

A patient-centred evaluation of thermal resilience practices in temperature-sensitive people with Multiple Sclerosis

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Introduction: Multiple sclerosis (MS) is a neurodegenerative disease characterized by temperature sensitivity, where changes in body temperature induce transient symptoms worsening. There is no pharmacological intervention for this condition and patients often develop their own thermal resilience practices. The aim of the study was to survey the experience of temperature sensitivity and the strategies used to combat it, in MS.

Method: 458 people with MS (58.7% relapsing-remitting; 20.7% secondary-progressive; 14% primary-progressive; 6.6% unknown) completed an anonymous online survey. The questionnaire comprised sections aimed at characterizing participants' general medical history; the symptoms worsening as a result of heat or cold, and thermal resilience techniques for heat and cold sensitivity.

Results: Overall, 53% of responders reported suffering from heat sensitivity, 15% from cold sensitivity, and 32% from both. Fatigue (79%), weakness (60%) and balance difficulties (56%) were prominent heat-induced symptoms. Muscle cramps (43%), fatigue (40%) and poor walking (36%) were prominent cold-induced symptoms. Participants reported exercise (91%) and long periods of inactivity (92%) as the greatest triggers of heat and cold sensitivity, respectively, that affects their MS symptoms. The most common thermal resilience practices in the heat were wearing lightweight, breathable clothes (95%) and using fans (91%) ($p < 0.01$), whereas wearing layers of clothes (93%) and staying in a heated environment (91%) ($p < 0.01$) were commonly adopted to combat cold sensitivity.

Conclusions: Temperature sensitivity in MS worsens quality of life and disease management. The patient-centred information presented here will help guiding evidence-based interventions and investigations that are individually tailored to the specific experiences of temperature-sensitive people with MS.