 4-6 weeks and our focus is on recruiting more healthcare professionals, in particular MS nurses and neurologist, frontline MS society staff, and carers of people with MS.

E2 Interviews

Formal qualitative analysis of the interview data is ongoing. We aimed to conduct 20 interviews and depending on data saturation we may surpass this target slightly. Similarly, our focus is on recruiting more healthcare professionals, in particular MS nurses and neurologists, frontline MS society staff, and carers of people with MS.

E3 Stakeholder consultation

We will plan a meeting towards the end of July – early August to table our findings to all investigators and stakeholders for feedback and determine next steps for further research and dissemination of findings. We have the opportunity to include survey questions in the Australian MS Longitudinal study (a cohort study of a representative sample of Australians with MS), if we are able to secure additional funding.