

A validity study of Ullanlinna Narcolepsy Scale in Hong Kong Chinese

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Abstract

Objective: To validate the Chinese version of Ullanlinna Narcolepsy Scale (CUNS). **Methods:** A total of 234 subjects [163 male (69.7%) and 71 female (30.3%)] including 17 patients with narcolepsy, 21 normal controls and 196 patients with various sleep and psychiatric disorders were studied. The diagnoses of these patients were independently ascertained with sleep laboratory confirmation whenever indicated. All the subjects were interviewed through the telephone by a trained lay interviewer who was blind to the diagnosis. The questionnaire included demographic information, sleep habits and CUNS. **Results:** Narcoleptic patients had a significantly higher CUNS score (18.6 ± 4.7 ; 95% confidence interval (CI) 16.2–21.0) and differentiated well from all the other groups ($F_{6,227} = 28.4$, $P < 0.001$). The CUNS has a

satisfactory internal consistency with Cronbach's alpha of 0.75. The principal component analysis with varimax rotation revealed two factors, namely sleepiness and cataplexy factors, which accounted for 45.5% of the total variance. The best cut-off point for the CUNS scale was found to be at 13/14 with high specificity (93.5%), sensitivity (94.1%), negative predictive value (NPV, 99.5%) and modest positive predictive value (PPV, 53.3%). The AUC of receiver operating characteristic (ROC) analysis was 0.97 (95% CI 0.95–0.99). **Conclusions:** The CUNS was validated with satisfactory psychometric properties. The cross-cultural validation of UNS scale suggested that it could be used across the ethnic groups. © 2000 Elsevier Science Inc. All rights reserved.

Keywords: Narcolepsy; CUNS questionnaire; Chinese; Cross-cultural; Validity

Introduction

Sleep disorders are common but under-recognized and under-treated. Excessive daytime sleepiness (EDS), in particular, is a frequent clinical problem and as many as 5% of general population might be suffering from it [16,17]. The causes of EDS are numerous ranging from the more frequent sleep deprivation, sleep–wake schedule disturbance, drug/alcohol effects and sleep-related breathing disorders to relatively rarer but perhaps more disabling narcolepsy. Characterized by EDS, cataplexy, nocturnal sleep disturbance and other REM sleep-related phenomenon such as sleep paralysis and hypnagogic

hallucination, clinically, narcolepsy is a lifelong crippling sleep disorder with conspicuous physical and psychosocial complications [2,6,7,15]. Recent research suggested that narcolepsy has more marked academic and occupational difficulties, negative socioeconomic impact and crippling effect on daily life than other chronic medical disorders such as epilepsy [6,7].

Although the exact etiology is unknown, both genetic and possibly ethnic and environmental factors are believed to play an important part [2,11]. It has been estimated that the prevalence rate of narcolepsy in general population varies from 0.59% in Japanese to 0.00023% in Israel Jews [11,18,25,26]. One of the major reasons for such nearly 2500-fold difference in the prevalence rate was clearly related to the differences in the methodology and studying population, but possible ethnic predisposition cannot be excluded [18]. Similar data on Chinese narcolepsy has been even more limited. Based on our clinical and laboratory data, the estimated rate of narcolepsy in Hong Kong

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Chinese population was projected to be ranging from 0.04% to 0.001% [28,29]. Alternatively, based on the suggestion that the prevalence rate of narcolepsy is closely related to the frequency of human leukocyte antigen (HLA) typing (like DR2, DQ1) in the general population, then the similar prevalence of HLA typing between Chinese and Japanese should suggest a similarly high prevalence of narcolepsy among Chinese subjects [28,29]. Hence, it is clear that a definitive account of prevalence of narcolepsy in Chinese could only come from a well-designed epidemiological study together with sleep laboratory confirmation.

One of the major limitations in clarifying the controversy of the exact prevalence of narcolepsy across the globe has been the lack of availability of a convenient and suitable screening tool to detect the presence of narcolepsy in a large population. To date, the best estimation of population prevalence rate came from the Finnish twin cohort study with 11,354 subjects. By using the screening questionnaire [Ullanlinna Narcolepsy Scale (UNS)] at the initial stage and then followed by the phone interviews, polysomnography and HLA typing of selected subjects; they reported a population prevalence rate of 0.026% (95% CI 0.0–0.06) in Finland [13,14]. The UNS was an 11-item scale that investigated the subjects' two main aspects of narcolepsy, namely abnormal sleep tendency and cataplexy. Four main stem questions about daytime sleepiness (45.5% of the total score), napping (9.0%), nocturnal sleep latency (9.0%) and cataplexy-related questions (36.5%) will be asked and the scale has a range of scores from 0 to 44 [13,14]. The Finnish study suggested that the scale was very sensitive (100%) and specific (98.8%) for screening narcolepsy [13,14]. However, as suggested by the authors, this simple but very useful questionnaire needed to be replicated and validated in other ethnic populations [13,14]. In addition, the scale has not been subjected to rigorous statistical analysis, which limited the interpretation of the validity and reliability of the scale [13,14].

Methods

The Chinese version of UNS (CUNS) was translated from the English version to Chinese and then translated back to English by bilingual fluent Chinese physicians. A total of 213 subjects of mean age 44.8 (S.D. 12.7, range 15 to 78) were recruited from the patients who visited the Sleep Assessment Unit and psychiatric clinic. The diagnoses of these patients were independently ascertained by the clinicians with sleep laboratory confirmation whenever indicated. These included patients suffering from narcolepsy ($n = 17$), psychiatric disorders ($n = 62$), sleep apnea syndrome (SAS) ($n = 117$), REM sleep behavioral disorders ($n = 11$) and hypersomnia ($n = 6$). The remaining 21 healthy controls were recruited from the advertisement posted in the university and hospital. All the subjects were then interviewed through the telephone by a trained lay interviewer (the

second author) who was blind to the diagnosis. The structured questionnaire included demographic information, sleep habit and CUNS. This study was approved by the university research ethical committee.

Normal control group

All the healthy control subjects were assessed by the first author with detailed clinical interview. Those with suspected psychiatric, sleep or medical disorders were excluded. All the control subjects underwent at least one night of sleep assessment. People were excluded if their respiratory disturbance index (RDI) is greater than or equal to 5. The overall RDI of these control subjects was 1.3/h (S.D. 1.0).

Narcolepsy group

The criteria for diagnosing narcolepsy is based on the following:

- (a) EDS for more than 3 months,
- (b) Definite cataplexy,
- (c) A mean sleep latency (MSL) of <8 min during multiple sleep latency test (MSLT),
- (d) Presence of three or more sleep-onset REM periods (SOREMPs) in the five naps during MSLT,
- (e) Exclusion of other serious sleep disorders that may account for the EDS such as SAS.

In order to satisfy the diagnosis of narcolepsy, the subjects should either satisfy criteria a+b or a+c+d+e for those with probable cataplexy [4].

Altogether 17 narcoleptic patients were enrolled into the study. All the narcoleptic patients also fulfilled the minimal criteria of the International Classification of Sleep Disorders (ICSD) criteria except one noncataplectic subject who had an MSL of 5.6 min during MSLT [15]. During the interview, seven people were on drug treatment including stimulants and/or anti-cataplectic drug. The remaining 10 subjects were drug-free. There was no difference of CUNS scores between the two groups ($t = 0.95$, $P = 0.36$). Fourteen of them (82.3%) had also HLA typing done. All were DR2 (100%) and DQ1 (100% for all tested subjects) positive except one subject who did not have further DQ typing. Thirteen patients had a history of definitive cataplectic attacks (76.5%) and the remaining four patients had a history of probable cataplexy. The MSL of the whole group was 3.0 min (S.D. 2.2). The MSLT and the number of SOREMPs did not differ between those with definite and probable cataplexy (MSLT: $t = 0.78$, $P = 0.45$; SOREM: $U = 21$, $P = 0.51$). The MSL of those with definite cataplexy and probable cataplexy were 3.2 (S.D. 2.2) and 2.3 min (S.D. 2.3), respectively. The number of SOREMPs during MSLT in the definite group were: 1–3 (23.1%), 4 (15.4%) and 5 (61.5%) and probable group: 4 (25%) and 5 (75%) SOREMPs, respectively.

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