Exploring activity levels in people with Charcot-Marie-Tooth disease or Inclusion Body Myositis in comparison to healthy controls

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Introduction

Our group has studied physical activity levels, recorded using the SenseWear activity monitor (SAM), in people with Charcot-Marie-Tooth disease (CMT). Small, early studies have indicated that people with CMT are less active than the general population. This has implications for deconditioning and prevention of co-morbidities.

Here we present results from our work in CMT and some preliminary data from people with Inclusion Body Myositis (IBM).

Methods

Twenty people with CMT (11 male; aged 46 ±15 years) and 20 healthy matched controls (11 male; aged 46 ±15 years) participated. The SAM was worn for 7 days. Primary comparisons of calorie expenditure, energy expenditure (METs), step count, time spent performing sedentary (<3 METs) and moderately vigorous (≥3 METs) activities were measured using the SAM. Unpaired T-Tests were performed to explore between group differences. Patterns of sedentary behaviour were assessed by power law analyses of the lengths of sedentary bouts and the number of transitions from being inactive to active were also recorded.

Results

There were no significant group differences between calorie expenditure, energy expenditure, or time in sedentary or moderate activities. However, people with CMT took significantly fewer steps each day than the control group (6814 ±2587 and 11218 ±2846 respectively; T=2.024, P<0.00001). Numbers of sedentary to active transitions were significantly higher in patients with CMT compared with controls.

Increased METs (P=0.009) and steps per day (P=0.02) each predicted a reduction in BMI whereas increased time in sedentary activities predicted an increase (P=0.006).

Conclusions

These results indicate that people with CMT have comparable levels of energy expenditure to controls but take fewer steps per day, suggesting they experience increased effort during walking. They also demonstrate more sedentary to active transitions, indicating more frequent periods of activity but for shorter duration. Although 10,000 steps per day are recommended for maintaining health; people with CMT may require fewer daily steps due to their increased energy expenditure per step. However, we acknowledge that the Sensewear may over estimate energy expenditure in people with muscle atrophy and we are proposing a validation study in people with CMT and IBM compared to healthy controls.

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