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Survey of people with Myalgic Encephalomyelitis (ME) to explore their use and experiences of physiotherapy services in the UK

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Purpose:

250,000 people live with Myalgic Encephalitis (ME) in the UK, this compares to 100,000 living with Multiple Sclerosis. In 2019, a survey by MEAction of 1,906 people with ME identified that over 50% of people who attended specialist ME clinics were unsatisfied with the services, including physiotherapy. People with ME (PwME) are also seen in regular musculoskeletal, community, neurological and paediatric physiotherapy services but the views of PwME related to these services are not known.

Methods:

A survey comprising of open and closed questions was devised by four researchers with feedback from PwME and representatives of the ME Association. The ME Association website hosted the survey from 2nd July 2019 to 2nd August 2019. An information sheet was provided on the website and consent assumed if participants completed the online survey. All data was anonymous and data held securely on the University of Leicester databases. Qualitative and quantitative data analysis was completed by the four researchers.

The aim of this present survey, therefore, was to identify PwME's experiences of physiotherapy services throughout all areas of physiotherapy practice.

A significant number of People with Myalgic Encephalomyelitis are having negative experiences of physiotherapy, and state that physiotherapy treatment made their symptoms worse.



SCAN ME



Results:

441 PwME completed the survey, respondents ranged from paediatric to adult and mild to severe ME.

Themes included: types of treatments, co-morbidities, symptoms, positive experiences and negative experiences

54% had a negative experience. 53% said symptoms were worse after physiotherapy. 70% of those who had a positive experience said it still did not help their symptoms.

"My symptoms definitely increased during the physio course. I am deeply disturbed by the level of prejudice, negligence and dishonesty still present in the NHS when dealing with ME patients."

"The physio refused to manage risk and refused to report adverse effects. They said I was uncooperative & non receptive to treatment."

"I was made to cycle / row / cross train under threat the course would end if I refused... it set off a major relapse which lasted weeks"

Limitations: It is recognised that this is a small sample of PwME and further research is needed to fully understand the experiences of PwME of physiotherapy

Impact: It is imperative that physiotherapists are aware of the latest exercise physiological evidence so they can treat and advise PwME about how to exercise safely and without adverse effects.

Please see Physiosforme.com, Meassociation.org.uk and Workwellfoundation.org for more information

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