



Report on the High Levels of Disability in Participants of an ME/CFS/FMS Management Patient Education Program

Catharine Powell^{1,2}, Bei Zhang³, Neta Best^{1,2}, Dominic Chong⁴, Jennifer Faulkner^{1,2} Kathleen Riding^{1,2}

1. Bridges and Pathways Institute Inc., Adelaide, SA 5159, Australia 2. Fibromyalgia Australia, Adelaide, SA 5159, Australia 3. College of Education, Psychology & Social Work, Flinders University, Adelaide, SA 5042, Australia 4. Faculty of Health and Medical Sciences, University of Adelaide, Adelaide, SA 5000, Australia

Background and Objectives

Many Australians living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FMS) face challenges accessing disability support due to underestimations of their disability levels.

This pilot study describes the disability levels of participants attending an Australian ME/CFS/Fibromyalgia patient education program conducted during 2022. It utilises established assessment tools, such as the Bell's Disability Scale, Bateman Upright Hours/Good and Bad days, and the Fibromyalgia Impact Questionnaire.

Methods

A Self-reporting survey was distributed to 30. Of these, 27 provided responses. Participants reported their diagnoses, symptom levels, disability levels, and daily activity hours. Data analysis was conducted using MailChimp and Excel.

Results

Diagnosis: Among the respondents, 34.4% had diagnoses of both ME/CFS and Fibromyalgia. Of those with ME/CFS, 61% also had Fibromyalgia, while 44% of those with Fibromyalgia also had ME/CFS.

Illness Burden, Symptom Impact: Participants rated the severity of selected symptoms, using a scale from 1-10 (10 = most severe).

All symptoms received ratings of 6 or higher, with sleep disturbances rated most severe at 8.

Bell's Disability Scale: The survey used the Bell's Scale to assess the participants' ability to engage in daily activities. The majority (88.8%) reported having less than 5 hours of daily activity, with 1 person bedridden (less than 1 hour /day).

Levels of disability measured by Bateman's Hours Upright Activity (HUA): On **Good Days**, 51.8% respondents reported HUA as 6 or less hours, with 18.5% of those having less than 4 hours and 3.7% bedridden. On **Bad Days**, those reporting 6 hours or less rose to 77.7%, with 59.2% of those having less than 4 hours, and 14.8% being bedridden.

Symptom	Mean Score
Pain	6
Energy	7
Sleep quality	8
Memory difficulties	7
Stiffness	6
Cognitive Difficulties	7
Mean	6.8

Discussion and Conclusions

ME/CFS and Fibromyalgia significantly affect individuals' disability levels and their daily functioning. (Bell score (88.8% <5 hours), HUA Good (51.8 % <7 hrs) and Bad Days (77.8% <7). Participants also reported significant impact (mean 6.8) from selected ME/CFS symptoms, signifying a high burden of illness.

These disability levels would typically disqualify individuals from employment and emphasizes their need to access appropriate disability services.

The dual diagnoses (34.4%) of ME/CFS and Fibromyalgia is noteworthy, with 61% of ME/CFS participants also having a diagnosis of Fibromyalgia which would exclude them from many research projects.

The participants in this pilot study are representative of our clients, Australians who face difficulties in accessing welfare benefits and disability services (NDIS). Many of them are also struggling with basic medical care because they are on GP waiting lists.

Given the high levels of disability and the impact of these illnesses, there is an urgent need for Australian Government programs to establish effective measures that can be utilised in clinical settings, particularly in General Practice, to provide documentation to Centrelink and NDIS.

We recommend funding for a more extensive clinical-based study to validate disability assessments for use in GP settings.

Additionally, these findings underscore the necessity of establishing clinic/s to provide reliable assessments and ongoing medical and rehabilitation care for the 1 million Australians affected by ME/CFS and Fibromyalgia.

References

- Bateman, L., Bested, A. C., Bonilla, H. F., Chheda, B. V., Chu, L., Curtin, J. M., Dempsey, T. T., Dimmock, M. E., Dowell, T. G., Felsenstein, D., Kaufman, D. L., Klimas, N. G., Komaroff, A. L., Lapp, C. W., Levine, S. M., Montoya, J. G., Natelson, B. H., Peterson, D. L., Podell, R. N., Yellman, B. P. (2021). *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management*. Mayo Clinic Proceedings, 96(11), 2861–2878. <https://doi.org/10.1016/j.mayocp.2021.07.004>
- Bridges and Pathways (n.d.) *Self-Management Programs*. <https://bridgesandpathways.org.au/service/e-learning/>
- Bridges and Pathways, (2021). *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Handbook for Practice Nurses*, South Australian ME/CFS/FMS Clinical Research Collaboration, Bridges and Pathways Institute Inc. ISBN-978-0-6451613-6-6.
- Fibromyalgia Australia. (2021). *Fibromyalgia Handbook for Practice Nurses*. Fibromyalgia Australia Working Group, Bridges and Pathways Institute Inc. ISBN-978-0-6451613-2-8
- Flinders Human Behaviour & Health Research Unit. (2020). *What is the Flinders Program*. Flinders University. <https://www.flindersprogram.com.au/about/>
- Fong, K., Deed, G., Ankenu, R., Broodbent, S., Lloyd AM, A., Gradisnik, S.M., Rowe, K., Eyssens, S., Missing, S., McMillan, P. (2019). Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Advisory Committee Report to the NHMRC Chief Executive Officer. *ME/CFS Advisory Committee*. <https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer>
- Hardcastle, S. L., Brenu, E. W., Johnston, S., Staines, D., Marshall-Gradisnik, S. (2016). Severity Scales for Use in Primary Health Care to Assess Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. *Health care for women international*, 37(6), 671-686. <https://doi.org/10.1080/07399332.2014.962139>
- Health Pathways South Australia, 2021, *South Australian ME/CFS Health Pathways* <https://southaustralia.communityhealthpathways.org/44978.htm>
- Salaffi, F., Sarzi-Puttini, P., Girolimetti, R., Gasparini, S., Atzeni, F., Grassi, W. (2009). Development and validation of the self-administered Fibromyalgia Assessment Status: a disease-specific composite measure for evaluating treatment effect. *Arthritis research & therapy*, 11(4), R125. <https://doi.org/10.1186/ar2792>
- Services Australia. (2023). *Chronic disease GP Management Plans and Team Care Arrangements*. Services Australia. <https://www.servicesaustralia.gov.au/chronicdisease-gp-management-plans-and-team-care-arrangements?context=20>.
- U.S. ME/CFS Clinician Coalition. (2021). *WHAT IS ME/CFS?* <https://mecfsciniciancoalition.org/>