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*Growing up with narcolepsy: Consequences for adolescents and young adults*

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**GROWING UP WITH NARCOLEPSY:  
CONSEQUENCES FOR ADOLESCENTS AND YOUNG ADULTS**

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## **GROWING UP WITH NARCOLEPSY: CONSEQUENCES FOR ADOLESCENTS AND YOUNG ADULTS**

### **Abstract**

#### **Background**

Narcolepsy, a disorder of excessive daytime sleepiness, often has its major onset in adolescence. The aim of the present study was to focus on the scope and psychosocial impact of narcolepsy symptoms in adolescence.

#### **Materials and Methods**

Semi-structured interviews with nine adolescents and young adults with narcolepsy provided detailed descriptions of the topic as perceived by the participants.

#### **Results**

Narcolepsy symptoms in adolescence varied, and often worsened at puberty onset. Sleep may be experienced as unrefreshing. The widespread and often severe psychosocial effects partially arose from a delay in diagnosis. Severe educational failure was a common consequence. Symptoms affected work and life goals. Increased social withdrawal and lower self esteem were often evident. Sleepiness was a problem both for public transport and driving, substantially affecting independent mobility.

#### **Conclusion**

Increased awareness of the disease and the provision of psychoeducational support, in conjunction with early diagnosis and medical treatment, are strongly warranted to prevent the most common educational and psychosocial problems including risk of depression.

**Keywords:** narcolepsy, adolescent development, psychosocial aspects, age of onset, disease management

## **Zusammenfassung**

### **Hintergrund**

Narkolepsie, eine Erkrankung mit exzessiv erhöhter Tagesschläfrigkeit, beginnt oft im Jugendalter. Ziel dieser Studie ist es, die Bandbreite und die psychosozialen Auswirkung von Narkolepsiesymptomen bei Jugendlichen aufzuzeigen.

### **Material und Methoden**

Halbstrukturierte Interviews mit neun Jugendlichen und jungen Erwachsenen mit Narkolepsie erlaubten eine detaillierte Beschreibung, wie das Thema von den Betroffenen erlebt wird.

### **Ergebnisse**

Narkolepsiesymptome bei Jugendlichen zeigten eine hohe Variabilität, und verschlimmerten sich häufig mit Beginn der Pubertät. Schlaf wurde meist als unerholsam beschrieben. Die häufig schweren psychosozialen Auswirkungen resultierten teilweise aufgrund verspäteter Diagnosestellung. Probleme in Schule und Ausbildung waren eine häufige Konsequenz, auch beeinflussten die Symptome das Erreichen von Lebenszielen. Oft wurde ein sozialer Rückzug und niedriges Selbstwertgefühl beschrieben. Die exzessive Schläfrigkeit erschwert sowohl das Nutzen öffentlicher Verkehrsmittel als auch das eigenständige Fahren und behindert daher eine unabhängige Mobilität.

### **Schlussfolgerung**

Ein höherer Bekanntheitsgrad der Erkrankung und psychosoziale Unterstützung, in Verbindung mit rechtzeitiger Diagnose und medikamentöser Behandlung sind dringend notwendig, um die häufig problematischen Folgen in Ausbildung und psychosozialem Befinden einschließlich erhöhten Risikos für Depressionen einzugrenzen.

**Schlüsselwörter:** Narkolepsie, jugendliche Entwicklung, psychosoziale Aspekte, Erkrankungsalter, Umgang mit der Erkrankung

## INTRODUCTION

Narcolepsy is a chronic condition characterized by the major symptoms of excessive daytime sleepiness (EDS) and cataplexy, a sudden loss of muscle tone upon emotional triggers. Cataplexy may be limited to facial and upper limb muscle groups, but may also lead to a total collapse. Narcolepsy is commonly diagnosed in adults, with a prevalence of about 30-50/100 000 [12]. However, symptoms, especially the core symptom EDS, often first appear in early adolescence or even in childhood. Main peak of onset is seen before age 20 [25, 29], usually at age 15 in retrospective studies [12, 13]. Approximately half of the adult patients report their first experience of symptoms during adolescence [36]. Adolescence is well recognized as a period in life where not only physical, but basic psychological and emotional changes occur, when formation of self concepts and life goals is a major topic [30].

In contrast to this, knowledge on narcolepsy in this age group is relatively rare, although there are increasing reports investigating childhood narcolepsy [8, 10, 15, 19-21, 23, 34, 36-38], with some including adolescents [17, 22, 28, 32].

Symptoms of the disease are often not recognized. It frequently takes several years to reach a diagnosis and receive proper treatment [12, 16, 25, 27]. It is widely known that clinical symptoms of this life-long disorder have a severe impact on the quality of life [5, 7, 11, 14, 18], but the consequences of narcolepsy symptoms during adolescence have so far not been comprehensively described. To expand the knowledge on this topic, a phenomenological approach was taken to both the self-reported symptomatology and psychosocial consequences for adolescents and young adults [35]. The aim was to present a detailed clinical picture of the scope of symptoms in order to facilitate recognition of the disease, and to develop a comprehensive understanding of the consequences of living with narcolepsy in order to facilitate symptom management.

## METHOD

## **Design**

Given the scarcity of studies on this topic, qualitative research methods were used to enable phenomenological insights into experiencing a situation without the constraint of restrictive hypotheses [35]. Qualitative approaches are often applied when entering research into new and complex phenomena. Qualitative work is based on the fact that individuals more openly and best describe their feelings and experiences in their own words. It is useful when only small samples can be studied. Another advantage is to direct attention to new details and stimulate further research instead of verification of already existing assumptions [3, 24, 26, 35].

Adolescents and young adults (15-29 years) diagnosed with narcolepsy were identified via the local Australian narcolepsy self-help group (NODSS) in Melbourne. Initial telephone contact was made to all potential participants (n=10), and, on their agreement this was followed by a plain language statement about the research. One subject became unavailable for interview.

## **Participants**

Nine adolescents and young adults (4 females, 5 males, 15 - 29 years, mean age 20.8  $\pm$  4.7) agreed to participate. Written informed consent was obtained both from the affected adolescents, as well as from a parent of those younger than age 18 (n=3). The two elder participants (age 27 and 29) had only recently started work. Six participants experienced narcolepsy with cataplexy. Narcolepsy without cataplexy (n=3) is to be expected more frequent in early age as cataplexy may not be present initially [1]. All had received prior medical diagnosis by a sleep specialist and met the ICSD-2 criteria [1] comprising daily EDS for at least 3 months, a definite history of cataplexy and/or MSLT with sleep latency  $\leq$  8 minutes and  $\geq$  2 SOREMS. Hypocretin levels were not available.

## **Procedure and data analysis**

Semi-structured interviews of about 90min were conducted alone with each adolescent in their home by one of the authors (RW). The interviews were tape recorded and transcribed soon afterwards by the interviewer. Data collection involved a mixture between directing the respondent to address certain themes (e.g. effects at school) and allowing them to talk spontaneously about issues that were important to them. The more directed interview questions were related to a series of themes that had been derived from previous qualitative work with adults with narcolepsy, completed by one of the authors (DB) [6, 9]. The data was re-iteratively analysed and grouped to identify common emerging issues and key themes. Themes were reviewed regarding basic psychological and social domains. The present report contains direct quotations from the interviews to provide a genuine description for health care givers (pseudonyms following each quotation indicate individual participants and their gender). The research was approved by the Victoria University Ethics Committee.

## **RESULTS**

Clinical characteristics of narcolepsy in adolescents, as reported in the present sample, are summarized in Table 1.

*insert Table 1 about here*

### **CLINICAL SYMPTOMS**

While EDS occurred several times every day, the frequency of all other symptoms described in the following ranged from occasionally to daily, with a high variability both between and within participants. Quite substantial waxing and waning of symptoms occurred over time, without apparent underlying factor for such variations.

#### **Sleepiness**

*"I was always a good sleeper" [G,m]*

All participants reported excessive sleepiness as most disabling symptom. They had been “good sleepers” since childhood. A clear onset of EDS was hard to define, except in one case where symptoms started after a head trauma.

Exacerbation of sleepiness was reported around age 12 in all female and in several male informants, with falling asleep in very unusual situations or urgent need to nap. Sleepiness was worst in passive situations, especially during transportation; when feeling stressed; in warm environment; and after food consumption. Awakening from sleep was mostly described as not at all refreshing; however there were a few exceptions.

### **Cataplexy**

*“I was out in a dance place, we changed partners .. then suddenly my knees buckled, I just all of a sudden almost fell on the floor. It was just terrible.” [A,m]*

*“People, when they laugh, they quite often start to fall forward, bounce around. I didn’t think it different. I really kept it to myself” [A,m]*

Onset of cataplexy, the sudden loss of muscle tone upon emotional triggers, was easier to define, mostly reported at age 10-12.

Strong emotions – laughter but also competitive situations in sports – trigger this pathognomonic symptom. In addition, sleep pressure or consumption of sweets increased the probability of cataplectic attack. Unless participants experienced very frequent or complete cataplectic attacks with dropping to the floor, these events were perceived as an exaggerated form of common laughing-related behaviour – and therefore not mentioned to other people (including doctors). One subject reported a spontaneous discontinuation of cataplexy.

### **Automatic behaviour**

*“I was talking to a woman, and I was just so tired .. suddenly a pause, that means to me I’ve obviously to say something, so whatever the dream, whatever was going on in*



*my mind, I just verbalized. And I said something like, 'I met my boyfriend at the supermarket'. And the woman went 'Excuse me?!' ” [A,m]*

Automatic behaviour was mentioned to happen frequently during social communication when in the waxing and waning of sleepiness informants started talking about unrelated issues. It also happened during schoolwork and while driving a car. Half of the participants mentioned attentional and memory deficits in relation to sleepiness.

### **Disrupted night sleep and irregular sleep-wake-patterns**

Disruptions of night sleep were present in half of the subjects. One informant described a sleep pattern of consecutively four hours awake / sleep, with a current shortening to a 3-hour-pattern. Another participant reported a highly unpredictable, variable need for sleep.

### **Sleep paralysis**

*“My brother calls it ‘sleep lock’ “ [A,m]*

*“You’re mentally awake. Your brain’s telling your body to move and you just can’t” [D,f]*

Sleep paralysis, a lack of muscle control upon awakening, was experienced infrequently by half of the participants, most likely at the end of a daytime nap. Not specific for narcolepsy, it was also reported by other family members.

### **Hypnagogic hallucinations, nightmares**

*“Being shot .. dinosaurs chasing me” [F,m]*

*“Some of these dreams can quite upset you emotionally, they are extremely real” [A,m]*

One third reported high incidences of REM sleep-related phenomena that intrude into waking consciousness. One participant remembered being threatened while waiting at a bus stop, but could not tell whether this episode had really happened or had been a hypnagogic hallucination. Such vivid experiences including nightmares of being chased or threatened, were described as strongly frightening:

*"I felt like someone was coming into my room, trying to stab me. I had nightmares all the time" [D,f]*

In one case the dream-like experiences would continue during wakefulness:

*"That section of my brain just wouldn't stop; shut your eyes, the film comes back" [A,m]*

## **Diagnosis**

*"Doctors first said it's only a puberty problem .. it was only when the neurologist who finally diagnosed asked if anything was funny about laughter that they realized the link between being sleepy and cataplexy" [C,f]*

The median age of symptom onset was 12 (range 9-16) years for those who could define a timepoint when symptomatology started (n=3) or significantly worsened (n=5). Strikingly, all female informants mentioned symptom worsening at age 12. Delay to an appropriate diagnosis of narcolepsy was up to 10 years, with a median of 4,5 (range 0,1-10) years. Teachers were sometimes the first to recommend medical advice, but participants were often suspected of having a mental/affective problem, being referred to a psychologist or psychiatrist. Consequently, participants had been misdiagnosed with epilepsy (n=2), schizophrenia (n=2), or puberty-related symptoms (n=2). Sudden onset of cataplexy facilitated diagnosis.

## **Treatment and Staying in Control**

Stimulant or REM-suppressing medication was taken as needed (n=6). Limited effectiveness of stimulants of a few hours were described. Side effects were especially mood changes (n=4), lack of appetite (n=2) or memory problems (n=1). Two participants without cataplexy consumed up to 15 cups of coffee per day.

*"I have to keep myself actually stimulated" [A,m]*

*"I sing to myself or shake me, move my face, slap myself around the face, really hurt"*

*[B,f]*

Reported preventive behavioural countermeasures for EDS included constant strong, mental or physical stimulation, and having a regular sleep pattern and naps.

*“If you squeeze a muscle somewhere else in your body, make yourself sort of rigid as you feel it coming, it washes over you” [B,f]*

To prevent cataplectic attacks, participants tried to stay controlled or even unemotional. They would use a body position where the least muscle groups were involved. In addition, exertion of single muscles was reported helpful to retain muscle control, and moving the eyes helped getting out of a cataplectic attack.

### **LIFE GOALS AND PSYCHOSOCIAL CONSEQUENCES**

Informants reported negative impacts of narcolepsy symptomatology on all major areas of their every-day life and well-being (Table 2).

*insert Table 2 about here*

#### **School, university**

*“I was really tired, couldn’t cope, couldn’t study late at night, couldn’t concentrate” [B,f]*

*“After an exam, I came up to the teacher and said ‘that question, we never ever had this in this whole course’ And he said, ‘Sorry, we did it once at some stage.’ Looking back, my page of that day was just scribbles” [A,m]*

All participants experiences consequences due to narcolepsy symptoms such as a severe dropping in grades leading to repeating a class (n=1), quitting school or university (n=4), being referred to a school for disabled children after not attending school for months (n=1), losing a job (n=2), not starting university (n=2), trying to get into external studies (n=1). Overwhelmingly, these events occurred before diagnosis.

*“I could have been a lot better if I didn’t have it” [C,f]*

In the course of trying to manage schoolwork, more struggle was needed and regular naps required, consuming the majority of spare time. Increasing demands at higher educational levels meant that coping was no longer possible.

*“Teachers threw things at me” [A,m]*

To stay in control, informing the teachers and supervisors was an inevitable step; otherwise teachers assumed late nights or laziness and reacted accordingly. Informed teachers can help by allowing naps, or granting longer time for exams.

### **Work choices**

*“No energy for a full-time job” [C,f]*

Independent of symptom level, narcolepsy had an effect on work choices. Monotonous work with sitting or reading worsened EDS. Participants sought parttime jobs, work that may be organized in a self-paced mode instead of 8-hours-work (e.g. computer programming), or work including physical activity (e.g. fitness trainer). The unpredictable symptom onset renders jobs with high responsibilities for others unsuitable.

*“Because I didn’t really interest myself in my work and kept falling asleep, I got fired.*

*They didn’t know I had narcolepsy” [B,f]*

Informants were even afraid of job interviews, trying to hide narcolepsy and associated limitations. However, if symptom level was moderate to severe, informing supervisors and colleagues appeared to be mandatory.

In order to stay awake, participants increased stimulant medication (up to 3-4 times the recommended daily dosage) or rely on a constant intake of caffeine. While scheduled naps were superior in fighting off EDS, they were less tolerated by colleagues or supervisors.

### **Transport**

*“Public transport, I was asleep, didn’t wake up till the stop at the end .. train is a killer, I drop off” [B,f]*

*“I made sure I don’t have a (driving) licence for instance ‘cause I self-diagnosed” [A,m]*

Being able to reach school, university or work was a substantial problem due to EDS. Public transport, often the only way to travel apart from being driven by family members, was a real difficulty for the young people suffering from narcolepsy. Not only would they often sleep through their destination, but falling asleep in public left them in a very vulnerable

situation. Many informants reported avoiding it whenever possible. Those eligible to drive either refrained from getting a licence, did not drive, or only went short distances with the help of stimulants or naps.

### **Social functioning**

*“I remember mum, she threw a glass of wine in my face to get me under control, she wouldn’t know why I was doing it” [B,f]*

Without diagnosis, the clinical appearance of tiredness or drowsiness was attributed to laziness or lack of willpower. Cataplexy triggered by emotions is highly likely to appear in social situations, and may be interpreted as misbehaviour. Symptoms were regarded as personality traits, leading to severe conflicts. People with narcolepsy may be less involved in family life and appear inactive. Frequently, only mothers were reported as the main sources of support and protection, informing others about narcolepsy.

EDS and the need for more effort to satisfy school requirements left less time for friends and leisure activities. In addition, narcolepsy informants tended to be socially withdrawn because of constant tiredness, avoiding situations where experiencing symptoms might be dreaded or dangerous, including sports (cataplexy) or being alone at night (falling asleep).

*“Some friends would make me laugh so I would hit the floor” [A,m]*

*“The kids used to tease me. Called me Captain Snooze” [D,f]*

*“I was asleep, he teased me till nuts. Put a pencil in my ear, and I was sick of it, I punched the guy out” [D,f]*

In the developmental stage of adolescence healthy peer interactions play an essential role, but young people with narcolepsy often become targets of bullying (teasing, physical attacks, etc.). An understanding peer group is a main condition to facilitate age-related activities. Not wanting to be different from peers induced suppression of symptoms, which may actually aggravate symptom severity. Severely affected individuals hardly participated in social encounters, reported not having many friends.

*“You try to hide it as much as you can” [C,f]*

As sleepiness issues are also experienced in general population, narcolepsy symptoms are not evaluated as disease-related, misjudging their disabling dimension. People may not accept irresistible sleepiness or a need to nap, be it at school, workplace, at home or with friends. Consequently, narcoleptic adolescents learned pretending to be awake.

### **Self concept and affective functioning**

*“Without narcolepsy, I’d be finishing my studies instead of starting them” [B,f]*

Having narcolepsy implicated more planning and controlling of everyday-life. In contrast to this, participants perceive a reduced ability to successfully perform and reach goals. In comparison to peers or to periods before symptom worsening, the number of activities, perceived self-efficacy and success rate was reduced.

*“And I went through these years ‘I’m dumb, I’m dumb, I’m dumb, I can’t do anything”  
[B,f]*

Low self esteem and lack of confidence became a part of the ego identity. Regarding illness management the participants who accept the limitations made by the disease experienced less severe impacts than those struggling to appear healthy.

*“Oh it’s so embarrassing. That’s why I don’t take the train” [B,f]*

Embarrassment and feeling ashamed were very frequent descriptions of how symptoms were experienced in social situations (e.g. humiliation when falling asleep at own birthday party). Because of the humiliating nature of thus losing control, some participants revealed strong emotional responses like being afraid of getting symptoms, or rage.

*“Asleep, I get angry with myself” [F,m]*

Symptoms were usually not mentioned to others. Social distance, loneliness and isolation appeared aggravated in persons strongly affected.

*“I don’t think I talked to friends about it. You know, everyone likes to be normal, and you don’t like to be other.” [F,m]*

Recurrent experiences of being helpless (symptoms, reaching goals, need to rely on others) induced feelings of anger, even depressive periods. Struggling with the disease and negative feelings were reported when set goals were not reached, especially when having to quit school.

*"I used to be so frightened .. my windows locked, checked my cupboards before I went to bed" [B,f]*

*"(Cataplexy) I felt like a terrible idiot" [D,f]*

Many of the REM-sleep related features like hypnagogic hallucinations, vivid dreams or nightmares were associated with intense fear. Cataplexy, a vulnerable state without control created an additional aspect of anxiety. Thus, people experiencing such symptoms encounter more negative emotions than usual.

*"Not allowed to get emotional, being unemotional" [G,m]*

Cataplectic attacks are minimized when avoiding strong emotions. Participants described themselves as unemotional due to constantly suppressing affects.

*"Feels like a defect. Not normal. Body can't function" [F,m]*

Overall, narcolepsy-cataplexy was regarded as a disability or handicap, whereas participants with only EDS viewed symptoms more as a major nuisance. Persons with a high amount of REM-intrusion into wakefulness (cataplexy, hallucinations) also consider narcolepsy as a mental condition or a threat. Accepting narcolepsy appears as prerequisite for communication about the embarrassing symptoms and thus activation of social support.

## DISCUSSION

The present study, qualitatively analysing life experiences of young persons with narcolepsy, delineates the scope of clinical symptoms as well as psychosocial sequelae of narcolepsy symptoms in adolescence. In spite of peak symptom onset during adolescence, the disease and its clinical spectrum are still often not recognized in this age group [12, 16, 36]. The early onset of narcolepsy symptoms was found to have a negative impact on all basic areas of psychosocial functioning and well-being, similar to as documented in prepubertal children with narcolepsy [15, 22, 28, 34]. These widespread and often severe effects, mostly due to the waxing and waning of sleepiness, partially arose from lack of diagnosis and adequate treatment.

In contrast to previous studies, our participants reported an onset or exacerbation of symptoms as early as age 12. This applied to all female and several male participants. Previous, retrospective studies in adults have reported a main peak of onset at age 15 [13]. The advanced onset in the present sample may be putatively related to earlier puberty [30]. An association between puberty onset and narcolepsy has been suspected earlier [2, 31, 33]. Unfortunately this also implies that narcolepsy symptoms may be interpreted as a puberty-related phenomenon. Further studies linking narcolepsy to puberty onset may provide some etiological clues.

Contrary to reports in adulthood [12], most adolescents did not report a refreshing value of sleep and naps, but difficult awakenings with sleep inertia, moodiness and consequently social conflicts. Described in childhood narcolepsy, this persists throughout adolescence [8, 36]. Such sleep inertia may constitute an important differentiation for diagnostic procedures. Frightening nightmares or hypnagogic hallucinations may additionally characterize narcolepsy in this age group.

A striking feature was the waxing and waning of symptoms, especially of the so called 'auxiliary' symptoms like sleep paralysis, hypnagogic hallucinations, nightmares and disrupted night sleep. Delay from EDS onset to cataplexy may take several years. Thus, a



full range of narcolepsy-related symptoms is not constantly present [36]. Diagnosis is enhanced when doctors actively ask about symptoms, which are perceived rather as personality traits than related to a medical condition.

Consistent with adult retrospective reports, this study found that academic achievements and a satisfactory working environment depend on a sufficiently early diagnosis and treatment [4, 16]. Knowing about the disease allows adaptation – even if still difficult – with the help of medication, naps or flexible work hours. Being informed about the scope of the disease and knowing about treatment options before beginning a work life is a prerequisite to avoid job situations that will inevitably fail.

Developmental problems normal to the transition to adulthood may be magnified by chronic diseases [3]. Although behavioural changes and social conflicts are associated with puberty [30], conflicts with parents appeared to be highly prevalent in this sample of young people with narcolepsy. However, other puberty issues such as the important intensification of peer interactions or making new, stimulating experiences were reduced [22]. Lack of peer acceptance due to overt symptoms and perception of being different when conformity is important can be painful effects of diseases in adolescence. Trying to avoid stigmatisation by suppressing symptoms and struggling to appear normal induce poorer adjustment, also observed in adolescents with other chronic diseases eg with epilepsy [3, 24, 24]. Particularly severely affected narcoleptic adolescents or those struggling with the disease appeared socially withdrawn and internalising. The increased prevalence of depressive symptoms in narcolepsy may very well originate in this period of maturation, a phase of high risk to develop mental health problems, if achieving autonomy is impaired and low self esteem becomes a part of ego identity {Boyce, 1998 14645 /id}.

Due to the small sample size, it may be argued that findings may not be generalised to the larger population. However, qualitative research rarely aims to draw conclusions that can necessarily be generalised to the overall population under study, rather this analysis provides new insights on the psychosocial difficulties which may be experienced by young people with narcolepsy, often based on issues the participants chose to highlight. These may

stimulate further research, including quantitative research. The fact that participants were contacted via a self-help group might bias towards more articulate knowledge on the disease. However, as most participants were not actively involved in self-help group activities (although their parents may have been), such a major bias appears unlikely. The small sample size precluded any clear differences to emerge between males and females, but this does not mean they may not exist across the population of young people with narcolepsy. The findings reinforce the call for health professionals to be trained to recognize the clinical scope of narcolepsy in adolescence, and to understand the developmental, social and educational consequences of this incapacitating disorder [4, 7, 16, 18]. Increased community awareness of narcolepsy is important to reduce preventable negative interactions with teachers, family and peers. Apart from medical assistance, psychoeducational help to increase acceptance of the disease and its limitations is strongly indicated for young people, both to manage and prevent detrimental effects of this disabling chronic condition.

## **CONCLUSIONS**

Narcolepsy symptoms in adolescents show high variability and can be mistaken as puberty-related misbehaviour. Sleep may be perceived as unrefreshing. Symptoms interact with efficiency at school or work, and also strongly affect social situations, inducing increased conflicts, withdrawal and feelings of helplessness. Treatment, counseling and public awareness are needed to prevent socioeconomic and affective sequelae.

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## **Conflict of interest**

The authors declare no conflict of interest.

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**Table 1**

## Symptomatology of narcolepsy in adolescents

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Excessive daytime sleepiness	usually present since childhood, urgent need to nap, unrefreshed after sleep
Cataplexy	may be present or delayed for years after sleepiness onset
Automatic behaviour	frequent in social situations or during monotonous situations (schoolwork)
Disrupted night sleep	associated with irregular (sometimes changing) sleep patterns
Sleep paralysis	most often at end of daytime naps, may be also experienced by other family members
Hypnagogic hallucinations	intrusion of REM sleep mentation into wakefulness as well as vivid dreams can be very frightening

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Note: Apart from excessive daytime sleepiness, symptomatology can show high variability both across subjects and, in terms of frequency or intensity of symptoms, also within affected subjects.

Exacerbation of symptoms was frequently reported at puberty onset.

**Table 2**

Major concerns and problematic issues associated with narcolepsy as frequently raised by the adolescent informants

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Not achieving life goals	<ul style="list-style-type: none"> <li>• academic failures (school / university / workplace)</li> <li>• lack of time for social and recreational activities</li> <li>• frequent interpersonal problems with supervisors</li> <li>• difficulties finding appropriate work choice</li> </ul>
Transportation	<ul style="list-style-type: none"> <li>• falling asleep in public transport and unable to drive: immobility or dependence on others</li> </ul>
Social problems	<ul style="list-style-type: none"> <li>• symptoms attributed to laziness / misbehaviour, resulting in everyday conflicts</li> <li>• target of bullying/teasing</li> <li>• consequences: pretending to be awake, avoiding social situations, isolation</li> </ul>
Affective functioning / self concept	<ul style="list-style-type: none"> <li>• reduced self-efficacy, not reaching goals</li> <li>• lack of confidence, low self esteem</li> <li>• symptoms cause embarrassment and distress</li> <li>• loneliness and isolation</li> <li>• helplessness and depression</li> <li>• anxiety due to nightmares and hallucinations</li> <li>• need for increased self-control due to symptoms</li> </ul>

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Note: Academic failures (and consecutive work choice and socioeconomic problems) are a major issue during adolescence. Public knowledge about nature of the disease helps to reduce pressure, misunderstandings, and failures.