

CASE REPORTS

Parental Fitness Questioned on the Grounds of Narcolepsy: Presentation of Two Cases

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We report two cases of fathers whose parental fitness was questioned during divorce and custody litigation because of narcolepsy type 2 and type 1, respectively. These cases highlighted both the existence of a narcolepsy-related stigma and the need to involve sleep experts in custody assessments when concerns about the parental fitness are related to a sleep disorder, expanding the field of interest of the growing “sleep forensics.”

Keywords: child custody, divorce, forensics, parenting, sleep disorders

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INTRODUCTION

Narcolepsy is a chronic disease that usually begins at a young age and may be associated with significant health-related quality of life impairment and stigma.^{1,2} Although people with narcolepsy may report problems with specific parenting tasks (eg, supervising and disciplining children, performing household chores, feeding and nursing newborn infants),^{3–5} no data about the risk of accidents for children of parents with narcolepsy nor evidence of their parental unfitness are available.

Herein we describe two cases of fathers with narcolepsy, whose parental fitness was questioned because of their disease during divorce and custody litigation.

REPORT OF CASES

Case 1

A 32-year-old man presented with excessive daytime sleepiness (EDS), hypnagogic hallucinations, sleep paralysis, and disrupted sleep complaints since the age of 22 years. The patient was treated with continuous positive airway pressure for obstructive sleep apnea syndrome for 2 years, but because of the persistence of symptoms he underwent a sleep work-up study leading to the diagnosis of comorbid narcolepsy type 2. Modafinil treatment (200 mg/d) and scheduled naps efficaciously reduced EDS. When 3 years later a trial for legal separation from his wife started, the wife, claiming that the patient was not able to take care of their 3-year-old daughter because of narcolepsy, asked for grandparents' supervision when the daughter was with the father. Waiting to appoint an expert, at the first hearing the judge approved the request. The appointed expert, a neurologist, confirmed the mother's concerns stating that narcolepsy, even under medical treatment, was a “serious

illness that can cause unexpected sleep attacks.” The expert appointed by the judge also insisted that the Multiple Sleep Latency Test (MSLT) showed pathological sleepiness, overlooking that the test was performed for diagnostic purposes and in the absence of pharmacological treatment. Accepting the expert advice, the judge established that the patient could see his daughter only in the presence of social workers. At the patient's request, we provided an expert sleep medicine report explaining that MSLT had only diagnostic value and that the patient's clinical condition was under control (ie, lack of sleep attacks and only mild EDS in the evening). On the basis of our report the patient's attorney obtained new expert advice. That time, the judge appointed a psychologist, who, despite the very favorable report from the social services' psychologist (describing the patient as an “attentive, joyful, and affectionate father”), concluded that the patient “had intelligence just around average limits and was not able to respect rules.” The judge confirmed his ruling but, after a further attorney request to reconsider the case, allowed the patient to stay with his daughter in the presence of his relatives.

Case 2

A man affected with EDS, disrupted sleep, cataplexy, sleep paralysis, and rare hypnagogic hallucinations since the age of 21 years received a diagnosis of narcolepsy type 1 at the age of 28 years. He was initially treated with modafinil 100 mg/d without benefit, and then with sodium oxybate 4+4 g/night, with good response. At the age of 35 years the patient ended his relationship, and his partner claimed that he could not take care of their 11-month-old son because of narcolepsy symptoms and that the presence of a person was necessary during the child care. Waiting to appoint an expert, at the first hearing the judge established that the patient could pick up the baby by car only if another person drove. The patient then asked for a sleep

medicine expert for a report about his clinical condition. Nocturnal sleep was improved as well as EDS (Epworth Sleepiness Scale score of 10), and cataplexy was abolished. The expert appointed by the court concluded that it was not necessary that a driver accompany the patient. The judge decided accordingly.

DISCUSSION

These are, to our knowledge, the first reported cases of fathers affected by narcolepsy whose parental fitness, despite their good response to treatment, was questioned by their former partners during custody litigation. These cases highlighted both the existence of a narcolepsy-related stigma, regardless of the narcolepsy type, and the need to involve sleep experts in custody assessments when concerns about the parental fitness are related to a sleep disorder, expanding the field of interest of the growing “sleep forensics.”⁶

Data regarding difficulties in parental tasks of effectively treated patients with narcolepsy are lacking. The single study investigating parental problems of mothers with narcolepsy found that they reported more problems than mothers without narcolepsy, especially with regard to activities requiring continuous alertness (eg, driving children anywhere, preparing dinner, helping them to study, disciplining, assigning the child chores, performing household chores).³ However, this study is outdated and past knowledge about narcolepsy and possible therapeutic options were very limited. In the more recent study by Maurovich-Horvat et al.,⁵ more than half of the mothers with narcolepsy reported some difficulties in coping with their baby during the puerperium, especially due to EDS, but almost all mothers were untreated. These findings indicated that people with narcolepsy may need support in child care that does not reflect any parental unfitness. Supporting parents, if needed, is essential also to prevent them from concealing their worries for the child’s safety.⁷ Indeed, as reported by drug-resistant patients with epilepsy, we hypothesized that parents with narcolepsy may fear losing custody of the child when reporting possible disease-related risks for their children.⁷

We acknowledge that narcolepsy might affect a parent’s ability to take care of his/her child, especially in drug-resistant

cases and when the patient is a single parent or the child is in infancy. However, contrary to what happened in the presented cases, any custody assessment should be carried out by qualified experts with knowledge about narcolepsy, avoiding any stigma. Sleep disorder specialists should investigate possible parental difficulties in order to individually adjust treatment over time and provide adequate counseling and support.

REFERENCES

1. Thorpy MJ, Krieger AC. Delayed diagnosis of narcolepsy: characterization and impact. *Sleep Med.* 2014;15(5):502–507.
2. Kapella MC, Berger BE, Vern BA, Vispute S, Prasad B, Carley DW. Health-related stigma as a determinant of functioning in young adults with narcolepsy. *PLoS One.* 2015;10(4):e0122478.
3. Nehring WM, Cohen FL. The development of an instrument to measure the effects of a parent’s chronic illness on parenting tasks. *Issues Compr Pediatr Nurs.* 1995;18(2):111–123.
4. Daniels E, King MA, Smith IE, Shneerson JM. Health-related quality of life in narcolepsy. *J Sleep Res.* 2001;10(1):75–81.
5. Maurovich-Horvat E, Kemlink D, Högl B, et al. Narcolepsy and pregnancy: a retrospective European evaluation of 249 pregnancies. *J Sleep Res.* 2013;22(5):496–512.
6. Delgado-Rodrigues RN, Allen AN, Galuzzi dos Santos L, Schenck CH. Sleep forensics—a critical review of the literature and brief comments on the Brazilian legal situation. *Arq Neuropsiquiatr.* 2014;72(2):164–169.
7. Gauffin H, Flensner G, Landtblom AM. Being parents with epilepsy: thoughts on its consequences and difficulties affecting their children. *Neuropsychiatr Dis Treat.* 2015;11:1291–1298.

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DISCLOSURE STATEMENT

All authors have seen and approved the manuscript and declare they have no conflicts of interest.