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SCIENTIFIC INVESTIGATIONS

Resilience and its correlates in patients with narcolepsy type 1

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Study Objectives: This study aimed to explore resilience and its possible association with sociodemographic and clinical features in patients with narcolepsy type 1 (NT1).

Methods: This was a cross-sectional study involving patients with NT1 and age-/sex-matched controls (comparison group). Sociodemographic and clinical data were collected through semistructured interviews and validated questionnaires, including the Epworth Sleepiness Scale (ESS), State-Trait Anxiety Inventory (STAI)–State Anxiety, Beck Depression Inventory (BDI), 36-item Short Form Survey (SF-36), and the Resilience Scale (RS). Different statistical approaches were used to investigate the relationship between resilience and NT1 and associations with sociodemographic and clinical features.

Results: The participants comprised 137 patients (mean age, 38.0 years; 52.6% female) and 149 controls (39.6 years; 55.7% female). Compared with controls, patients had a significantly lower (122.6 vs 135.5) mean RS score and a 2-fold risk of having low/mild-range resilience (adjusted odds ratio = 1.99, 95% confidence interval 1.13–3.52). Patients with high resilience had sociodemographic and narcolepsy characteristics similar to patients with low resilience, but they reported anxiety and depressive symptomatology less frequently (4.2% vs 55.8% and 58.3%, respectively), and their SF-36 scores were comparable to those of the comparison group. In patients, RS score was strongly associated with STAI-State Anxiety and BDI (rho = −0.57 and −0.56, respectively) and weakly with ESS (rho = −20) scores.

Conclusions: The results of this study suggest that resilience may play a key role in patients' adaptation to NT1. Furthermore, this study supports interventions aimed at increasing patients' resilience and provides a base for further studies, preferably longitudinal and including objective measures, directed toward understanding the relationship between resilience, depression, and quality of life in patients with narcolepsy.

Keywords: narcolepsy, cataplexy, sleepiness, anxiety, depression, quality of life, adaptation, resilience

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BRIEF SUMMARY

Current Knowledge/Study Rationale: Narcolepsy type 1 is a central disorder of hypersomnolence that may strongly affect patients' quality of life despite effective symptomatic treatment. It has been hypothesized that psychological factors could play a key role in patients' adaptation to the disorder, but research on this subject is scarce.

Study Impact: The results of this study support the hypothesis that resilience may play a key role in patients' adaptation to the disease, supporting early interventions aiming to foster resilience in patients with narcolepsy type 1. The results may stimulate future research, preferably with a longitudinal design and including objective measures, aimed at clarifying the relationship between resilience, depression, and quality of life in patients with narcolepsy and other chronic disorders.

INTRODUCTION

Narcolepsy is a rare central disorder of hypersomnolence that is currently divided into 2 categories—narcolepsy type 1 (NT1) and narcolepsy type 2—both of which are associated with excessive daytime sleepiness (EDS), sleep paralysis, hypnagogic hallucinations, and disrupted nocturnal sleep.[1] Cataplexy (ie, a sudden loss of muscular tone in response to strong emotions) is pathognomonic for NT1, which is associated with low cerebrospinal orexin A levels. Orexins are neuropeptides involved in the regulation of a wide range of complex behaviors, including sleep/wakefulness, emotion, and feeding and metabolism.[2]

Narcolepsy onset typically occurs during childhood or young adulthood, but the disease is largely under- or misdiagnosed and may remain undiagnosed for several years, exacerbating the disease burden.[3–7] Endocrine and metabolic comorbidity, especially precocious puberty and obesity, are frequent in NT1.[7–9]

Narcolepsy is associated with a higher risk of developing anxiety and depression or depressive symptoms.[10,11] Due to the role of the orexinergic system in stress response,[12–14] and the anxiolytic and antidepressant activity of orexins demonstrated in murine models,[15,16] it was suggested that the high psychiatric comorbidity in patients with NT1 could be due to the orexin deficiency. However, the similar prevalence of depressive symptoms found in patients with NT1 and narcolepsy type 2 indicates that this orexin deficiency alone cannot be the cause.[11] On the other hand, the high frequency of psychiatric disturbances might reflect the psychosocial burden of narcolepsy.[10,17] The disease is indeed associated with a substantial quality of life (QoL), social, and work impairment,[3,18–21] and with social stigma.[22–24]

NT1 treatment is still symptomatic, and the most widely used drugs are stimulants, wake-promoting agents, sodium oxybate, and anti-cataplexy drugs, often in association. Pharmacologic treatment, together with planned daytime naps, is effective in improving symptoms, but evidence of an effect on QoL is scarce,[25] and considerable interindividual variation is reported.[20,26,27] Indeed, some studies indicated that EDS and cataplexy are not the only factors that contribute to a reduced QoL in patients with NT1,[28,29] suggesting that the existence of personal factors that influence the patient's adaptation to the disorder might buffer the adverse effects related to this condition.[3,20,29–31] Since NT1 affects mental well-being more than physical well-being,[21] the role of psychological factors such as resilience is worth exploring, with the goal of identifying potentially modifiable targets for intervention in order to improve disease adaptation. Resilience refers to the ability of individuals to effectively adapt to acute stress, adversity, or trauma, without losing their psychological well-being and physiological equilibrium.[32] While the involvement of the orexinergic system in stress resilience is being increasingly explored,[13–15,33,34] studies investigating resilience in patients with NT1 are scarce. The objective of our study was to fill the knowledge gap by (1) describing the resilience profile of patients with NT1 in contrast to people without narcolepsy and (2) assessing correlations between resilience and sociodemographic variables, NT1 symptoms, anxiety, depression, and QoL in patients with NT1.

METHODS

Study design

This as a cross-sectional study with a comparison group.

Setting and participants

The "Psychosocial Impact of Narcolepsy" study involved patients with a definite diagnosis of NT1 according to the *International Classification of Sleep Disorders*[1] and persons without sleep complaints (comparison group or controls). To be eligible, participants had to be adults who were able to understand the study purposes and read written Italian.

Patients were recruited from the Narcolepsy Center of Bologna. The center is located in the Emilia Romagna Region but takes patients that, for the most part (71%), come from other Italian regions.[35] Controls were recruited from among people (specifically, parents, children, partners, or friends) from all over the country accompanying patients with narcolepsy or other neurological disorders (eg, headache, neuromuscular disorders) at the tertiary neurological outpatient clinic of the IRCCS Institute of Neurological Sciences of Bologna (ISNB). The study was performed between February 2017 and July 2019.

Protocol approval and informed consent

The study was approved by the local ethics committee (Comitato Etico Interaziendale Bologna-Imola; protocol number 16181). All participants provided written informed consent; confidentiality was guaranteed.

Data collection

All participants underwent a semistructured interview to investigate the following: (1) sociodemographic features (including sex, age, education, sentimental status, and working status), (2) age at onset of symptoms and age at diagnosis (only patients), and (3) height and weight (in order to calculate body mass index [BMI]).[3]

Questionnaires

Patients were asked to complete a self-administrated questionnaire regarding NT1 symptoms (ie, cataplexy, disrupted nocturnal sleep, hypnagogic hallucinations, and sleep paralysis), whereas both patients and controls were asked to complete in the following validated questionnaires:

- Epworth Sleepiness Scale (ESS) for the assessment of sleepiness (a score ≥ 11 indicates EDS).
- 36-Item Short Form Survey (SF-36) questionnaire to assess health-related QoL. The SF-36 consists of 36 questions that can be divided into 8 scales. Each of the 8 summed scores is linearly transformed on a scale from 0 (negative health) to 100 (positive health) to provide a score for each subscale, and 2 summary measures can thus be calculated: a physical (Physical Component Summary [PCS]) and a mental component (Mental Component Summary [MCS]).
- State-Trait Anxiety Inventory (STAI) State–Anxiety scale to assess the respondents' feelings of anxiety "at this point in time"; the total score ranges from 20 to 80 (scores < 40 indicated no anxiety, 40–50 mild anxiety, 51–60 moderate anxiety, and > 61 severe anxiety).
- Beck Depression Inventory (BDI) to assess depressive symptoms (total score > 13 suggests presence of clinically relevant depressive symptomatology).
- 24-Item Italian version of the Resilience Scale (RS) for the assessment of the degree of individual resilience,[36] considered as a positive personality characteristic that enhances individual adaptation[37] (total scores of ≥ 147 indicate high resilience, scores from 121 to 146 mid-range resilience, and scores < 121 low resilience).[36]

Statistical analysis

Descriptive statistics are presented as absolute (N) and relative frequencies (%) for categorical variables and as means with standard deviations for continuous variables. Normality distributions were checked using the Shapiro-Wilk test.

Differences between patients and controls in terms of sociodemographic and clinical characteristics were evaluated with a *t* test or Mann-Whitney *U* test for continuous variables and with a chi-square test for categorical variables.

A multivariable logistic regression model was performed to evaluate the association between level of resilience (low/mid-range vs high, dependent variable) and group (patients vs controls), and sex and age (independent variables). The results are presented as odds ratio (ORs) and 95% confidence intervals (95% CIs).

Finally, a 1-way analysis of variance (ANOVA) or Kruskal-Wallis test was performed to assess differences in sociodemographic and clinical characteristics of patients with NT1

according to their level of resilience (low, mid-range, and high categories), while Spearman's rho correlation was used to evaluate the correlation between continuous scale of resilience (RS) and EDS (ESS), anxiety and depressive symptomatology (STAI State-Anxiety and BDI), and QoL (PCS and MCS).

A P value ≤ 0.05 was considered significant. Statistical analysis was performed with Stata SE 14.2 (StataCorp, College Station, TX).

RESULTS

One hundred and thirty-seven patients with NT1 who completed the RS were matched for age and sex with 149 controls. Sociodemographic and clinical characteristics of patients and controls are reported in **Table 1**, while **Table 2** summarizes the characteristics of patients related to narcolepsy (age at onset, age at diagnosis, symptoms, etc.).

Sociodemographic characteristics

There were no significant differences in age or sex between the group of patients with NT1 and the comparison group: the mean age was 38.0 and 39.6 years, respectively, and 52.6% and 55.7% of participants were female, respectively. Educational level, sentimental status, and work activity all significantly differed, with patients more frequently having a low level of education (25.6% of patients had completed, at most, elementary or middle school vs 13.4% of controls) and less frequently having a partner (50.4% vs 80.5%) or a work/study activity (73.7% vs 84.6%).

Table 1—Sociodemographic and clinical characteristics: comparisons between patients and controls.

	Patients with NT1 (n = 137)	Controls (n = 149)	*P*
Female, n (%)	72 (52.6)	83 (55.7)	.593
Age, mean (SD), y	38.0 (15.6)	39.6 (14.0)	.159
Education, n (%)			< .001
Elementary/middle	35 (25.6)	20 (13.4)	
High school	80 (58.4)	75 (50.3)	
More than high school	22 (16.0)	54 (36.3)	
Had a partner, yes, n (%)	62 (50.4)	120 (80.5)	< .001
Student or employed, yes, n (%)	101 (73.7)	126 (84.6)	.024
BMI class, n (%)			< .001
Normal	45 (32.9)	99 (66.9)	
Overweight	40 (29.2)	33 (22.3)	
Obesity	32 (23.4)	16 (10.8)	
ESS, mean (SD)	12.3 (4.9)	5.5 (3.4)	< .001
ESS ≥ 11, n (%)	74 (60.7)	10 (7.3)	< .001
STAI-State Anxiety, mean (SD)	39.5 (11.4)	35.6 (10.6)	.002
STAI-State Anxiety, n (%)			.001
No anxiety	19 (13.9)	42 (28.4)	
Mild	58 (42.3)	53 (35.8)	
Moderate	16 (11.7)	28 (18.9)	
Severe	44 (32.1)	25 (16.9)	
BDI, mean (SD)	11.4 (10.3)	6.1 (6.7)	< .001
BDI > 13, n (%)	45 (32.9)	18 (12.4)	< .001
Quality of life, mean (SD)			
SF-36 PCS	48.7 (9.0)	53.4 (7.3)	< .001
SF-36 MCS	40.7 (12.0)	47.4 (9.2)	< .001
Resilience, mean (SD)	122.6 (25.7)	135.5 (17.6)	< .001
Resilience level, n (%)			< .001
Low	52 (38.0)	28 (18.8)	
Mid-range	61 (44.5)	76 (51.0)	
High	24 (17.5)	45 (30.2)	

BDI = Beck Depression Inventory, BMI = body mass index, ESS = Epworth Sleepiness Scale, MCS = mental component score, NT1 = narcolepsy type 1, PCS = physical component score, SD = standard deviation, SF-36 = 36-item Short Form Survey, STAI = State-Trait Anxiety Inventory.

Table 2—Patients' narcolepsy-related characteristics.

	Values
Age at onset, mean (SD), y	20.1 (12.5)
Age at diagnosis, mean (SD), y	28.3 (13.5)
Symptoms/last month, n (%)	
Cataplexy	87 (63.5)
Disrupted nocturnal sleep	86 (62.8)
Hypnagogic hallucinations	51 (37.2)
Sleep paralysis	44 (32.1)
Pharmacological treatment, n (%)	
Stimulants	76 (55.5)
Sodium oxybate	86 (62.8)
Anti-cataplexy*	32 (23.4)
Other	6 (4.4)
None	12 (8.8)

n = 137. *The anticataplectic drug was venlafaxine in 25/32 cases and clomipramine or duloxetine chlorhydrate in the remaining 7/32 cases. SD = standard deviation.

Clinical characteristics

According to BMI, patients were significantly less frequently of normal weight (32.9% vs 66.9%) and more frequently obese than controls (23.4% vs 10.8%). Patients showed higher levels of EDS (mean ESS 12.3 vs 5.5 and ESS score ≥ 11 in 60.7% of patients vs 7.3% of controls) and anxiety (mean STAI-State Anxiety score of 39.5 vs 35.6), and reported experiencing no anxiety less frequently (13.9% vs 28.4%) and severe anxiety more frequently (32.1% vs 16.9%) than controls. The patient group also presented depressive symptomatology more frequently in terms of both mean BDI (11.4 vs 6.1) and rate of patients with a BDI score >13 (32.9% vs 12.4%) and lower SF-36 PCS (48.7 vs 53.4) and MCS (40.7 vs 47.4) mean scores.

Resilience

With regard to resilience, the mean RS score was significantly lower in patients with NT1 than in controls (122.6 vs 135.5), and patients had a low level of resilience more often (38.0% vs 18.8%) and a high level of resilience less frequently (17.5% vs 30.2%) compared with controls (**Table 1**). There were no significant associations between levels of resilience and sociodemographic characteristics, except for age, which was positively associated with resilience (data not shown). Therefore, only sex and age were included in the multivariable analysis. This model (**Table 3**) showed that patients with NT1 (vs the comparison group) had a 2-fold risk of having low or mid-range resilience (vs the high category) with an adjusted OR of 1.99 (95% CI 1.13–3.52). An inverse correlation trend was found between age and resilience (adjusted OR = 0.98, 95% CI 0.96–1.00; $P = .057$); no association was found between sex and resilience ($P = .621$).

Table 3—Multivariable logistic model with resilience (low/midrange vs high) as the dependent variable.

Independent Variables	OR	95% CI	*P*
Narcolepsy type 1			.017
No	Reference	—	
Yes	1.99	1.13–3.52	
Sex			.621
Female	Reference	—	
Male	1.15	0.65–2.00	
Age	0.98	0.96–1.00	.057

CI = confidence interval, OR = odds ratio.

Factors associated with resilience and resilience levels in patients with NT1

In patients with NT1, there were no significant associations between levels of resilience and age at onset, age at diagnosis, or diagnostic delay (data not shown).

The comparisons between patients according to their level of resilience (**Table 4**) showed that patients with low, midrange, and high resilience did not significantly differ with regard to sociodemographics, BMI, or NT1 symptoms. However, there was a trend ($P = .059$) concerning the mean ESS score, which was 13.1 in patients with low resilience, 12.1 in those with midrange resilience, and 10.0 in patients with high resilience.

On the other hand, from the group of patients with low resilience to that with high resilience there was a significant decrease in the rate of patients with severe anxiety (from 55.8% to 4.2%) and a BDI >13 (from 58.3% to 4.2%); mean STAI-State Anxiety and BDI scores decreased from 46.3 to 30.1 and from 18.3 to 4.1, respectively, while PCS and MCS increased (from 46.3 to 53.5 and from 34.1 to 48.5, respectively), with patients with high resilience showing scores that were comparable to those of the controls.

With regard to pharmacological treatment, there were no significant differences, even when comparing patients in terms of their use of different antidepressant drugs (data not shown).

Table 5 shows Spearman's correlations (always significant) between RS score and ESS, STAI-State Anxiety, BDI, PCS, and MCS scores in patients with NT1: PCS and MCS increased according to RS (rho = 0.31 and rho = 0.44, respectively), while increasing resilience was associated with a reduction in the ESS (rho = –0.21), STAI-State Anxiety (rho = –0.57), and BDI (rho = –0.56) scores.

DISCUSSION

This study explored resilience and its possible association with symptoms, anxiety, depression, and QoL in patients with NT1 through a comparison with a sex- and age-matched control group.

We found that, compared with controls, patients with NT1 had significantly lower resilience and a 2-fold risk of having low/mid-range resilience, while there was a trend suggesting

Table 4—Sociodemographic and clinical characteristics of patients with NT1 according to their resilience level.

	Low Resilience (n = 52)	Mid-range Resilience (n = 61)	High Resilience (n = 24)	*P*
Female, n (%)	28 (53.8)	31 (50.8)	13 (54.2)	.935
Age, mean (SD), y	37.0 (15.8)	38.6 (16.2)	38.6 (13.9)	.764
Education, n (%)				.104
Elementary/middle	11 (21.1)	13 (21.3)	5 (20.8)	
High school	37 (71.1)	29 (47.5)	14 (58.3)	
More than high school	4 (7.7)	19 (31.1)	5 (20.8)	
Had a partner, n (%)	20 (46.5)	27 (47.4)	15 (65.2)	.228
Student or employed, n (%)	33 (63.4)	49 (80.3)	19 (79.2)	.102
BMI class, n (%)				.702
Normal	17 (39.5)	22 (41.5)	6 (28.6)	
Overweight	14 (32.6)	16 (30.2)	10 (47.6)	
Obese	12 (27.9)	15 (28.3)	5 (23.8)	
ESS, mean (SD)	13.1 (5.5)	12.1 (3.9)	10.0 (5.7)	.059
ESS ≥ 11, n (%)	34 (65.4)	36 (59.0)	11 (45.8)	.273
Symptoms/last month, n (%)				.578
Cataplexy	34 (65.4)	40 (65.5)	13 (54.2)	
Disrupted nocturnal sleep	36 (70.6)	36 (61.0)	14 (58.3)	.467
Hypnagogic hallucinations	21 (41.2)	22 (37.3)	8 (33.3)	.798
Sleep paralysis	17 (34.0)	20 (35)	7 (29.2)	.873
STAI-State Anxiety, mean (SD)	46.3 (11.3)	37.4 (9.5)	30.1 (6.8)	< .001
STAI-State Anxiety, n (%)				< .001
No anxiety	1 (1.9)	9 (14.8)	9 (37.5)	
Mild	14 (26.9)	31 (50.8)	13 (54.2)	
Moderate	8 (15.4)	7 (11.5)	1 (4.2)	
Severe	29 (55.8)	14 (22.9)	1 (4.2)	
BDI, mean (SD)	18.3 (11.5)	8.8 (7.1)	4.1 (4.6)	< .001
BDI > 13, n (%)	28 (58.3)	16 (26.2)	1 (4.2)	< .001
Quality of life, mean (SD)				
PCS	46.3 (10.2)	48.9 (8.3)	53.5 (5.5)	.038
MCS	34.1 (11.7)	43.1 (10.6)	48.5 (8.2)	< .001
Pharmacological treatment for narcolepsy, n (%)				
Stimulants	25 (48.1)	36 (59.0)	15 (62.5)	.379
Sodium oxybate	32 (61.5)	40 (65.6)	14 (58.3)	.802
Anticataplexy	16 (30.8)	11 (18.0)	5 (20.8)	.266
Other	4 (7.7)	1 (1.6)	1 (4.2)	.292
None	6 (11.5)	3 (4.9)	3 (12.5)	.359

BDI = Beck Depression Inventory, BMI = body mass index, ESS = Epworth Sleepiness Scale, NT1 = narcolepsy type 1, MCS = mental component score, PCS = physical component score, SD = standard deviation, SF-36 = 36-item Short Form Survey, STAI = State-Trait Anxiety Inventory.

that age was a protective factor: as age increased, the RS score decreased. Patients with high resilience had sociodemographic and narcolepsy characteristics similar to those with low resilience, but they reported anxiety and depressive symptomatology almost never, and their QoL was comparable to that of controls. In patients, resilience was strongly associated with anxious and depressive symptomatology, and only weakly with sleepiness.

In this study, we used the RS, which is considered one of the best tools for investigating resilience in both adults and adolescents.[36] Several studies using the RS have reported that patients who have chronic diseases had a low or mid-range resilience level.[38] However, most studies did not have a comparison group and those with a comparison group did not find significant differences.[39,40] Focusing on neurological disorders, the mean RS score was found to be in the mid-range (136.8 ± 17.3) in

Table 5—Spearman correlations between resilience and sleepiness, anxiety, depressive symptoms, and quality of life in patients with NT1.

Continuous Variable	rho	*P*
ESS	−0.20	< .015
STAI-State Anxiety	−0.57	< .001
BDI	−0.56	< .001
SF-36 PCS	0.31	< .001
SF-36 MCS	0.44	< .001

BDI = Beck Depression Inventory, ESS = Epworth Sleepiness Scale, NT1 = narcolepsy type 1, MCS = mental component score, PCS = physical component score, SF-36 = 36-item Short Form Survey, STAI = State-Trait Anxiety Inventory.

patients with epilepsy[41] and low in patients with multiple sclerosis (113.4 ± 21.4) and neuromyelitis optica spectrum disorder (117.0 ± 29.0).[42] However, the only study investigating resilience in older patients with multiple sclerosis compared with healthy older adults did not find significant differences with regard to the RS score (148.4 vs 148.3).[43] Therefore, an association between neurologic disorders and lower RS scores cannot be confirmed, due to the scarcity of studies comparing patients with people without neurologic disorders.

On the other hand, preclinical findings suggest that orexins are involved in stress resilience.[15,16,33] It is therefore possible that the lack of orexin predisposes patients with NT1 to lower resilience, but the finding that 30% of patients had a high level of resilience indicates that other factors are involved.

Studies investigating resilience in neurologic disorders generally did not find associations between resilience and disease severity.[43] In our study, only a trend for reduced ESS scores in patients with higher resilience and a weak correlation between ESS and RS were observed. These results could suggest a relationship between sleepiness and resilience, especially when considering that patients with high resilience had a mean ESS score in the normal range. Further studies are needed to better address this issue, and in light of the positive correlation between resilience and sleep quality found in studies involving healthy participants.[44,45]

On the other hand, in our study, both anxious and depressive symptomatology were strongly correlated with resilience, and among patients with high resilience fewer than 5% had psychological problems. Interestingly, the high-resilience group of patients had sociodemographic and NT1 characteristics similar to patients with lower resilience, but their QoL was comparable to that of people without narcolepsy. The finding that patients with high resilience have an unimpaired QoL suggests that, as we hypothesized, resilience may play a key role in patients' adaptation to NT1, consistent with what happens in several neurodegenerative diseases.[46] From this perspective, the positive trend showing a protective role of age toward low resilience could contribute to explain the positive association between age and QoL in patients with narcolepsy found by several studies.[21] On the other hand, since almost all of the patients with high resilience also reported a lack of depressive symptomatology, it is possible that our results reflect the complex relationship between resilience, depression, and QoL. Finally, due to the cross-sectional nature of our study, it is not possible to exclude the possibility that lower RS scores are consequent to the development of anxiety or depression.

In any case, the results of our study may have several implications. First, our findings support pilot trials to test interventions that foster resilience in patients with NT1 in order to help them better adapt to the disorder. It is commonly recognized that psychological interventions have positive effects on individual resilience,[38,47] and interventions promoting resilience in other neurological conditions have been successfully tested.[48–50] Since psychological resilience can aid in the successful adjustment to illness, targeting resilience early on may help patients deal with all of the different facets of the disease and live a better life.[46] Second, these results suggest that the measures of resilience like the RS could help identify patients with low and mid-range resilience who, in light of the strong association between resilience and anxiety and depressive symptoms, should be routinely screened and monitored for anxiety and depression. Finally, the empirical evidence provided by our study may stimulate new hypotheses regarding the role of orexin in terms of both resilience and depression.

A limitation of this study may be the small number of patients enrolled. Nevertheless, NT1 is a rare condition, and our study was one of the few involving a population of patients with a diagnosis of NT1 according to the more recent internationally accepted criteria. Another critical point could be the strategy used to recruit participants included in the comparison group. On one hand, the recruitment of family members and people within the support network who are close to patients with neurologic disorders may explain the high levels of anxiety and depressive symptoms found in the control group. On the other hand, since a genetic predisposition to narcolepsy[2,17] may be shared within family cohorts, the presence of relatives in the comparison group may have made some differences between patients and controls smaller or undetectable. Unfortunately, we did not record information regarding the existence of family relations between patients and controls. Therefore, we could not calculate the proportion of relatives of patients with NT1 in the comparison group. However, sociodemographic and clinical features differed between patients and controls in a manner that was consistent with previous studies and the mean RS score of the comparison group mirrored that of the Italian general population, suggesting that the recruitment strategy had little or no influence on the main study results.

Finally, longitudinal studies are required to clarify the relationship between resilience, depression, and QoL in patients with narcolepsy; future investigations should consider collecting more objective (ie, biological) measures from blood or cardiovascular metrics that could support the subjective (self-reported) inventory correlations, since studies on resilience and depression have demonstrated that there are many potential neural and nonneural factors involved in both humans and animal models.[51,52]

The strengths of this study include the comprehensive description of participants, including both clinical and sociodemographic features, and the use of several validated scales to

explore different domains. Furthermore, our study examines a psychological phenomenon that has not yet been explored in narcolepsy, laying the groundwork for future research into modifiable factors associated with disease adaptation.

CONCLUSIONS

The results of this study support the hypothesis that narcolepsy symptoms are not the only determinants of the QoL impairment experienced by people with NT1 and that resilience may have a key role in patients' adaptation to the disease. In line with patients' request for a more holistic approach to their care,[53] the study supports the testing of early interventions in order to increase patients' resilience and help them to better adapt to the disorder. Our results also encourage further studies, preferably with a longitudinal design and including objective measures, aimed at clarifying the relationship between resilience, depression, and QoL in patients with narcolepsy and other chronic disorders.

ABBREVIATIONS

BDI, Beck Depression Inventory
BMI, body mass index
CI, confidence interval
ESS, Epworth Sleepiness Scale
MCS, mental component score
NT1, narcolepsy type 1
OR, odds ratio
PCS, physical component score
QoL, quality of life
RS, resilience scale
SF-36, 36-item Short Form Survey
STAI, State-Trait Anxiety Inventory

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DISCLOSURE STATEMENT

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