The Impact of Symptom Severity on Health-Related Quality of Life in Patients with Narcolepsy

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Abstract

Background: Narcolepsy has deleterious implications on daily life. However, few studies have fully assessed the severity of pentad symptoms of Chinese adults with narcolepsy type 1 (NT1), as well as the relation with health-related quality of life (HRQoL). It is still not clear how the global functioning of patients with NT1 are affected by these pentad symptoms and which does specific symptom affect HRQoL. This is the first study to assess the pentad symptom severity and its correlation with HRQoL in patients with NT1.

Methods: Our cross-sectional study is to assess the pentad symptom severity and its correlation with HRQoL in patients with NT1. A total of 174 patients with NT1 were recruited. They completed Narcolepsy Severity Scale (NSS) and European Quality of Life-5 Dimensions Questionnaire (EQ-5D) including five dimensions (EQ-5D utility values) and a visual analog scale (EQ-5D VAS). The relation between severity of symptoms and HRQoL dimensions was assessed by Pearson correlation analyses. Logistic regression was used to identify the significant predictors of HRQoL. Nomogram was established based on results of independent predictors factors on logistic regression analyses.

Results: The scores for NSS, EQ-5D utility values and EQ-5D VAS were 29.89±10.08, 0.78±0.09 and 64.30±19.84 in patients with NT1 respectively. NSS score showed a significantly correlation with self-care (r=0.157, P<0.05), usual activities (r=0.236, P<0.01), pain/discomfort (r=0.174, P<0.05), anxiety/depression (r=0.2, P<0.01) and EQ-5D utility values (r=-.261, P<0.01). EDS (excessive daytime sleep), cataplexy, hallucinations, paralysis and disrupted nocturnal sleep (DNS) were significant associated to EQ-5D VAS (r ranged from -0,154 to -0.354, P<0.05). EDS (OR=-0.297, 95% CI -1.892- -0.634) and DNS (OR=-0.16, 95% CI -0.7307- -0.446) were predictors of HRQoL. Regards the NSS scores, NSS score (OR=-0.360, 95% CI -0.979- -0.438) and treated (OR=0.215, 95% CI 3.567-16.188) were predictors of the metrics of HRQoL. The C-indices of the nomogram was 0.726 (95% CI 0.686-0.766). **Conclusio**n: The severity of symptoms could disrupt self-care and usual activities and increase pain/discomfort and anxiety/depression. NSS score could be used for predicting HRQoL, but with a modest precision.

Introduction

Narcolepsy is a chronic and debilitating neurological disorder of sleep-wake state instability(1). It has deleterious implications on daily life. The five core symptoms of narcolepsy type 1 (NT1) including excessive daytime sleep (EDS), cataplexy, hypnagogic/hypnopompic hallucination, sleep paralysis and disrupted nocturnal sleep (DNS). Among the pentad symptoms of NT1, EDS is the most common manifestation and is necessary for a diagnosis, cataplexy is most specific, and DNS is more of a complaint than sleep paralysis and hypnagogic hallucinations(2–4). A prominent feature of narcolepsy is related to a number of comorbidities, including psychiatric conditions, cardiac disease, sleep apnea, metabolic disorders, diabetes, and overweight(5). The persistence of narcolepsy and the burden of chronic management can compromise health-related quality of life (HRQoL) and there is evidence that narcoleptics have lower HRQoL(6).

There symptoms have been indicated to have a detrimental effect on HRQoL in patients with NT1. Previous studies provide evidence that EDS (measured by ESS) has a great impact on HRQoL, rather evidently more than other symptoms, such as cataplexy, hypnagogic/hypnopompic hallucinations and sleep paralysis(7–9). The constancy of EDS was cited as a key factor in contributing to poor HRQoL. More specifically, those with NT1 reported that anxiety and avoidance related to having cataplexy in social situations had negative impacts on psychosocial functioning(6). However, for the influence of EDS on HRQoL, there are studies reporting opposite results(9, 10). One study did not find any association between the severity of the main symptoms (EDS and cataplexy, measured by the Ullanlinna Narcolepsy Scale) and HRQoL in patients with narcolepsy (11).

Cataplexy may disappear with advancing age due to lifestyle adjustments or natural history of narcolepsy, which may bias the research on the effect of cataplexy on quality of life(12). Although there are also few studies involving the influences on HRQoL by cataplexy, their conclusions are inconsistent. For instance, Daniels et al. [11] point out that avoiding behaviors adopted by narcoleptics to prevent cataplexy attacks may impair social function. However, the finding by Vignatelli et al.(10) is that cataplexy did not show any correlation with HRQoL (assessed by SF-36 scales). Unfortunately, few studies focused on the effects of hallucinations and sleep paralysis on HRQoL. Thus, the accurate assessment of symptoms and the choice of tools for severity assessment are very important for the study.

The clinical experience indicates that only a minority of patients with NT1 have all five symptoms, however, few studies evaluated NT1 symptom severity comprehensively. Whereas, Epworth sleepiness score (ESS), Stanford Sleepiness Scale (SSS) and Multiple Sleep Latency Test (MSLT), which are widely used to monitor symptom severity in clinical practice, mainly focus on the evaluation of the severity of excessive sleepiness, lacking comprehensiveness. To evaluate the symptom severity of NT1 patients comprehensively, the Narcolepsy Severity Scale(NSS)was developed by Dauvilliers et al. in 2017, and it has been proved to be a reliable and valid clinical tool (13). The revised Chinese version NSS had good reliability and validity with Cronbach's α of 0.821 and could be used to evaluate the pentad symptoms of narcolepsy in adult narcoleptics(14).

However, few studies have systematically assessed the severity of pentad symptoms of Chinese adults with NT1, as well as the relation with HRQoL. It is still not clear how the global functioning of patients with NT1 are affected by these pentad symptoms and which does specific symptom affect HRQoL. The aim of this study, therefore, is to evaluate the effect of severity of pentads symptoms on HRQoL and confirm the predicators of HRQoL in patients with NT1.

Materials And Methods

Study design and participants

This was a questionnaire-based cross-sectional study. The study was approved by the Institutional Review Board of Peking University People's Hospital, China. All patients who agreed to participate in the study signed the informed consent, and all collected information were anonymous and confidential and used for this study only. For this study, a total of 174 consecutive subjects with NT1 were recruited from the Sleep Medicine Center of the Peking University People's Hospital. Patients who were included, aged more than 18 years and were diagnosed NT1 following the ICSD-3 (International Classification of Sleep Disorders-Third Edition)(2): a subjective complaint of sleepiness more than 3 months, a history of clear cataplexy, more than two sleep-onset rapid eye movement periods (SOREMPs), a mean latency of ⩽8 min on MSLT, and/or cerebrospinal fluid hypocretin-1 deficiency (less than 110 pg/mL or one-third of the normative values). Participants were excluded for the following reasons: comorbidity of other sleep disorders or clinically unstable medical conditions. NTI patients completed the questionnaires under the researcher's instruction after signing the informed content.

Assessment Categories

Demographic data such as gender, height, weight, education, onset age, Duration of disease, diagnosis delayed and polysomnography measurements were collected. In addition, all participants completed The Narcolepsy Severity Scale(NSS) and European Quality of Life-5 Dimensions Questionnaire (EQ-5D).

Assessment Of Narcolepsy Symptom Severity

The Narcolepsy Severity Scale(NSS)was used to evaluate the severity of symptoms. NSS was developed by Dauvilliers in 2017(13). NSS consisted 3 factors (factor 1: EDS; factor 2: cataplexy; factor 3: sleep paralysis, hallucinations and DNS), including 15 items, and had good psychometric properties with satisfactory Cronbach's α coefficient, which were 0.74–0.85. Five narcolepsy symptoms could be evaluated, including EDS (7 items, total score ranged from 0 to 25), cataplexy (3 items, total score ranged from 0 to 13), hallucinations (2 items, total score ranged from 0 to 8), sleep paralysis (2 items, total score ranged from 0 to 8) and DNS (1 item, total score ranged from 0 to 3). The six items assessing symptoms frequency were measured by using a six-point Likert scale ranging from 0 to 5, and the remaining nine items evaluating the effect of symptoms on daily life were rated using a four-point Likert scale ranging from 0 to 3. Total score of NSS ranged from 0 to 57 and higher scores implied more severe and frequent symptoms. The revised Chinese version NSS had good reliability and validity with Cronbach's α of 0.821 in Chinese adult narcoleptics (15). For this study, Cronbach's α coefficient is 0.824.

Assessment Of Hrqol

HRQoL was assessed by European Quality of Life-5 Dimensions Questionnaire (EQ-5D). The EQ-5D essentially comprised EQ-5D utility values (EQ-5D descriptive system) and a visual analog scale (EQ-5D VAS) (16). It measured patients' outcomes across five dimensions: mobility, self-care, usual activities,

pain/discomfort, and anxiety/depression, corresponding to three levels (no problems, some problems and extreme problems). Based on the national norms, the five dimensions were combined and scaled to confirm unique health state. Higher scores indicate better HRQoL. The EQ-5D VAS score was used to measure the overall health, ranging from 0 (worst health) to 100 (best health). In mainland China, the EQ-5D has been improved to have good validation and reliability(17).

Statistical analysis

Descriptive analysis, independent-samples T-test and one-way analysis of variance (ANOVA) were used to describe and compare the demographic data, as well as the distribution of NSS, EQ-5D utility values and EQ-5D VAS. Pearson correlation analyses was used to assess the relationship between NSS and five dimensions of EQ-5D utility values, as well as the relationship between five symptoms of narcolepsy and EQ-5D VAS. Logistic regression analysis (enter method) was used to evaluate the independent predictors of HRQoL. Based on the logistic regression analysis results, a nomogram was performed by using the rms package in R software version 3.6.3. The predictive accuracy of nomogram was determined by the consistency index (C-index) and evaluated by calibration. The higher the C-index, the more accurate the prediction. The model was internally validated by using bootstrap (1000 samples).

Data analysis was performed using SPSS 20.0 software (SPSS Inc, Chicago, IL, USA) and R software version 3.6.3 (https://www.r-project.org/). A level of statistical significance was set to $P < 0.05$.

Results

Sample Characteristics

One hundred and seventy-four eligible patients, including 131 drug-free patients and 43 treated NT1 patients, were recruited in this study. The mean age, onset age (years), duration of disease (years) and diagnosis delayed years were 31.14 (11.28) 17.19 (12.82), 12.74 (8.45) and 8.86 (8.11) respectively. Scores of NSS, EQ-5D utility values and EQ-5D VAS were 29.89 ± 10.08, 0.78 ± 0.09 and 64.3 (19.84) in patients with NT1 respectively. The sociodemographic, clinical, and polysomnographic features of all patients were shown in Table 1.

Table 1
Sociodemographic and clinical characteristics of participants (N = 174)

Variables	Value
Age (years), Mean (SD)	31.14 (11.28)
Gender (%)	
Male	119 (68.4)
Education (%)	
Primary education	5 (2.9)
Junior middle school	26 (14.9)
High school education	43 (24.7)
Bachelor degree or above	100 (57.5)
BMI (kg/m^2)	27.86 (4.26)
Onset age (years)	17.91 (12.82)
Duration of disease (years)	12.74 (8.45)
Diagnosis delayed (years)	8.86 (8.11)
Treated (%)	43 (24.7)
Scores of questionnaires	
NSS total scores	29.89 (10.08)
Domain 1	15.88 (4.67)
Domain 2	5.67 (3.78)
Domain 3	8.33 (5.18)
EQ-5D utility values, Mean (SD)	0.78 (0.09)
EQ-5D VAS, Mean (SD)	64.30 (19.84)
Lab testing	
% HLADQ0602+	174/174
%Hcrt-1 < 110 pg/ml	54/174
Sleep test	

BMI: Body Mass Index; NSS: Narcolepsy Severity Scale; EQ-5D: European Quality of Life-5 Dimensions Questionnaire; Domain 1: excessive daytime sleepiness accessed by NSS; Domain 2: cataplexy accessed by NSS; Domain 3: sleep paralysis, hallucinations and disrupted nocturnal sleep accessed by NSS; AHI: Apnea hypopnea index; MSLT: multiple sleep latency test; SOREMPs: numbers of sleep onset rapid eye movement periods.

Variables	Value
Sleep efficiency (%)	83.74 (17.14)
Total sleep time (min),	435.21 (86.37)
AHI	9.08 (14.12)
MSLT sleep latency	2.13 (2.34)
SOREMPs	4.13(1.17)
BMI: Body Mass Index; NSS: Narcolepsy Severity Scale; EQ-5D: European Quality of Life-5 Dimensions Questionnaire; Domain 1: excessive daytime sleepiness accessed by NSS; Domain 2: cataplexy accessed by NSS; Domain 3: sleep paralysis, hallucinations and disrupted nocturnal sleep accessed by NSS; AHI: Apnea hypopnea index; MSLT: multiple sleep latency test; SOREMPs: numbers of sleep onset rapid eye movement periods.	

Difference in Scores of NSS and EQ-5D

The results of difference in EQ-5D VAS and NSS scores in participants' demographic data showed that the score of EQ-5D VAS was significant higher in treated group (t=-2.707, p < 0.01). There were no differences in EQ-5D VAS and NSS scores in other participants' demographic data (p > 0.05).

Correlation analysis of HRQoL

A Pearson correlation analysis among the polysomnography measurements and NSS scores was conducted. A statistically significant relationship was determined between the NSS scores and EQ-5D VAS scores (r=-3.52, P < 0.01) (Fig. 1).

We also performed correlation analysis to confirm the relationship between NSS and dimensions of HRQoL. As shown in Table 2, NSS scores were related to self-care, usual activities, pain/discomfort and anxiety/depression.

Table 2
Correlation between NSS scores and HRQoL

	E1	E2	E3	E4	E5	EQ-5D VAS
NSS	.133	.157*	.236*	.174*	.200*	.-352**
Factor1 (EDS)	.087	.153*	.103	.102	.115	− .354**
Factor 2 (cataplexy)	.135	.038	.184*	.075	.085	− .154*
Factor 3	.083	.139	.231**	.191*	.223**	− .255**
Hallucinations	.120	.105	.188*	.139	.192	− .212**
Paralysis	.011	.126	.210**	.123	.158*	− .216**
DNS	.074	.115	.143	.334**	.242**	− .189*

NSS: Narcolepsy Severity Scale; HRQoL: health-related quality of life; E1: mobility; E2: self-care; E3: usual activities; E4: pain/discomfort; E5 anxiety/depression; EQ-5D VAS: a visual analog scale (EQ-5D VAS) of European Quality of Life-5 Dimensions Questionnaire (EQ-5D); EDS: excessive daytime sleepiness; DNS: disrupted nocturnal sleep; Factor 1: EDS accessed by NSS; Factor 2: cataplexy accessed by NSS; Factor 3: sleep paralysis, hallucinations and DNS accessed by NSS.

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 2 also showed the relationship between pentad symptoms of NT1 and HRQoL. EDS, cataplexy, hallucinations, paralysis and DNS were all associated to EQ-5D VAS (r ranged from − 0.154 to -0.354, p < 0.05).

Predictors of HRQoL

Logistics regression analysis indicated EDS (OR=-0.297, 95% CI -1.892- -0.634), DNS (OR=-0.16, 95% CI -0.7307- -0.446) were predictors of HRQoL (Table 3).

Table 3
Predictors of pentad symptoms on HRQoL

	β	S.E.	P value	Exp (B)	95% C.I.for EXP(B)		Collinearity Statistics	
					Lower	Upper	Tolerance	VIF
Constant	90.443	5.259	.000		80.061	100.826		
Treated	9.055	3.263	.006	.197	2.613	15.496	.940	1.063
EDS	-1.263	.319	.000	− .297	-1.892	− .634	.848	1.179
Cataplexy	− .103	.429	.810	− .020	− .949	.743	.714	1.400
Hallucinations	− .509	.628	.419	− .072	-1.750	.731	.598	1.672
Paralysis	− .417	.723	.565	− .055	-1.843	1.010	.521	1.919
DNS	-3.877	1.737	.027	− .160	-7.307	− .446	.926	1.080

HRQoL: health-related quality of life; EDS: excessive daytime sleepiness; DNS: disrupted nocturnal sleep.

Regards the NSS scores, logistics regression analysis indicated NSS (OR=-0.360, 95% CI -0.979- -0.438) and treated (OR = 0.215, 95% CI 3.567−16.188) were predictors of the metrics of HRQoL (Table 4). Subsequently, multivariable logistic regression was performed to develop the predictive model and a nomogram. The nomogram for predicting low HRQoL among patients with NT1 was shown in Fig. 2. The C-index for low HRQoL prediction was 0.726 (95% CI, 0.686−0.766). The calibration plot for the probability of low HRQoL showed an optimal agreement between the prediction by the nomogram and actual observation

Table 4
Predictors of NSS on HRQoL

	β	S.E.	P value	Exp (B)	95% C.I.for EXP(B)		Collinearity Statistics	
					Lower	Upper	Tolerance	VIF
Constant	83.028	4.369	.000		74.403	91.653		
Treated	9.877	3.197	.002	.215	3.567	16.188	.999	1.001
NSS	− .708	.137	.000	− .360	− .979	− .438	.999	1.001

HRQoL: health-related quality of life; NSS: Narcolepsy Severity Scale.

Discussion

In our study, we are the first to evaluate the symptom severity and its correlations with HRQoL in Chinese patients with NT1 and found a significant correlation between severity of symptoms (especially EDS, cataplexy and DNS) and self-care, usual activities, pain/discomfort, anxiety/depression and EQ-5D VAS.

EDS, DNS and treated were the significant factors to predict the HRQoL. NSS score could be used for predicting HRQoL in patients with NT1.

Our present analysis indicated that there was no difference of HRQoL in gender, age, and level of education. Patients with NT1 who were treated had less impaired HRQoL. There was strong emerging evidence for the effectiveness of medicine in symptom management and improvement of study and daily life(18). In one study, type of education had no effect on HRQoL, which was in line with our research(11). Our study also found EDS, cataplexy hallucinations and sleep paralysis and DNS, as reflected by the NSS scores, were significantly associated to HRQoL. It appeared plausible that symptoms more than demographic features affected HRQoL.

HRQoL was a multidimensional construct and numerous studies evidenced that HRQoL was significantly impaired among patients with narcolepsy when compared with healthy population. Several domains of HRQoL were impaired, including mood, psychopathology, marital and work problems(8, 9, 19). To assess the relation between severity of NT1 and five domains of HRQoL, we performed correlation analyses. The results showed severity of symptoms was significantly related to self-care, usual activities, pain/discomfort and anxiety/depression, but not to mobility, which was consistent with other studies. Several investigators had reported that narcolepsy may greatly disrupt social, educational, and professional development(20, 21). According to the study, patients with narcolepsy had two to three times the rate of mood and anxiety disorders and significantly higher work absenteeism(22). Evidence had confirmed that there was a higher frequency of depressive symptoms and the major impact on HRQoL in patients with NT1, so a more thorough assessment of mood impairment in NT1 patients was recommended(23). One study showed that when compared with the general population, narcolepsy could affect all dimensions of HRQoL (reflected by SF-36) except for physical function and bodily pain(8).

As can be shown by logistic regression analysis results, EDS, DNS and treatment were predictors of the metrics of HRQoL. Sleepiness was irresistible and may to be worse with inactivity, and the sleep attacks often came on suddenly, which could be brief enough to lost consciousness. In many narcoleptics, severe sleepiness would lead to difficulty focusing and staying awake at work and during periods of inactivity (e.g., when watching a movie or reading)(24). Cataplexy, as the hallmark of NT1, was not the independent predictors of HRQoL. The possible explanation was that cataplexy commonly triggered by emotions(25), thus, adult patients might control their emotions to avoid the occurrence of cataplexy, without affecting the perceived HRQoL much. Moreover, cataplexy may be relieved or disappear with advancing age due to lifestyle adjustments or natural history of narcolepsy(12, 26, 27).

Furthermore, our study used a nomogram-based method to predict low HRQoL of patients with NT1 rather than evaluating the relationship between symptoms and HRQoL, as had been done in other studies. The C-indices of the nomogram was 0.726 (95% CI, 0.686–0.766) and it showed an acceptable accuracy of prediction. The nomograms integrated the significantly independent variables associated with HRQoL and could provide us with quantitative risk of low HRQoL.

Our study provided a useful contribution to the impact of symptom severity on HRQoL in Chinese patients with NT1, it still had several limitations. Firstly, this study was conducted at single site in Beijing with a relatively small sample of participants from Peking University People's Hospital, larger samples and multicenter should be conducted to futher verify our results. Secondly, data collection was carried out by self-reported NSS and EQ-5D, which might not reflect more objective. Lastly, the nomogram uses information, which were based on symptom severity, thereby excluding its use with other variables.

Conclusion

For Chinese patients with NT1, the severity of symptoms could disrupt self-care and usual activities and increase pain/discomfort and anxiety/depression. EDS, DNS and treatment were the significant factors to predict the HRQoL. NSS score could be used for predicting HRQoL in patients with NT1, but with a modest precision.

Declarations

Conflicts of Interest

None of the authors has potential conflict of interests with respect the content of the manuscript.

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Author contributions

Chenyang Li, Xiaoling Wang, Wei Zhang and Yinghui Gao acquired data. Chenyang Li and Huijie Yi analyzed data. Chenyang Li completed draft manuscript. Fang Han, Shaomei Shang, Xiaosong Dong and Jun Zhang supervised the project and reviewed the manuscript. All authors read and approved the submitted manuscript.

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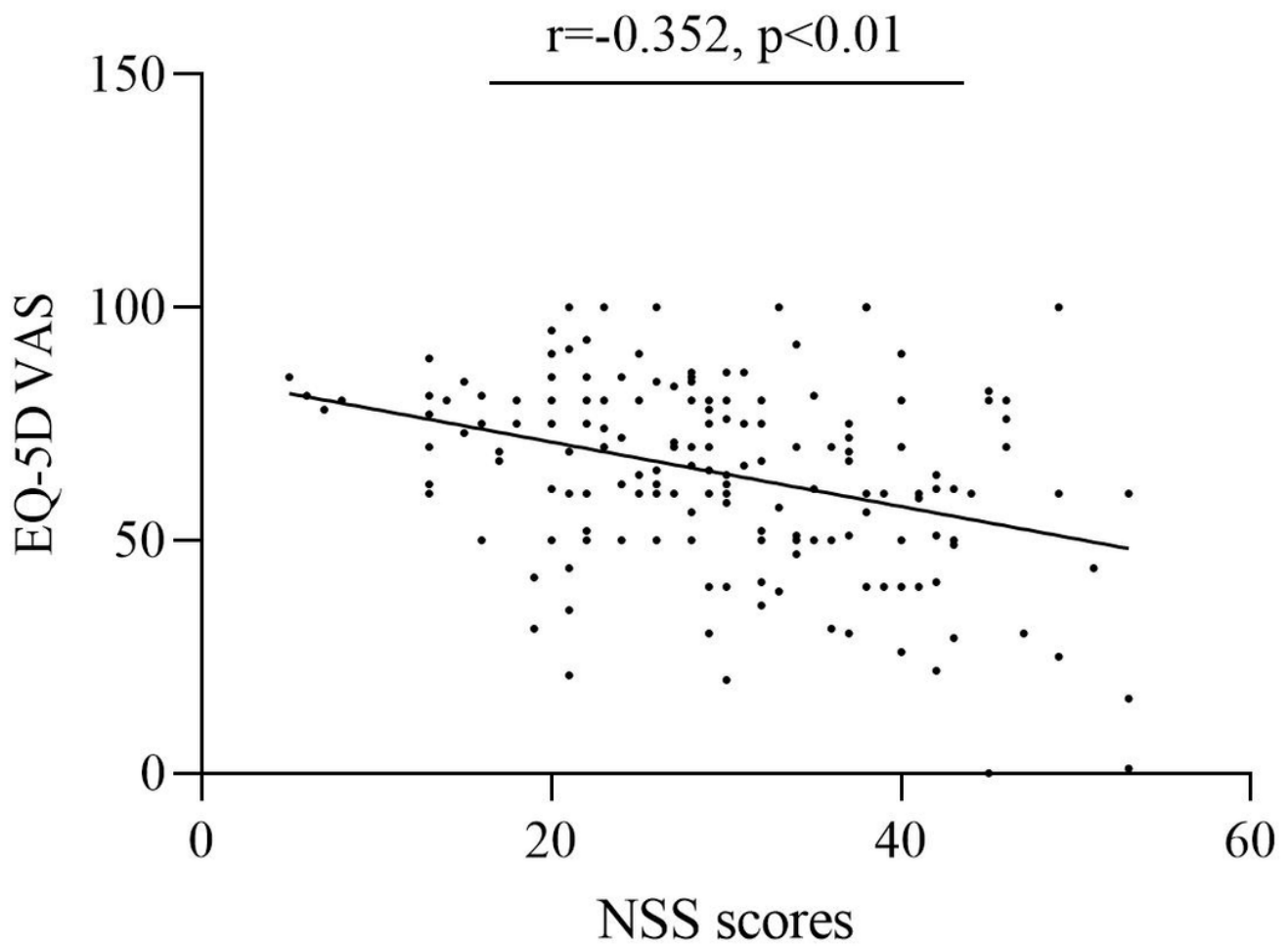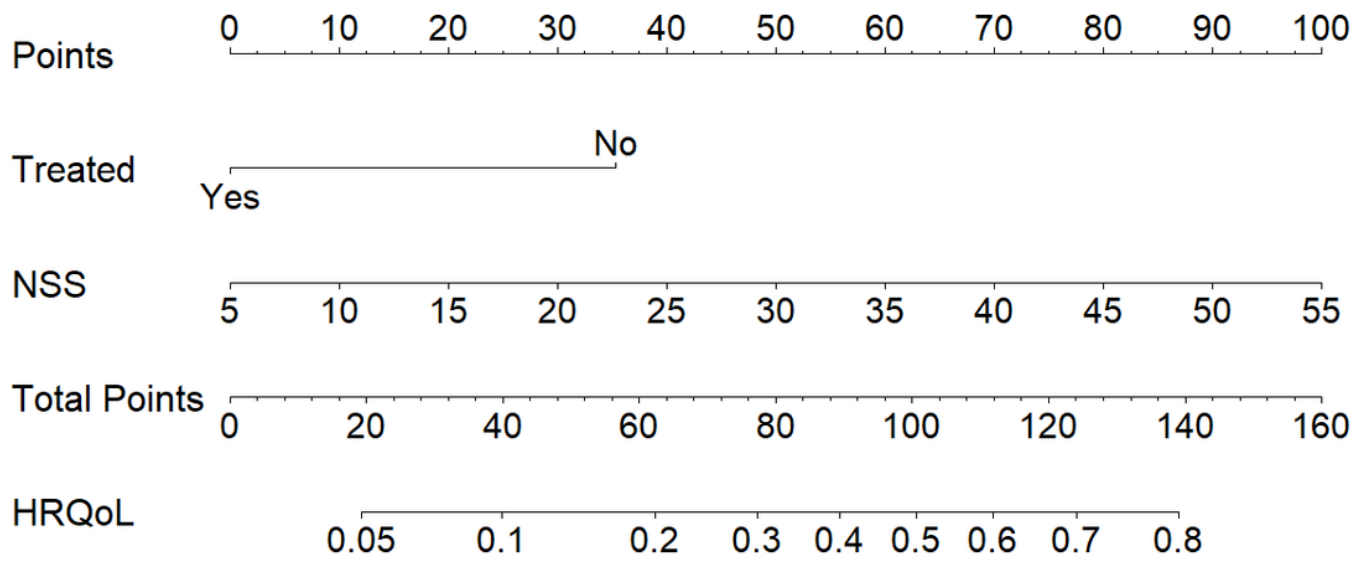
Figures

Figure 1

Scatterplot of EQ-5D VAS against NSS

Figure 2

The nomogram for predicting low HRQoL among narcoleptics.