Participant led lifestyle clusters map to established disability and quality of life measures in Multiple Sclerosis

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Background: Lifestyle questionnaires co-developed by people with multiple sclerosis (pwMS) and the UK MS Register (UKMSR) capture aspects of day-to-day functioning that are not well represented in 'standard' clinical practice. We previously identified five lifestyle clusters using participant-reported data on sleep, exercise, social participation, and bowel/bladder symptoms. Here, we examined how these clusters aligned with established patient-reported outcomes (PROs) completed at the same time point.

Methods: We analysed 1,288 pwMS who completed both lifestyle questionnaires and contemporaneous PROs. Lifestyle variables were clustered using k-medoids (PAM) with Gower distance, and a five-cluster solution was retained. Clusters were then compared on disability and health status measures not used in the clustering procedure: webEDSS, EQ-5D-5L Index, EQ-5D-5L VAS, Fatigue Severity Scale (FSS), Hospital Anxiety and Depression Scale (HADS), MSIS-29 physical, and MSWS-12.

Results: The clusters showed a clear and consistent gradient across all external measures. Clusters 1 and 2 had the highest burden, with worse disability, walking limitation, fatigue, anxiety, depression, and physical impact of MS (EDSS), alongside poorer quality of life. Cluster 5 had the most favourable profile across measures (median [IQR]), with lower EDSS (4 [2.5, 6]), MSWS-12 (30 [16, 48]), MSIS physical (30 [10, 55]), fatigue (4.67 [3.11, 5.57), and better EQ-5D Index (0.71 [0.56, 0.84]) and EQ-5D VAS (73 [52.5, 85]). Cluster 3 was consistently intermediate, and cluster 4 showed a relatively favourable profile; although generally not to the same extent as cluster 5. Overall differences between clusters were statistically significant for all PRO measures (all $p<0.001$).

Conclusion: Lifestyle clusters derived from participant led questionnaires map closely to simultaneously measured disability and health statuses. This suggests that these lifestyle measures capture clinically meaningful variation in MS burden and may offer a useful summary of functioning beyond conventional clinical measures.