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<https://doi.org/10.1177/1352458519872904>

PUBLISHER

SAGE Publications

VERSION

AM (Accepted Manuscript)

PUBLISHER STATEMENT

A. Christogianni, J. O'Garro, R. Bibb, N. Evangelou, D. Filingeri. A patient-centred evaluation of thermal resilience practices in temperature-sensitive people with multiple sclerosis, *Multiple Sclerosis Journal* (25:S2) pp. 886-886. Copyright © 2019 (SAGE Publications). DOI: 10.1177/1352458519872904. Users who receive access to an article through a repository are reminded that the article is protected by copyright and reuse is restricted to non-commercial and no derivative uses. Users may also download and save a local copy of an article accessed in an institutional repository for the user's personal reference.

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Christogianni, Aikaterini, J O'Garro, Richard Bibb, N Evangelou, and Davide Filingeri. 2019. "A Patient-centred Evaluation of Thermal Resilience Practices in Temperature-sensitive People with Multiple Sclerosis". figshare. <https://hdl.handle.net/2134/9994574.v1>.

A patient-centred evaluation of thermal resilience practices in temperature-sensitive people with multiple sclerosis

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Introduction: Multiple sclerosis (MS) is neurodegenerative disease characterised 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. Yet, there is no formal evaluation of the variety and perceived effectiveness of those practices. The aim of the study was to survey the experience of temperature sensitivity and the individual strategies used to combat it, in MS.

Methods: 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 characterising 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 cramping (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, loose, breathable clothing (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.

Disclosure: Nothing to disclose