

Validity and Reliability of the Persian Version of the Swiss Narcolepsy Scale in Iranian Patients with Narcolepsy

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Abstract

Background: The challenges associated with diagnosing narcolepsy and its impact on patient's quality of life have led to the use of screening questionnaires as an initial diagnostic step. The Swiss Narcolepsy Scale (SNS), known for its higher specificity than others, had not been translated and validated in Persian. In this study, we aimed to assess the validity and reliability of the Persian version of the SNS questionnaire.

Methods: The translation process involved a rigorous backward and forward translation approach followed by an expert panel review comprising ten sleep specialists to evaluate the questionnaire's validity. A cross-sectional sampling method was employed to recruit 79 participants, including patients with hypersomnolence complaints who underwent polysomnography (PSG) and multiple sleep latency tests (MSLT), as well as healthy non-shift workers without any history or complaints of sleep-related disorders. The questionnaire's value for diagnosing narcolepsy was assessed using measures such as Cronbach's alpha, content validity ratio (CVR), content validity index (CVI), accuracy, sensitivity, and specificity.

Results: The Persian version of the SNS questionnaire demonstrated acceptable validity and reliability, with notably higher specificity and accuracy than the Epworth Sleepiness Scale (ESS) for narcolepsy screening. The CVR, CVI, and Cronbach's alpha values were 0.926, 0.880, and 0.603, respectively, while the accuracy, specificity, and sensitivity were 69.6%, 84.0%, and 44.8%, respectively.

Conclusion: The Persian version of the SNS questionnaire exhibits acceptable validity and reliability, and it outperforms the ESS in terms of specificity and accuracy for narcolepsy screening.

Keywords: Narcolepsy; Epworth Sleepiness Scale; SNS; Swiss Narcolepsy Scale; Persian Version

Introduction

Narcolepsy is an incapacitating disorder of the hypothalamus that disrupts the wake-sleep cycle. The most common and annoying symptom is excessive daytime sleepiness (EDS). Other associated symptoms include sleep fragmentation, disturbed sleep, sleep paralysis, and hypnagogic and hypnopompic hallucinations. There are two narcolepsy subtypes. Type 1 is characterized by cataplexy and low

hypocretin levels in cerebrospinal fluid. In contrast, type 2 comprises a more heterogeneous group of patients who lack the above features and are typically diagnosed with daytime sleepiness, characteristic polysomnography (PSG), and multiple sleep latency tests (MSLT) [1,2].

The diagnosis of narcolepsy is mainly clinical and presents significant challenges [2,3], often leading to a delay in diagnosis and negatively impacting patients' quality of life [3]. Considering diagnostic interviews' costly and time-consuming nature, screening questionnaires as the first step in diagnosing narcolepsy has become common.

Over the years, questionnaires such as the Ullanlinna Narcolepsy Scale (USS) [4], Epworth Sleepiness Scale (ESS) [5], and SWISS Narcolepsy Scale (SNS) [6] have been widely used for screening and diagnosing narcolepsy. SNS was developed by Sturzenegger C, Bassetti CL in 2004, and in 2018, they demonstrated its superiority in specificity (88% vs. 54% and 62%) and accuracy (86 vs. 70% and 61%) against UNS and ESS [7]. While SNS has not been translated into other languages, its English version is extensively used in research and clinical contexts.

Considering that SNS is recognized as the most specific narcolepsy screening questionnaire and has no validated Persian version, it is imperative to develop an authentic Persian version of the SNS questionnaire.

Aim of the Study

This study aimed to assess the validity and reliability of the Persian version of the SNS questionnaire so that it can be used as an efficient tool in clinical and research matters.

Methods

This cross-sectional study was conducted in 2022 at the sleep clinic of the Imam Hospital, Tehran University of Medical Sciences, Tehran, Iran, to analyze the validity and reliability of the Persian version of the SNS questionnaire.

SNS is a 5-question subjective questionnaire that screens for the symptoms that may be associated with narcolepsy. Each question is on a Likert scale and can get a score of 1 to 5. The following formula is used to calculate the overall SNS score, and a score less than 0 is suggestive of narcolepsy: $6 \times Q1 + 9 \times Q2 - 5 \times Q3 - 11 \times Q4 - 13 \times Q5 + 20$ [6,7].

Two bilingual translators translated the original questionnaire from English to Persian separately. One translator was aware of the objectives, and one was naive and unaware of the objectives. The discrepancies were later discussed with a third bilingual person. Backward translation was done by two bilingual people unaware of the questionnaire's intended concepts. Then, an expert committee, including backward and forward translators and two experts on sleep health, reached a consensus on all items, producing a prefinal Persian version of the SWISS narcolepsy questionnaire. We then included an expert panel of 10 sleep specialists to assess the validity by individually scoring each question based on clarity, simplicity, and relevance.

After finalizing the questionnaire, we included participants who met one of the following inclusion criteria: 1. Patients with complaints of narcolepsy-related symptoms who had undergone standard PSG and MSLT. 2. Healthy non-shift workers from our clinic with no history of sleep or neurological disorders. Written informed consent was obtained from all participants, and the study protocol was approved by the ethics committee of Tehran University of Medical Sciences (IR.TUMS.NI.REC.1401.045).

79 participants completed the Persian version of the SNS questionnaire (Supplementary file). They also completed the Persian version of the ESS questionnaire, which was previously validated by Sadeghniat, *et al.* [8].

All data was analyzed using SPSS, IBM, version 22.0. There was no missing data on SNS and one missing data in ESS scores. To evaluate internal consistency (reliability), Cronbach alpha was calculated, and a value greater than 0.7 was considered a high level of reliability. To assess validity, the content validity ratio (CVR) and the content validity index (CVI) were calculated, and according to Lawshe [9], a value greater than 0.62 (based on the number of panelists) was considered an acceptable level of CVR and a value greater than 0.78 was considered as an acceptable value of CVI. We used false negative, false positive, true negative, and true positive values to calculate the questionnaire’s accuracy, sensitivity, and specificity.

Results

To assess the validity of the Persian version of SNS, we included ten panelists, who evaluated each question for its clarity, simplicity, and relevance using Lawshe’s method. All questions showed an acceptable content validity as indicated by the CVI and CVR values (See table 1). The total CVR and CVI were 0.926 and 0.880, respectively.

Item	Item content	Clarity	Simplicity	Relevancy	CVI	CVR
1	How often are you unable to fall asleep?	0.90	0.90	0.90	0.90	1.00
2	How often do you feel bad or not well rested in the morning?	1.00	0.90	0.90	0.93	0.80
3	How often do you take a nap during the day?	0.90	0.90	1.00	0.93	1.00
4	How often have you experienced weak knees/buckling of the knees during emotions like laughing, happiness, or anger?	0.90	1.00	1.00	0.97	1.00
5	How often have you experienced sagging of the jaw during emotions like laughing, happiness, or anger?	0.90	0.80	1.00	0.90	0.60

Table 1: Validity of the items of the Persian version of the Swiss Narcolepsy Scale.

To assess reliability, accuracy, sensitivity, and specificity, we included 79 participants who underwent PSG and MSLT and completed the SNS questionnaire. Of 79 participants, 43 (54.4%) were males, with a mean age of 37.0 ± 11.8 and a range of 20 to 72 years (See table 2).

Variable	Value
Age, Mean ± SD	37.0 ± 11.8
Median (Q1-Q3)	35 [27.75-44]
Gender	
Female	36 (45.6)
Male	43 (54.4)
Marital status	
Single	27 (35.1)
Married	49 (63.6)
Divorced	1 (1.3)
Education	
Highschool	9 (12.7)
Diploma	16 (22.5)
Associate degree	8 (11.3)
Bachelor	27 (38.0)
Master’s and higher	11 (15.5)

ESS score, Mean ± SD	13.5 ± 7.2
Median (Q1-Q3)	13 [7-20]
Definite narcolepsy*	29 (36.7)
NT1	13 (45.5)
NT2	16 (55.5)

Table 2: Participants' characteristics.

Data presented as N (%) and Mean ± SD, Median [Q1-Q2].

*Confirmed with polysomnography and multiple sleep latency tests.

ESS: Epworth Sleepiness Score; NT: Narcolepsy Type.

Figure 1 displays the frequency distribution of participant responses across the SNS questions. Twenty-one (26.6%) participants scored <0 in SNS, which is suggestive of narcolepsy. In comparison, PSG and MSLT results indicated that 29 (36.7%) of participants had a diagnosis of narcolepsy.

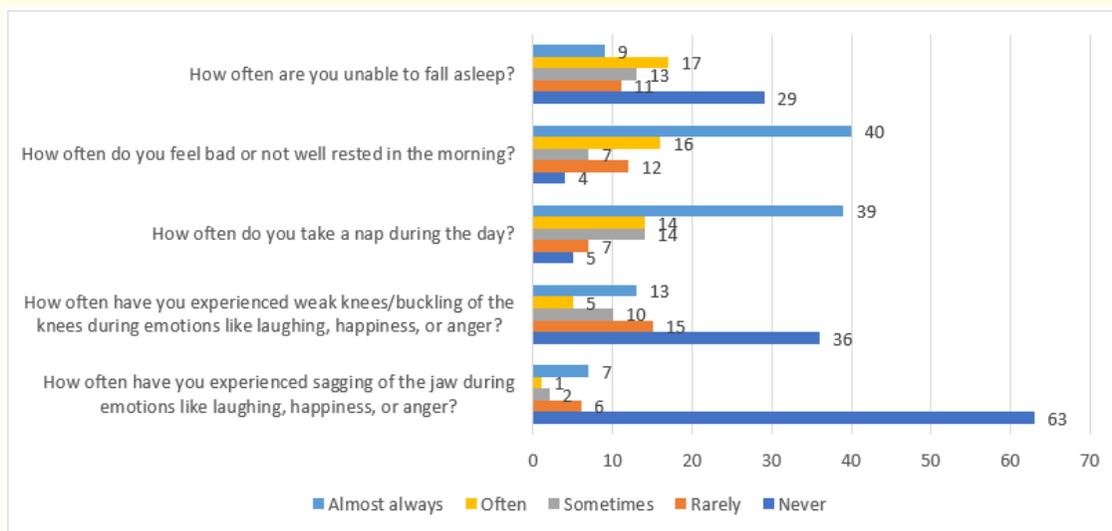


Figure 1: Frequency distribution of participant responses across the SNS questions. A SNS score ($6 \times Q1 + 9 \times Q2 - 5 \times Q3 - 11 \times Q4 - 13 \times Q5 + 20$) less than 0 is suggestive of narcolepsy. Twenty-one (26.6%) participants scored <0 in SNS.

For five items of the questionnaire, the Cronbach alpha was 0.603. Our results, using the SNS questionnaire, showed 42 true negatives, 13 true positives, 16 false negatives, and 8 false positives (See table 3). The Persian version of SNS showed an accuracy of 69.6%, a sensitivity of 44.8%, and a specificity of 84.0%. While the ESS questionnaire with a cut-off of ≥ 10 showed an accuracy of 64.1%, sensitivity of 89.6%, and specificity of 49.0%.

		Swiss Narcolepsy Questionnaire	
		Suggestive of narcolepsy	Not suggestive of narcolepsy
PSG+MSLT	Suggestive of narcolepsy	13	16
	Not suggestive of narcolepsy	8	42

Table 3: Assessing the diagnostic performance of the Swiss Narcolepsy Questionnaire against polysomnography and MSLT.

Discussion

In this study, we aimed to assess the validity and reliability of the Persian version of the SNS questionnaire. Due to the challenges in diagnosing narcolepsy and its impact on patient's quality of life, screening questionnaires have become a common initial step in the diagnostic process. The SNS questionnaire, known for its specificity and accuracy, had not been translated and validated in Persian. Validation of the Persian version of the SNS questionnaire fills the gap in the assessment of narcolepsy within the Persian-speaking population. We demonstrated that the Persian version of the SNS questionnaire is valid, reliable, and specific for screening narcolepsy.

Comparing the diagnostic performance of the Persian versions of SNS and ESS, our results demonstrated that the Persian SNS outperformed the ESS in terms of accuracy (69.6% vs. 64.1%) and specificity (84.0% vs. 49.0%). This observation aligns with the original study by Sturzenegger, *et al.* and Bassetti, *et al.* where the SNS exhibited superior specificity compared to the ESS [6,7,10]. The enhanced specificity of the SNS is particularly crucial in narcolepsy screening, considering the potential overlap of symptoms with other sleep disorders like other central disorders of hypersomnolence (CHD).

Examining our results in the context of previous studies, such as Sturzenegger's 2004 study and the 2018 update, as well as Bargiotas' study, provides a broader perspective on the diagnostic performance of the SNS across diverse populations. Notably, our study demonstrated a specificity of 84%, which remains comparable although slightly lower than the reported values in the mentioned studies [6,7,10].

The research suggests that the SNS questionnaire is generally more specific than sensitive in detecting narcolepsy [6,7,10], especially demonstrating lower sensitivity for identifying type 2 narcolepsy [10]. This could clarify why our study showed lower sensitivity than previous ones. The reason being that those studies either had no type 2 narcoleptic patients or a smaller percentage (5% to 18%), while our sample included a higher proportion of type 2 narcolepsy patients (16 out of 29, accounting for 55% of narcoleptic patients in our study).

The disparity in sensitivity can also be attributed to the fact that all previous studies were conducted in European countries, while our research was conducted in Iran. According to a recent review article, developing countries like Iran are less likely to have sleep health on their national health agenda, indicating lower public awareness about sleep health compared to European countries [11]. Since the SNS questionnaire relies on the patient's personal experiences, the varying levels of sleep awareness among different populations could play a crucial role in shaping the results. This contrast in sleep awareness might be a key factor contributing to the differences in sensitivity, underscoring the significance of taking cultural and regional aspects into account in narcolepsy research [12,13].

Conclusion

The Persian version of the SNS questionnaire emerges as a valuable tool for narcolepsy screening within the Persian-speaking population, focusing on its enhanced specificity compared to other screening instruments. Our study contributes to the global understanding of the SNS's diagnostic utility, highlighting its effectiveness even in populations with a higher prevalence of NT2. Future research could further explore the nuanced performance of the SNS in diverse populations and its potential for refining narcolepsy subtyping.

Author's Contribution

AB has contributed to the statistical analysis of data, interpretation of data, drafting the work, and substantively revising it. NR has contributed to the data acquisition and substantively revising the draft. FJ and MS have contributed to the conception and design of the work. AN and HA have contributed to the conception and design of the work, interpretation of data, drafting the work, and substantively revising it.

Data Availability

Datasets are not publicly available but are accessible upon reasonable request from the corresponding author.

Competing Interests

The authors declare no competing interests.

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Ethics Approval and Consent to Participate

The study protocol was approved by the ethics committee of Tehran University of Medical Sciences (IR.TUMS.NI.REC.1401.045). Informed consent for participation and publication was obtained from all participants.

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