

Exploring exercise, physical wellbeing and the role of physiotherapy: perspectives from people with narcolepsy

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Introduction

Narcolepsy is associated with significant symptom burden, which can negatively influence quality of life and physical performance. It can also result in social exclusion, increased healthcare usage, as well as decreased employment and education opportunities. This study aimed to explore the attitudes of people with Type 1 narcolepsy towards exercise and physical activity, their physical wellbeing, and the potential role of physiotherapy.

Results

- A total of 22 participants undertook semistructured interviews.
- Just over half of the sample was female (n = 12 [56.52%]), and all participants were diagnosed with narcolepsy with cataplexy.
- The mean (SD, range) age of the participants was 31.4 (13.2, 20–63) years.
- The majority of participants lived with their families (n = 19 [86.36%]), and 45.45%
 (n = 10) were in full-time education.

Theme	Subtheme
Barriers to Exercise	Psychological Barriers Fatigue and Tiredness Fear of Cataplexy Accessibility
Facilitators to Exercise	Career/Education Social Wellbeing Health and Wellbeing
Social Concerns	Impact of Narcolepsy on Career and Education Impact of Narcolepsy on Familial Relationships Impact of Narcolepsy on Social Life
Health Concerns	Weight Gain Following Diagnosis Reduction of Physical Fitness Pain
Role of Physiotherapy	Physiotherapist Prescribed Exercise Programme Advice on Reintroducing Exercise External Motivation to Promote Adherence

Conclusion

People with narcolepsy reported several barriers to exercise related to, fatigue, psychological factors, cataplexy and accessibility-related issues. Participants also reported significant impairment of their physical wellbeing caused by issues such as fatigue, weight gain and pain. Future research should explore the potential role of exercise to help manage narcolepsy-related symptoms in this population.

References

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