Deterioration of the symptom and quality of life of patients with narcolepsy after the COVID-19 pandemic: a 4-year long-term follow-up study

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Objectives：The COVID-19 pandemic can have great impacts on patients with narcolepsy, but currently there was no long-term follow-up study. We collected data of patients with narcolepsy retrospectively during the pre-lockdown period in 2020 and the lockdown period in 2021 and prospectively follow these patients in the post-lockdown period in 2022 and the post-pandemic period in 2023 to investigate the changes of symptom severity and quality of life of patients with narcolepsy during and after the pandemic.

Methods：Patients with type 1 and type 2 narcolepsy (NT1 and NT2) aged 6–40 years were retrospectively recruited and prospectively followed during 2020 to 2023. These patients received evaluation for their symptom severity, quality of life and sleep patterns, by the Epworth Sleepiness Scale (ESS), the visual analog scale (VAS) for hypersomnolence, the VAS for cataplexy, the Short Form 36 Health Survey questionnaire (SF-36), and sleep diary. We compared the differences between the pre-lockdown (2020), the lockdown (2021), the post-lockdown (2022) and the post-pandemic periods (2023) and analyzed subgroup differences by narcolepsy subtypes, age and gender.

Results：A total of 100 patients with narcolepsy completed the 4-year follow-up (mean age, 24.06 ± 7.00 years; 55% male). They had significant differences in the ESS (p=0.037) and VAS-C scores (p=0.024), total nighttime sleep (p=0.03), total sleep time (p=0.035) and sleep efficiency (p=0.035) during follow-up, and significantly worse physical role functioning in the post-pandemic period (p= 0.014). The NT1 group had significantly decreased VAS-C scores in the post-pandemic period (p<0.001) and significantly worse physical role functioning in the pre-lockdown and post-pandemic periods (p=0.009).Subgroup analysis found that adults and males had more significant changes in symptom severity. Adults had significantly decreased total nighttime sleep in the post-pandemic period compared with the pre-lockdown period (p=0.041), and males had significantly worse physical role functioning in the post-pandemic period compared with the lockdown period.

Conclusion：Patients with narcolepsy still face challenges in the post-pandemic period. Hypersomnolence can increase along with deteriorating physical role functioning, especially in adult and male patients with NT1. Cataplexy can be

improved with better compliance. Flexibility should be provided for work and study, and medication adherence and adequate sleep time should be emphasized.

Keywords: COVID-19, narcolepsy, daytime sleepiness, cataplexy, post-pandemic

中文題目：

猝睡症患者於 COVID-19 疫情後之症狀及生活品質變化：四年長期追蹤研究

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