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**Academic and professional paths of narcoleptic patients:
the NARCOWORK study**

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Highlights

- Narcolepsy has no major negative impact on educational and professional outcomes.
- However, this achievement requires more efforts and reorientations.
- Patients report less satisfaction about work/school and an impaired quality of life.
- Patients should be supported regarding disease consequences on education and work.

Abstract

Objective/background: To study educational and professional pathways of narcoleptic patients and examine demographic, disease-related and environmental factors associated with a better academic and professional prognosis.

Patients/Methods: Sixty-nine narcoleptic patients (51 narcolepsy type 1 and 18 narcolepsy type 2, age 42.5+/-18.2 years) were enrolled in this pilot monocentric cross-sectional study with a comparison group (80 age- and sex-matched controls) between October 2017 and July 2018 in Lyon Center for Sleep Medicine. They completed questionnaires about their academic and professional trajectories and specific scales of quality of life (EuroQol quality of life scale EQ-5D-3L), depression (beck depression inventory, BDI), sleepiness (Epworth Sleepiness Scale, ESS) and narcoleptic symptoms severity (narcolepsy severity scale, NSS).

Results: No difference in grade repetition or final obtained diploma was observed between patients and controls, but patients evaluated their academic curricula as more difficult (45.5% vs 16.9%, $p=0.0007$), complained for more attentional deficits (75% vs 22.1%, $p<0.0001$), and had needed more educational reorientation (28.6% vs 9.9%, $p=0.01$). Even if no difference was observed in occupational category and professional status, patients expressed significantly less satisfaction about their work. Patients had more signs of depression (OR severe depression=4.4(1.6-12.6), $p=0.02$) and their quality of life was significantly decreased (67.3+/-18.4 vs 80.6+/-13.2, $p=0.0007$) as compared to controls. Multivariate analysis showed that a more favorable professional career was associated with a better quality of life.

Conclusions: Educational and professional pathways do not seem to be significantly impaired in narcoleptic patients, but their experience and quality of life are affected. These findings may allow to reinsure patients and should lead to a more comprehensive management of the disease.

Key Words: Education, narcolepsy, school, quality of life, work.

Clinical trial registration: Narcowork, <https://clinicaltrials.gov/ct2/show/NCT03173378>, N° NCT03173378.

Abbreviations:

Narcolepsy type 1: NT1; Narcolepsy type 2: NT2; ESS: Epworth Sleepiness Scale; BDI: Beck Depression Inventory; NSS: Narcolepsy Severity Scale; ERQ: Emotion Regulation Questionnaire; EQ5D-3L: EuroQol quality of life scale; ADHD: attention-deficit/hyperactivity disorder; IQ: intellectual coefficient; SOREM: Sleep Onset Rapid Eye Movement sleep period.

1. Introduction

Narcolepsy is a chronic, disabling neurological sleep disorder, characterized by excessive daytime sleepiness and symptoms related to REM sleep dysregulation: sleep paralysis, hypnagogic or hypnopompic hallucinations and, in some patients (narcolepsy type 1), sudden attacks of muscle tone weakness often triggered by emotions (cataplexies) [1,2]. The prevalence of narcolepsy reaches 1 per 2000 [2]. The disease usually begins in childhood or in young adulthood but delay in diagnosis is frequent [1,2]. Many comorbidities are associated with narcolepsy, such as depression, anxiety, attention-deficit/hyperactivity disorder (ADHD) and obesity [3]. Narcolepsy symptoms are disabling in everyday life and remain often misunderstood by both the family and the professional environment of patients. Few studies have investigated so far the impact of narcolepsy on patients' academic cursus and socio-professional careers. While several works have focused on the cognitive and psychosocial status of narcoleptic children, the specific question of educational course has been only marginally addressed, reporting academic difficulties while global IQ of the patients is normal [4-6]. Regarding professional trajectories, data are conflicting. Access to employment would be more difficult according to German and Danish studies, especially for patients with narcolepsy type 1 in a Japanese study, while employment rates in narcoleptic patients would be similar to those observed in control subjects or in the general population in North American and Italian studies [7-12]. Such discrepancies may result from methodology heterogeneity regarding patients, controls and outcomes. Some studies mention a possible impact of the disease on qualitative factors associated with work (ie, absenteeism, advancement) [10,13,14]. The presence of comorbidities may play a crucial role, particularly regarding depression and ADHD, obesity, as well as age at narcolepsy onset and diagnosis [3,5,11,15]. Overall, the disease and environment-related factors responsible for a poor integration remain insufficiently known. A better understanding of these factors could help in

providing more accurate and documented information to patients and in guiding them in their career choices.

The main objective of the Narcowork study was to compare occupational status in narcoleptic patients and age- and sex-matched non-narcoleptic subjects. Secondary objectives were to compare socio-professional categories, academic trajectories, qualification levels, states of health, quality of life, several work characteristics (eg, employment status, work satisfaction, etc.) between cases and controls. Finally, an analysis of the factors associated with a better educational and professional prognosis among narcoleptic patients was conducted, as well as a qualitative description of coping strategies developed by narcoleptic patients at work, and of how their disease is perceived and accepted in the work world.

2. Methods

Narcowork is a cross-sectional study with a comparison group performed between October 2017 and July 2018 at the Competence Center for Orphan Diseases, Narcolepsy and Rare Hypersomnia, Center for sleep Medicine and Respiratory Diseases, Croix-Rousse Hospital, Lyon, France.

2.1. Patients

One hundred and forty-six patients over the age of 18, usually followed-up at the Lyon Sleep Medicine Center and diagnosed with narcolepsy, were solicited by regular mail for the study. Narcolepsy type 1 (NT1) was defined according to the International Classification of Sleep Disorders 3 (ICSD3) by a clinic in favor of narcolepsy (excessive daytime time sleepiness over three months) associated with either cataplexy and a positive multiple sleep latency test (sleep latency \leq 8 minutes and $>$ 1 SOREM) or low orexin-A cerebrospinal fluid levels $<$ 110pg/L [16]. Narcolepsy type 2 (NT2) diagnosis was determined by a clinic in favor of narcolepsy (excessive daytime time sleepiness over three months), no cataplexy, a positive

multiple sleep latency test (sleep latency \leq 8 minutes and $>$ 1 SOREM), orexin-A cerebrospinal fluid level normal (or assay not performed) and no other cause for symptoms.

The control group consisted in one or two age- and sex-matched (\pm 5 years, age over 18) relatives of the patients (mainly friends or cousins) without narcolepsy.

Exclusion criteria were: uncertain diagnosis, poor knowledge of the French language, secondary narcolepsy, and cognitive impairment inconsistent with questionnaire completion or refusal to participate.

2.2. Data collection

Information notes about the study and self-administered questionnaires (case and control versions) were sent to the patients by regular mail. Patients were asked (1) to complete the “patient” questionnaires and (2) to look for one or two controls according to the inclusion criteria and to give them the information note and the “control” questionnaires. Patients were proposed either to fill the survey at home and send it back to the Sleep Center by regular mail, or to complete the study during their next medical visit at the Sleep Medicine Center. Controls were asked to send their own questionnaires back after completion by regular mail. Questionnaires included the Beck Depression Inventory (BDI) [17], the Epworth sleepiness scale (ESS) [18], the Emotion Regulation Questionnaire (ERQ) [19], the narcolepsy severity scale (NSS)[20], the EuroQol quality of life scale (EQ5D-3L) [21] previously used in several studies in the field [7,12,22], a socio-demographic and medical questionnaire (sex, age, marital status, medical past, treatments, tobacco and alcohol consumption), an educational questionnaire specifically designed for the study with an education specialist (SM) (including questions about last obtained degree, grade repetition, educational reorientation, encountered difficulties, provided help and adaptive measures) and a professional questionnaire specifically designed for the study with an occupational medicine specialist (BC). This last questionnaire was based on Siegrist questionnaire [23,24] and the French SUMER questionnaire (Medical Monitoring of Occupational Risk Exposure: SURveillance Médicale des Expositions aux Risques professionnels) and included questions about occupational status and professional category, job characteristics (eg, work location, working

hours schedule), journeys, link between work and handicap (work adaptation, reclassification in another job, loss of job, work accident, absenteeism, disability, official recognition as a disabled worker) and job satisfaction. Job satisfaction was evaluated upon the balance between efforts and rewards; it ranged from 7 (high effort, low reward) to 35 (low effort, high reward).

2.3. Outcomes

The primary outcome was the comparison of occupational status distribution (eg, active, unemployed [loss of job, housewife/househusband, invalidity], retired, student) between narcoleptic patients and matched controls. Secondary outcomes included comparison between cases and controls of (1) socio-professional categories, (2) academic trajectory and qualification levels, (3) health state, (4) employment trajectory, work characteristic, satisfaction about work and handicap status (5) quality of life and (6) depression.

The professional prognosis was assessed by a composite score including six different variables: (1) degree level (pre-high school graduation, high school graduation, post-high school graduation), (2) unemployment periods cumulative duration (>1 year, ≤ 1 year, none), (3) number of changes in job related to the disease or to dismissal (>2, 1-2, 0), actual employment status (long term employment (permanent contract / public servant / contractual agents / independent contractor), (4) unpaid activity and/or fixed-term work (student / fixed term contract / interim work / trainee / apprentice) and without activities (unemployed / housewife or househusband / in retirement / on invalidity leave), (5) frequency of delays at work (>1/ month / ≤1/month / never) and (6) number of sick leave days (>5days / ≤5 days / none) during the last year. The score ranged between 0 (worse prognosis) and 6 (best prognosis).

Finally, a description of how working narcoleptic patients adapt to their job and of how their disease is perceived and accepted in the work world was provided.

2.4. Statistical analysis

Descriptive statistics were presented as n (%) for categorical variables and as mean +/- sd, median, Q1, Q3 for continuous variables. Comparison between respondent and non-respondent narcoleptic patients were performed with Chi-squared test or Fisher's exact test for ≥ 2 modality nominal variables and with Wilcoxon test for quantitative variables. Comparisons between cases and controls were performed with MacNemar matched test for 2 modalities nominal variables, Stuart-Maxwell matched test for >2 modalities nominal variables and with Wilcoxon matched test for quantitative variables. Analyses of variables according to the type of narcolepsy or according to age at onset/diagnosis for the narcoleptics were made using the chi-squared test. Determining factors of narcoleptic patients' professional insertion were studied with a conditional logistic regression. A multiple stage analysis plan was conducted: first, a univariate matched analysis was performed, which allowed to identify better professional insertion determinant among patients with the following factors: narcolepsy type (NT1 vs NT2), sleepiness (Epworth scale: ≤ 10 or > 10), emotion regulation (ERQ), depression (BDI with four modalities: score <3 ; score 4-7, score 8-15 and score ≥ 16), life quality (EQ5D), number of narcolepsy drugs, weight and age at onset and diagnostic (< 18 ; ≥ 18 years). Afterwards, a multivariate matched analysis was performed, which allowed to identify one entry determinant in the model of 10% and a descending variables selection.

A p value ≤ 0.05 was considered as statistically significant. Analyses were performed with SAS software (version 9.4).

2.5. Ethical and regulatory issues

The study was approved by the Nord-Ouest III ethical committee (protocol N° 2017-A01335-48). All participants provided informed consent. Data collection and storage was approved by the protection and freedom of information committee of the Hospice Civils de Lyon. The study was registered on Clinical Trials website (N° NCT03173378).

3. Results

3.1. Description of the population

The questionnaires were sent to 146 narcoleptic patients regularly followed-up at the Lyon Sleep Medicine Centre (ie, who had had a visit at least once during the year preceding the study). Among them, 69 patients (51 NT1 and 18 NT2) completed and returned the questionnaires and were included in the study. No significant difference was found between patients of the active list who did (N=69) and did not (N=77) participate in the study regarding NT1/NT2 ratio (73.9 vs 75%, ns), sex ratio (women/men = 1.03 % vs 0.9%, ns), age (mean \pm sd: 42.5 years \pm 18.2 vs 42.5 years \pm 15.6, ns), age at diagnosis (mean \pm sd: 28.5 \pm 13.5 vs 30.1 years \pm 12.3; median 24 vs 26, ns), proportion of patient who had been diagnosed in childhood (10.4% vs 8.3%, ns) and treatment (number of wake-promoting and anticataleptic molecules, and dosage of each molecule).

3.1.1. Socio-demographic and clinical characteristics

Socio-demographic and clinical characteristics of the participants are presented in **Table 1**. Within the narcoleptic patients' group, NT1 patients were significantly more overweight or obese than controls (63.8% versus 30 %, $p=0.009$) and a strong trend was seen for NT2 patients (55.6% versus 25%, $p=0.054$), with no difference between NT1 and NT2. With respect to controls, narcoleptic patients were less often married or in couple (41.2% versus 65.8%) than single or divorced/widowed ($p=0.01$), but no difference was observed between NT1 and NT2 patients.

Wake-promoting substances consumption (tea, coffee, energizing drinks) and alcohol consumption did not differ between patients and controls, but tobacco consumption tended to be significantly higher in patients ($p=0.07$). This trend was significant for NT1 patients (41.1% of active smokers in patient group vs 15.8% in controls, $p=0.009$), but not for NT2. Medical history and treatments did not differ between patients and controls, nor between NT1 and

NT2, regarding autoimmune, psychiatric, and cardiovascular disease, as well as sleep apnea syndrome, cancer, diabetes, and bariatric surgery.

3.1.2. Characteristics of narcolepsy

Characteristics of the narcolepsy are presented in Table 2. Onset of the narcolepsy occurred during childhood in 33 patients, among which 15 were diagnosed before adulthood. Mean diagnosis delay was 7.6 years. Patients who had presented the disease earlier were significantly younger at the time of the study (median age: 32 years for a disease onset before 18 years, 45 years for a disease onset between 18 and 25 years, and 58 years for a disease onset after 25 years, $p=0.0012$).

No differences were found between NT1 and NT2 patients regarding age at disease onset and age at diagnosis. NT1 patients were more sleepy (ESS>10 in 91.8% NT1 vs 72.2% NT2 patients, $p=0.04$), with more frequent sleep attacks (more than 1/day in 86.4% NT1 vs 42.9% NT2 patients, $p=0.01$). Hallucinations were also more frequent in NT1 patients (experienced by 66.7% NT1 versus 29.4% NT2 patients, $p=0.007$), whereas NT1 and NT2 patients did not differ significantly for other clinical symptoms (sleep paralysis, sleep inertia, insomnia), nor for the number and type of wake-promoting treatments.

3.2. Academic outcomes

Distribution of graduation levels did not statistically differ between patients and controls (**Table 3**), whatever narcolepsy type, age at the onset of the disease (<18 years, 18-25 years, >25 years) and age at diagnosis. No significant differences for school absenteeism or delays, school year repetition or studies interruption were found between patients and controls whatever narcolepsy type, or age at disease onset. An educational reorientation had been necessary for 28.6% of patients versus 9.9% of controls ($p=0.01$). This difference was significant for NT1 (34.0% versus 9.8% $p=0.0035$) but nor for NT2. Reorientation was associated with age at onset disease as 53.3% patients with disease onset before 18 had undergone reorientation versus none of those whose disease had begun after 18 ($p<0.0001$).

Despite a low objective impact of narcolepsy on graduation, difficulties encountered during school course were reported by 45.5% of patients versus 16.9% of controls ($p=0.0007$). A higher level of difficulties was also reported by NT1 but not by NT2 patients, and was particularly mentioned when the disease had started during childhood (71.9% versus 35.7% for disease onset between age of 18 et 25 years and 6,3% for disease onset after 25 years ($p>0.0001$)) and when diagnosis had occurred before 18 (71.4% versus 38.1% for diagnosis adulthood ($p=0.026$)). Seventy five percent of patients reported concentration or attention troubles during their school course versus 22.1% of controls ($p<0.0001$). A higher rate of complains regarding attention impairment was also found both in NT1 (74% NT1 versus 25.93% ($p<0.0001$)) and NT2 (77.78% NT2 versus 10% ($p<0.0001$)) groups.

Among the 33 patients whose disease began during childhood, only 4 NT1 patients (12.12%) had obtained an official recognition of their handicap in their youth but 21.2% had obtained assistance during their studies (individual adaptation, special needs educational institutions or language assistance), and 42.4 % specific adaptations (extra-time for exams and tests, possibility to take naps during school time, etc.). More than half (57.6%) had informed school staff or classmates. Among patients who had been diagnosed before 18 years old, 33.3% had received assistance during their studies, 60 % had obtained adaptations and 86.7% had informed school staff or classmate.

3.3. Professional outcomes

Occupational status of patients and controls are presented in **Figure 1** (detailed results in **Table 1 suppl data**). Despite a trend toward a higher rate of unemployment (loss of job, housewife/househusband, invalidity) in patient group, no significant difference in the distribution of occupational status was found between patients and controls nor for NT1 and NT2 selectively or between NT1 and NT2. No differences were found in socio-professional categories between controls and patients (and no differences in the socio-professional categories of the parents or spouse between patients and controls).

Characteristics of professional background and actual job are detailed in **Table 4**. Frequency of job changes, mean duration of current or previous position, and proportion of participants who had experienced at least one period of unemployment (as well as the number and duration of unemployment periods) did not differ between patients and controls. No significant difference was found between patients and controls regarding work facilities and schedules. The rate of work accident and absenteeism did not significantly differ between patients and controls.

Control participants expressed significantly more satisfaction about their work than the patients did (satisfaction score: 16 +/- 5.3 for patients versus 13.1 +/- 3.9 for controls ($p=0.03$). More specifically, tendency toward a lower satisfaction was found in patients for promotion perspectives (29.6% patients agreed versus 39.0% , $p=0.07$) and for gaining satisfactory support in difficult situations (52.7% patients agreed versus 74.6% , $p=0.08$).

In addition, 48.2% of patients had informed the occupational health physician about their disease, 38.9% some colleagues (and 28.6% the majority of their colleagues), 38.2% their direct line manager and 37.5% their employer. Moreover, 56.6% of patients felt accepted/understood at work, whereas 15.1% thought they were considered as lazy and 13.2% felt misunderstood. The most disabling symptoms at work were sleepiness ($n=45$), cataplexies ($n=12$) and sleep inertia ($n=11$). Some patients spontaneously mentioned attention disorders. In order to cover up their symptoms, 55.8% of patients pretended that they were hyperactive, 46.2% avoided meetings, 36.5% hide themselves to take naps, 11.5% avoided exams/ contest and 5.8% promotion.

Official recognition as a “disabled worker” had been obtained by 33.9% patients, versus 4.8% controls. Fifty-nine-point seven percent patients had not requested it. There was no correlation between having obtained this official recognition and work satisfaction nor with quality of life after adjustment for age, sex and narcolepsy type. Invalidity status category 1 (possibility to work part-time) or 2 (no possibility to work, receipt of a disability pension) had been granted to 7.8% and 9.4% of patients respectively versus 1.4% and 1.4% of controls

($p=0.4$). During their career, 15% of patients had benefited from adaptation of their workstation versus 3% of controls. These adaptations mainly involved work schedules.

3.4. Educational and professional prognosis determinants

3.4.1. Potential prognosis determinants (**Table 1**)

According to BDI, narcoleptic patients were more likely to have moderate to severe (39.4%) rather than none or mild symptoms of depression than controls (20.3%, $p=0.02$). As expected, daytime sleepiness assessed by the EES (ie, $>10/24$) was abnormal in 86.6% of patients versus 21.1% of controls ($p<0.0001$) (91.8% of NT1 patients vs 24.1% of controls, $p<0.0001$ and 72.2% of NT2 patients vs 15.8% of controls, $p=0.0005$). The ERQ did not show any significant difference regarding cognitive re-evaluation and expression suppression between the patients and the controls even after adjustment for sex and narcolepsy type. Among patients with cataplexy, 49.9% reported keeping their feelings to themselves, 41.3% tried not to express any positive emotions they felt, 41.3% controlled their emotions by not expressing them and 30.4% tried not to express any negative emotions they felt in order to avoid cataplexy (N=46).

Quality of life assessed by EQ-VAS score was significantly lower for patients (67.3 (+/- 18.4) vs 80.6 (+/-13.2, $p=0.0007$). When compared to their own controls, this difference was also significant for NT1, but not for NT2 patients, and was not associated with gender. The EQ5D score also tended to be lower in patients than in controls. Notably, 43.3% of patients versus 5.2% of controls ($p=0.0004$) reported problems in accomplishing daily activities; 10.5% versus 1.3% ($p=0.04$) reported problems in walking and 59.1% versus 42.9% ($p=0.04$) felt moderately/extremely anxious or depressed. When the analysis was restricted to working-age patients (18-65 years), only difference for daily activities remained significant ($p=0.0014$).

3.4.2. Composite prognosis score

According to the composite score, which considered graduation level, cumulative duration of unemployment periods, number of changes of employment related to the disease or to dismissal, actual employment status, frequency of delays at work and number of sick leave days during last year, narcoleptic patients exhibited a significantly poorer professional prognosis than the controls. This difference was also significant for NT1 ($p=0.02$) but not for NT2 patients. Notably, a high heterogeneity was found within patients (**Figure 2**).

A better professional prognosis was significantly associated with narcolepsy type 2 vs type 1 ($p=0.028$), lower excessive daytime sleepiness ($p=0.0069$), lower depressive feelings ($p=0.035$), higher quality of life EQ VAS ($p=0.004$) and EQ5D-3L ($p=0.002$), and absence of overweight ($p=0.004$). A trend was observed for expression suppression ($p=0.06$) and age at disease onset (better prognosis when narcolepsy had begun before vs after the age of 18 (3.85 vs 3.37, ($p=0.09$))). Sex, age at diagnosis, presence of a narcolepsy treatment/number of wake-promoting drugs and cognitive reappraisal did not have a significant impact on prognosis ($p=0.73$, $p=0.45$, $p=0.24$, and $p=0.5$ respectively). After multivariate analysis, only quality of life remained significantly independently associated with professional prognosis.

4. Discussion

The Narcowork study allowed an exhaustive exploration of the educational and professional pathways of patients suffering from narcolepsy. Although several works have already investigated professional issues in narcoleptic patients, our study is the first to provide detailed information about both education and job characteristics, as well as factors influencing professional prognosis and subjective experience reported by patients. We confirm the results of previous studies in demonstrating the absence of any difference in professional careers of patients as compared to controls [10,12] and in highlighting the higher prevalence of depression [3,5,25-27] and the lower quality of life in patients [9,11,12,14,22,28]. Furthermore, we report that narcoleptic patients do not achieve lower

graduation level but require more frequent re-orientations, that school course is perceived as more difficult for patients than for controls, and that satisfaction toward work is lower. Finally, we emphasize that professional prognosis is strongly associated with quality of life in patients.

Patient population of the NarcoWork study exhibited clinical and demographic characteristics in line with those previously described in studies in the same field, especially regarding age at disease onset, diagnosis delay, body mass index, civil status and the proportion of NT1 (vs NT2) patients among our narcoleptic population [2,8,26,29,30]. The high level of depressive symptoms in narcoleptic patients as evaluated by the BDI in our study corroborates the results of several other studies which specifically investigated this issue, whatever the methodology applied or the population studied in adults (extraction from a database [25-27] or clinical interview [3]) and children (questionnaires 27-CDI [5]).

Regarding education, we did not find any difference between narcoleptic patients and controls in graduation and repeating school year, despite the fact that half of our population had a disease onset in childhood. Several studies have reported that narcolepsy had no impact on the education levels with even a tendency towards attaining a higher level than general population [10,12]. Ingravallo et al., observed that precocity of the disease was associated with a better educational level; this observation may result from a bias linked to the fact that better-educated patients might have easier access to an early diagnosis [12]. Other works have reported a worsening in academic achievement [28], more educational failures and a lower attendance at secondary school and university among patients than for healthy controls [4,3,32]. Contrary to our results which did not show that patients stopped their studies more frequently, Dodel and al., reported that 13% patients had not obtained any qualification because of their disease [22]. This contradiction might be explained by the high level of re-orientation (as opposed to cessation of studies) among our patients. The objectively satisfactory outcome contrasted with the subjective perception of a more difficult

course. Cognitive attentional disorders were reported by a high number of patients as being particularly disabling. A high prevalence in ADHD comorbidity has been reported in narcoleptic patients [27,28], in a form that is more difficult to treat than in the general population and may increase the risk of having to repeat a school year [15]. Other barriers to academic achievement might be worse results, conflicts with teachers, or feeling of being considered as lazy [31,32].

No significant difference between patients and controls was found regarding work status. Neither were found any socio-professional differences between patients and controls at the time of the study. These findings corroborate data reported by Broughton et al., in 180 Canadians, Japanese and Czechs narcoleptics with or without cataplexy (compared to matched controls) and from Ingravallo et al., in 100 Italian NT1 patients (compared to general Italian population statistics) who found 14% of unemployed + housewife/husband patients, which is very close to our results (15% of unemployment in our patients population) [10,12]. They differ, however, from three other studies: using records from the Danish National Patient Registry, Jennun et al., reported that 50% of 816 Danish narcoleptics with or without cataplexy (versus 64% of matched controls) were employed [8]. Dodel et al., also found higher rates of unemployment in 75 narcoleptic patients with or without cataplexy (59 % vs versus 9% of the general German population) with 42.7% of patients claiming that narcolepsy was responsible for their professional situation [7]. Ozaki et al., also reported lower employment rates in 83 NT1 patients versus patients suffering from NT2 or idiopathic hypersomnia [9]. These discrepancies might result from methodological issues (control group, data collection), patients' phenotype (NT1 vs NT2, severity of the disease), and cultural specificities regarding employment assistance measures. Studies about this topic does not generally address the issue of unemployment on a longitudinal cumulative basis whereas this approach would have allowed for a better estimation of the impact of the illness on unemployment during patient's career. In our population, cumulated periods of unemployment tended to be longer among patients, notably NT1, than among controls, but

this difference was not significant. A longer time spent in unemployment situation could be explained by the needed time for adaptation or reconversion at the onset of the disease, as suggested by Ingravallo et al., who reported changes in work in 31% of the patients because of their narcolepsy [12]. In addition, Ozaki et al., reported that 36.1% of NT1 and 25% of NT2 narcoleptic patients had been transferred or dismissed because of their symptoms and Jennun et al., showed that the level of employment decreased after the diagnosis for narcolepsy [8,9].

Regarding more qualitative aspects related to work, most patients did not benefit from adaptation of their position such as time and place for napping or flexible breaks and schedules. We did not observe any significant increase in delays at work or absenteeism among narcoleptic patients, which disagrees with Flores et al.'s findings [33]. Ingravallo et al., also reported at least one day absence from work in the year linked to the disease in 42% patients whereas it was the case for only 26.3% patients of the Narcowork study (with no significant difference with the controls) [12]. This discrepancy could be linked to a difference in the disease severity between the two populations, to the fact that our population also included type 1 and type 2 narcoleptic patients or to a possible difference between the Italian and French health systems regarding accessibility of medical consultations outside working hours.

A strong result of our study is that, despite the absence of notable difference in the professional characteristics between patients and controls, patients expressed less satisfaction at work especially concerning promotion prospects. As well, we observed that among patients, job changes tended to be less often linked to career progression, promotion, transfer than to dismissal or disease-associated disability. In Dodel et al., study, 40% patients thought that their career had been adversely affected by their disease [7]. Excessive daytime sleepiness, concentration and memory problems were the more frequent symptoms mentioned by patients when discussing their professional difficulties, which has already been reported in other studies [10,26,28].

Very few patients had applied for an official recognition as a disabled worker although it was almost always granted when requested. This status is delivered by the departmental office for disabled persons in France; it may allow easier access to employment and adaptation of the workstation following recommendations of the occupational health physician. The little recourse to this aid measure might reflect a low level of knowledge of the existing support systems, potentially due to a lack of information, a denial of the disease, a willingness to handle without assistance or a fear of being stigmatized. Accordingly, despite a high level of notifications of the disease to the occupational doctor, few patients benefited from specific position adaptations, which might result from a poor knowledge of narcolepsy, which is a rare disease, among occupational health physicians. More than half of our patients felt understood by their entourage which ties in with the results from the Broughton et al., and Ozaki et al., studies [9,10].

We found a decreased quality of life in narcoleptic patients, in line with previous studies [12,27,29,34]. Areas that were the most affected by narcolepsy were day-to-day activities, as previously noted by Dodel et al, [22]. Many determinants of a better quality of life in narcolepsy have been pointed out: NT2 vs NT1 [9], a lower level of depression [11,12,28,29], a longer disease duration [11,12,28], level of sleepiness [13,34], academic achievement [28], job situation [22], and to the fact of living in couple [22]. Indeed, private social and familial life may strongly influence quality of life, even if few studies have assessed this specific aspect. Our patients were less often married than controls, as previously reported by other teams [8,12]. Literature often points out that narcoleptic patients experience difficulties in social relationships, whether in childhood or adulthood [12,14,28,32]. Recently, Szakács et al., reported parental-child dysfunctional interaction in children and adolescent narcolepsy, which argue for familial consequences of the disease [35]. Contrary to work and education which seem to be little impacted in terms of performance, leisure may be particularly affected, more so than in other chronic neurological illnesses such as epilepsy [31]. Thus, it may be hypothesized that many narcoleptic patients

chose to sacrifice leisure and free-time for education and career. The reasons for this choice may involve different psychosocial dimensions including the fact that professional achievement is a mean of social valorization, that work has a defensive function in chronic diseases related to the need for patients to behave “normally”, or that normative expectation in the workplace may lead patients to overinvest their professional life in order to mask the disease [36].

Even if no significant difference in work and education between patients and controls were found for primary outcomes, more nuanced results are to be report according to the composite prognosis score. This score was specifically designed for the study, in order to compile and quantify various aspects of educational and professional prognosis and to look for prognostic factors. It highlighted a significantly worse global educational and professional prognosis in narcoleptic patients. This result is consistent with the possibility of a qualitative impact of the disease on patients’ work [10,13,14]. Different factors were associated with a worse prognosis: NT1 (vs NT2), higher level of sleepiness, overweight, depression, and quality of life. Only this latter prognosis factor remained significantly associated after multivariate analysis. The impact of these factors on education and work has previously been reported, may it be the link between depression and daytime sleepiness [5], the association between depression and learning difficulties among patients [5], or the association between unemployment and depression in the general population [37-39]. Quality of life on 7 of the 8 dimensions of SF36 quality of life questionnaire has also been associated with professional status among narcoleptic patients [22]. This association may be direct or indirect via depression, which has been shown to be associated with quality of life [11,28]. A mutual link between depression and BMI was also reported which may account for the link between BMI and professional prognosis, as well as the fact that obesity is a factor of disease severity associated with a greater orexinergic deficiency in NT1 patients [40,41]. Narcolepsy type 1 was associated with a worse prognosis than narcolepsy type 2, potentially reflecting the fact that NT1 symptoms are generally more severe: this was the case in our patients, especially

for excessive daytime sleepiness which particularly impacts academic and professional skills [29]. NSS score, however, was not a significant determining factor. The high level of attention disorders among NT1 might also be involved [15,42,43]. The fact that almost all of our patients were treated prevented us from seeing a potential treatment-related effect, whereas treatment is believed to alleviate disease burden [44,45]. We observed a trend toward a link between a good professional prognosis and the ability for expression suppression, which may allow patients to control better the occurrence of cataplexy and thus to manage more easily emotional situations at work. Finally, a better prognosis tended to be observed in patients with an early onset of the disease, which had already been noted by Ingravallo et al., who found a higher academic level achievement, a less frequently unemployment and fewer changes of job in patients whose narcolepsy had begun early [12]. This link might be explained by a more sensible choice in education and career path, better suited to the disease, and by the development of patients' ability to cope with narcolepsy symptoms.

We acknowledge for the following limits of our study. This pilot study was monocentric, which may limit extrapolation of the results to the whole population of narcoleptic patients due to potential cultural and social differences between regions or countries. Our population was of limited size, as about half of our patients did not participate to the study and fewer controls than expected were recruited, which might reflect psychosocial isolation and distress in patients suffering from narcolepsy, associated with reluctance to speak about their disease [46]. We have no strong argument however toward a difference between patients who did or did not participate in the study, as mean age, sex ratio, NT1/ NT2 ratio, age at diagnosis and treatment were not different in these two populations. The choice of controls in patients' relatives (aimed to homogenize socio-professional categories, which allowed us to state that there was no socio-professional difference at birth between patients and controls, and to facilitate the recruitment of controls) may have introduced a bias as the education of some controls might have been impacted by the fact of living or having lived close to a narcoleptic

person. We cannot rule out that some controls may have suffer from other sleep disorders (sleep apnea syndrome, insomnia, etc.) but they reflect general population as regard to potential sleep disorders except for narcolepsy. No neuropsychological assessment of Intelligence Quotient (IQ) was performed, while intelligence abilities are a strong determinant of educational and professional success [47]. Several teams found normal full scale IQ in children and adult suffering from narcolepsy; however, discrepancies between performance and verbal abilities, and impairment of specific cognitive functions such as executive control of attention or working memory have been reported and may account for the difficulties experienced by patients during their academic path [48-53]. Finally, according to numerous criteria, NT2 population seemed to differ from NT1 narcolepsy population and to be closer to the controls (tobacco, civil status, BMI, job situation, educational difficulties, depression, quality of life, etc.), which is in line with several studies [9,15,30]. It would be therefore relevant to make a distinction between NT1 and NT2 in future studies in order not to underestimate the impact of the disease.

Conclusion

As a conclusion, despite more difficult educational and professional trajectories, or at least perceived as such, academic levels and employability do not significantly differ between patients and controls. It seems important, therefore, to reassure patients on their academic and professional prospects. Success in academic and professional life however requires more effort in patients, sometimes to the detriment of their personal life. Cognitive attentional disorders appear as a particularly disabling symptoms, requiring deeper investigations and specific support. Improving disease acceptance, exploring and treating depression, providing information about existing social aids could help narcoleptic patients to face up to their educational and professional difficulties. Cognitive behavioral therapy developed for narcolepsy represent an important adjunctive treatment regarding these aspects as they aim to provide not only educational (behavioral and cognitive) but also psychosocial support [54].

This pilot study will be followed by the multicentric NarcoScol-NarcoVitae study, which will target a wider population of patients suffering from narcolepsy type 1, recruited among all the National Reference and Competence Center for Narcolepsy in France.

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Legends of the figures

Table 1. Sociodemographic and clinical characteristics of the participants

Note that the number of patients and control does not reach 69 and 80 for every item as some questions remained unfilled by the participants.

Table 2. Characteristics of the narcolepsy

Note that the sum of percentages of patients taking each wake promoting drugs exceeds 100 because several patients were taking more than one molecule.

Table 3. Graduation obtained by the participants

Level of graduation (N(%)). Levels from I to VI are defined by the French National Office for Information on Teachings and Professions.

Table 4. Characteristics of professional background and actual job (as some data were missing, or some questions did not concern all patients, number of participants who responded the question is indicated as N=...)

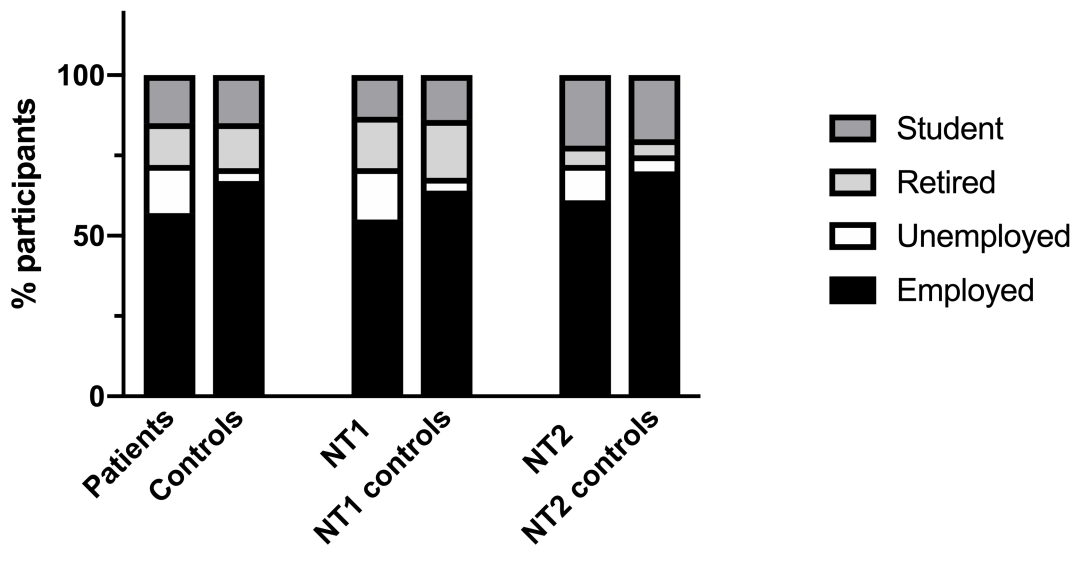
Figure 1. Occupational status of the participants

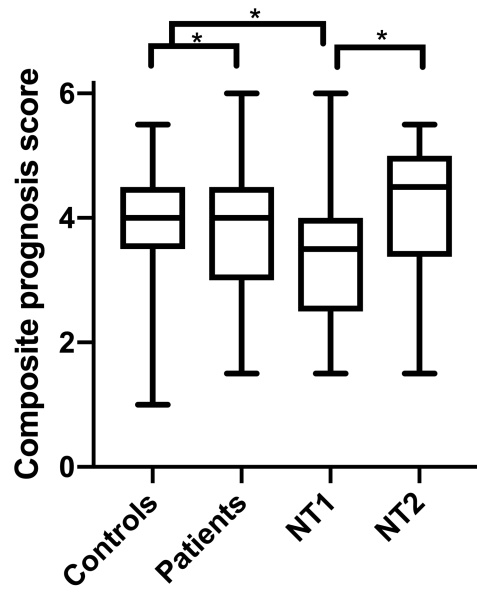
Proportion of patients and controls in the following 4 categories: employed, unemployed (loss of job, housewife/husband, invalidity), retired, student. No significative difference was observed in occupational status distribution between patients and controls.

Figure 2. Academic and professional prognosis composite score

The composite prognosis score was significantly lower in patients than in controls (3.67 (+/- 1.1), versus 3.99 (+/-1.01), $p=0.03$), and lower in NT1 than in NT2 (3.5 (+/- 1.04), vs 4.1(+/- 1.28), $p=0.02$).

Supplementary data Table. Professional status and socio-professional categories of the participants (N(%)).





Variable	Patients (n=69)	Control (n=80)	p
Men (N,%)	34 (49.3)	31 (38.8)	ns
Age (mean (+/-sd))	42.5 (+/- 18,2)	41.9 (+/- 16,1)	ns
BMI (N,%) > 25 kg/m² > 30 kg/m²	44 (63.8) 15 (21.7)	24 (30,0) 6 (7.5)	p=0.0006
Marital Status (N,%) Single Married/free union Divorced/widowed	31 (45.6) 28 (41.2) 9 (13.2)	21 (26.6) 52 (65.8) 6 (7.6)	p=0.01
Tobacco consumption (N,%) non-smoker ex-smoker smoker	33 (47.8) 13 (18.8) 23 (33.3)	53 (66.3) 13 (16,2) 14 (17,5)	p=0.07
Depression (BDI) (N,%) no mild moderate to severe	24 (36.4) 16 (24.2) 26 (39.4)	42 (56.7) 17 (23.0) 15 (20.3)	p=0.02
Abnormal Sleepiness (ESS > 10) (N,%)	58 (86.6)	16 (21.1)	p<0.0001
Emotional Regulation Questionnaire (mean (+/-sd)) cognitive reappraisal expressive suppression	26.2 (+/-7.4) 16.1 (+/- 5.9)	26.9 (+/- 7.2) 16 (+/- 5.3)	ns ns
Quality of Life (mean (+/-sd), median (Q1-Q3)) EQ VAS EQ5D index	67.3 (+/- 18.4), 70 (55-80) 0.69 (+/- 0.43), 0.8(0.64-0.91)	80.6 (+/-13.2), 81.5 (70-90) 0.86 (+/-0.28), 0.91 (0.89-1)	p=0.0007 p=0.056

Variable	Patients (n=69)
Age at onset (mean(+/-sd), median (Q1-Q3))	20.9 years (+/- 12.1), 17 (12-25.5)
Age at diagnosis (mean(+/-sd), median (Q1-Q3))	28.5 years (+/- 13.5), 24 (19-40)
Symptoms - Excessive daytime sleepiness - Disrupted nighttime sleep - Sleep inertia - Past or present cataplexy - Hallucinations - Sleep paralysis	86.8% 85.3% 75% 73.9% 57.3% 50%
Everyday napping	70%
Narcolepsy Severity Scale (mean(+/-sd),	31.1 (+/- 9.5) (NT1)
Treatments <ul style="list-style-type: none"> • Wake-promoting drugs (1 drug, 2 drugs, 3 or more drugs) Modafinil Methylphenidate Pitolisant Dexamphetamine • Anti-cataplectic drugs Antidepressant drugs Sodium Oxybate 	91.3% (75.4%, 11.6%, 4.3%) 67% 29% 19% 0.01% 54% 38% 17%

	Patients (N=69)	Type 1 Narcolepsy (N=51)	Type 2 Narcolepsy (N=18)	Control (N=79)	p
VI middle school level	11 (15,9)	9 (17,7)	2 (11,1)	6 (7,6)	ns
V certificate of professional competence	8 (11,6)	6 (11,8)	2 (11,1)	12 (15,2)	
IV High school graduation	16 (23,2)	13 (25,5)	3 (16,8)	20 (25,3)	
III Advanced Technician Certificate	8 (11,6)	7 (13,7)	1 (5,5)	9 (11,4)	
II Licence or M1 degree	9 (13,0)	8 (15,6)	1 (5,5)	13 (16,5)	
I M2 or doctorate	16 (23,2)	7 (13,7)	9 (50)	19 (24,0)	
Other diplomas	1 (1,5)	1 (2)	0 (0)	0 (0)	

Variable	Patients (n=69)	Control (n=80)	p
Changes in job None 1-4 >4	31.7% (N=63) 42.9% (N=63) 25.4% (N=63)	37.8% (N=74) 44.6% (N=74) 17.6% (N=74)	ns
Current position duration (years, mean +/- sd, median (Q1-Q3))	11.7 +/-14.4, 4.5(1-18) (N=46)	9.6+/-10.6, 6(1-16) (N=59)	ns
Unemployment At least one period (%) Number of period (mean +/- sd, median (Q1-Q3)) Unemployment duration (months: mean +/- sd, median (Q1-Q3))	50% (N=64) 2.5 +/-3.7, 1(1-2) (N=25) 19.8+/-22, 12(6-28) (N=28)	39.4% (N=71) 1.3 +/-1.5,1(1-1) (N=26) 11.3 +/-9.8, 6(5-12) (N=25)	ns
Night shifts per year (mean +/- sd)	16.2 +/- 21.4, 4(4-20) (N=5)	44.8+/-37.4, 45(12-60) (N=6)	ns
Autonomy in schedule organization Going back home for lunch Working at the employer's place Available area for napping at work	61.1% (N=54) 36.4% (N=55) 77.2% (N=57) 21.1%(N=57)	69.7% (N=66) 58.7% (N=63) 80% (N=65) 14.3% (N=63)	ns
Being late Absenteeism n of subjects during the past year duration (days: mean+/-sd, median (Q1-Q3))	37.9% (N=58) 38.5% (N=39) 48.7 +/- 77.4, 10(4-56) (N=15)	19.4% (N=67) 38.5% (N=40) 28 +/- 76.1, 5(2-14) (N=15)	ns
Work accident % of subjects n accident past 5 years (mean+/-sd, median, (Q1-Q3))	26.3% (N=57) 1.5+/-0.9, 1(1-1) (N=10)	20.6% (N=68) 1.2+/-0.4, 1(1-1) (N=11)	ns