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Assessing readiness to drive in adolescents with narcolepsy: what are providers doing?

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Abstract

Purpose There are no universally accepted guidelines for assessing driving readiness in adolescents with narcolepsy. The purpose of the present study was to survey pediatric sleep medicine providers regarding their current practice patterns for assessing driving readiness in adolescents with narcolepsy, knowledge of their state laws regarding physician reporting of unsafe drivers, and opinions regarding what physician duty ought to be.

Methods This was an anonymous web-based survey distributed via the PedSleep listserv, which serves as a hub of communication for pediatric sleep medicine providers.

Results A total of 52 pediatric sleep providers from 25 different states completed the survey. Eighty-eight percent of providers routinely assess driving readiness in adolescents with narcolepsy. Factors rated as "absolutely essential" by at least 50% of respondents included the following: history of previous fall-asleep crash or near miss, sleepiness (reported by patient), sleepiness (reported by caregiver), and cataplexy (reported by patient). Providers included maintenance of wakefulness testing: never (34%), if patient reports no/mild sleepiness (10%), if patient reports moderate/severe sleepiness (25%), or always regardless of patient symptoms (30%), and the median minimally acceptable result was 30 min (25–75th: 20–40 min). There was substantial lack of knowledge regarding legal obligations for reporting.

Conclusions These results demonstrate great variability in practice patterns among pediatric sleep medicine providers for assessing driving readiness in adolescents with narcolepsy. In addition, it shows limited knowledge of the providers about their respective states' laws. Further studies are required to identify the best approach to assess residual sleepiness in this population.

Keywords Narcolepsy · Pediatric · Drowsy driving

Introduction

Narcolepsy is a life-long neurological disease that results in profound daytime sleepiness. A previous study of adults with narcolepsy found that 66% report falling asleep at the wheel, 67% had near or actual accidents from drowsiness or falling asleep at the wheel, 29% experience cataplexy while driving, and 12% experience sleep paralysis while driving [1]. Overall, the risk of sleep-related accident is 3–4 times greater in individuals with narcolepsy compared to those without, with the incidence being 3–7% per year [2]. More recently, an analysis of data from the Second Strategic Highway Research Program found that patients with narcolepsy had increased risk of crashes or near-crashes [3].

Given the increased risk of motor vehicle accidents among patients with narcolepsy, effectively counseling patients regarding strategies to reduce their risk is important. For example, patients may break up longer drives with scheduled naps, take turns driving with a friend or colleague, or limit the duration of driving episodes [4]. As sleepiness is subjective and sometimes challenging to accurately judge, clinicians sometimes employ the maintenance of wakefulness test (MWT) as an objective measure of a patient's ability to stay awake [5, 6].

At present, there are no universally accepted guidelines for assessing driving readiness in adolescents with narcolepsy, what the physician's duty with respect to this assessment is, or what common practice patterns are among pediatric sleep disorder providers. Therefore, the purpose of the present

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investigation is to survey sleep medicine providers regarding their current practice patterns for assessing driving readiness in adolescents with narcolepsy, knowledge of their state laws regarding physician reporting of unsafe drivers, and opinions regarding what physician duty ought to be.

Methods

Participants

An invitation to participate in this research study was distributed with the PedSleep listserv, which is a listserv dedicated specifically to pediatric sleep medicine providers. In addition, an invitation was sent out to the email list for the Pediatric Sleep Case Conference, which is a web-based case conference of pediatric sleep providers from across the country. The sleep case conference list includes 70 sleep physicians from across the country, and the PedSleep listserv contains approximately 300 participants (mixture of physicians, psychologists, and other pediatric sleep providers/researchers).The survey was housed in REDCAP database. There were no questions regarding individual patients, and the survey itself was anonymous, so individual providers would not be identified. This study was approved by the institutional review board at Children's Mercy Hospital.

Survey

The questionnaire asked questions regarding respondent background and clinical practice including specialty board certification, years in practice, practice setting and location (State), percentage of practice dedicated to pediatric patients, number of narcolepsy patients seen per month. Physicians were asked to rate the importance of various factors ("not at all important," "of little importance," "of average importance," "very important," or "absolutely essential") for assessing readiness to drive in their patients, including patient-reported sleepiness, patient-reported cataplexy, parent-reported sleepiness, parent-reported cataplexy, type 1 vs 2 narcolepsy, sleepiness score from structured questionnaire, MWT results, MSLT results, medication regimen, history of prior fall-asleep crash or near miss, and comorbid mood disorder. Specific questions were asked regarding physician's use of the MWT in adolescents with narcolepsy, including in what situations did they employ the test ("never, regardless of patient-reported sleepiness," "if the patient reports no/mild sleepiness," "if the patient reports moderate/severe sleepiness," or "always, regardless of patient-reported sleepiness") and what a minimally acceptable result would be to indicate adequate alertness to drive. Finally, physician opinions regarding legal issues were assessed. Respondents were asked in what circumstances they would contact the department of motor vehicles regarding an adolescent patient with narcolepsy who wishes to drive, what they see as their duty with respect to reporting patients, and what their knowledge of reporting laws in their State are (mandatory vs non-mandatory, legal protection for the reporting physician). Finally, an open-ended question allowed for respondents to elaborate on their approach to assessing driving readiness not encapsulated by the other questions.

Data analysis

The distribution of responses was analyzed with descriptive statistics. In addition, we assessed for relationships between respondent characteristics (such as years in practice) and response patterns. Analyses were performed in IBM SPSS Statistics. When comparisons were made, a p value of < 0.05 was taken as statistically significant.

Results

Physician background

Fifty-two pediatric sleep providers completed the survey. Beyond sleep medicine, providers were board certified/eligible in pediatrics (71%), neurology (15%), internal medicine (3%), psychiatry (7%), pulmonology (44%), family practice (2%), and otolaryngology (2%). Most providers were in a primarily academic practice setting (88%). Providers had been practicing sleep medicine for < 5 years (23%), 5–9 years (19%), 10–15 years (28%), or > 15 years (28%). Most providers exclusively saw patients < 18 years (66%). The average number of patients with narcolepsy seen each month by providers were 0–5 (61%), 5–9 (23%), 10–15 (5%), or > 15 (10%). Respondents were from 25 different States, with the most from Pennsylvania (12%) and California (8%). Thirteen respondents were from mandatory reporting states (California, Pennsylvania, Oregon, and New Jersey). One participant practices outside of the USA, but did not indicate country of practice.

Practice patterns

The overwhelming majority (88%) of respondents answered that they routinely assessed driving readiness in their adolescent patients with narcolepsy. The importance of various factors in that assessment was varied and presented in Fig. 1. There was general agreement regarding the importance of some factors, including the following: history of previous fall-asleep crash or near miss, sleepiness (either patient or parent-reported), and cataplexy (either patient or parent-reported). In contrast, results from multiple sleep latency testing were felt to be "not important at all" or "of little importance" by 40–50%. Likewise, while 52% of respondents felt that

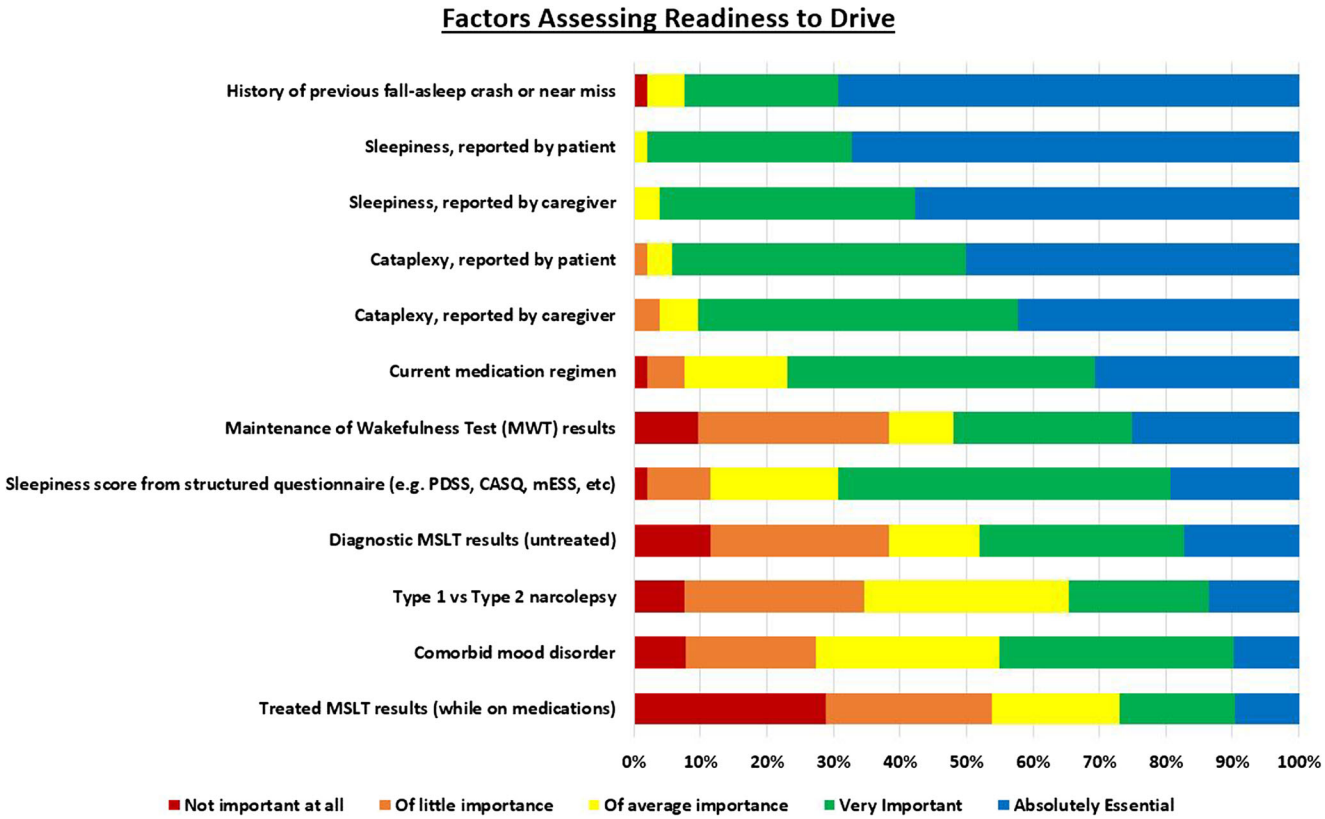

Fig. 1 Physician rating of factor importance in assessing readiness to drive

maintenance of wakefulness test results were "absolutely essential" or "very important," 38% felt that they were "not important at all" or "of little importance." When asked in what circumstance they typically use a MWT in the assessment of driving readiness, 34% reported never, 10% if the patient reported no or mild sleepiness, 25% if the patient reported moderate or severe sleepiness, and 30% always regardless of patient symptoms. The median minimally acceptable result on an MWT indicating that an adolescent is adequately alert to drive was 30 min (interquartile range of 20–40 min). Fifteen (29%) respondents felt the minimally acceptable MWT result would be 40 min, 15 (29%) felt 30 min was acceptable, 10 (19%) felt 20 min was acceptable, and the remaining 21% provided values < 20 min. Clinicians had various approaches to contacting the department of motor vehicles, with 28% never contacting, 10% contacting if there is any degree of sleepiness, 16% contacting if there is moderate/severe sleepiness, 26% if moderate/severe sleepiness and previous motor vehicle collision, and 8% in all circumstances.

Response patterns were assessed according to years in practice, number of narcolepsy patients seen per month, board certification in pediatrics, and practicing in a State mandating reporting (perceived by responded). Table 1 demonstrates ratings of factor importance by these respondent characteristics. Physicians seeing 0–5 patients with narcolepsy per month were more likely to rate MSLT results (either on or off medications) as more important compared to those seeing > 5 patients with narcolepsy per month. Neither pediatric board status, physician years in practice, nor practicing in mandating reported state were associated with differential ratings of factor importance.

Beliefs and legal knowledge

Physicians were asked their understanding of physician duties to patient and society and agreed most with the following statements: Clinicians have a duty to inform the department of motor vehicles if they feel their patient is unsafe to drive (23%); clinicians have a duty to maintain confidentiality and not inform the department of motor vehicles, even if they feel their patient is unsafe to drive (11%); clinicians must weigh their duty to protect the public against their duty to maintain patient confidentiality, and only inform the department of motor vehicles if they feel the patient is at high risk but insists on driving (65%).

Only 10% of respondents reported ever having contacted the department of motor vehicles or department of health regarding an adolescent patient with narcolepsy-related safe driving concerns. Forty percent of respondents believed their State allows physicians to report a patient who has a condition that makes driving unsafe to the department of motor vehicles, but 54% did not know for sure. Similarly, 39% of

Table 1 Survey responses to selected questions and potential associations

	Years in practice		No. of narcolepsy patients seen per month		Board certified/eligible in pediatrics		State mandates reporting unsafe drivers	
	< 10	≥ 10	0–5	> 5	No	Yes	No	Yes
Sleepiness, reported by patient	28.0	25.3	26.2	26.9	29.9	25.1	15.8	17.9
Sleepiness, reported by caregiver	29.5	24.2	27.0	25.7	29.14	25.4	14.6	20.5
Cataplexy, reported by patient	26.1	26.7	27.5	24.7	23.8	27.5	15.9	17.8
Cataplexy, reported by caregiver	26.9	26.1	27.3	25.1	24.7	27.2	15.9	17.7
Type 1 vs 2 narcolepsy	30.3	23.6	28.0	23.9	29.7	25.2	16.8	15.8
Sleepiness score from structured questionnaire	28.0	25.4	28.2	23.7	24.2	27.4	15.7	18.1
Maintenance of wakefulness test	30.0	23.8	24.5	29.6	23.2	27.8	16.6	16.1
MSLT results (untreated)	30.8	23.3	30.7*	19.7	27.1	26.2	14.5	20.9
MSLT results (on medications)	30.5	23.5	31.3*	18.8	24.6	27.2	15.1	19.5
Current medication regimen	27.0	26.1	28.0	24.0	25.0	27.0	14.8	20.1
History of fall-asleep crash or near miss	25.4	27.2	26.2	26.9	23.7	27.6	17.6	14.0
Comorbid mood disorder	31.4	21.8	28.8	21.1	28.1	25.2	16.1	17.3

Factor importance was recoded (not at all important = 1, of little importance = 2, of average importance = 3, very important = 4, and absolutely essential = 5) and Mann-Whitney Test was employed. Reported values are mean rank from Mann-Whitney Test. Bonferroni correction applied for each factor

*$p < 0.05$

respondents did not know if their State mandated reporting of such individuals, and 19% thought that their State did mandate reporting. Of the 13 respondents practicing in a mandatory reporting state (California, Pennsylvania, Oregon, and New Jersey), 6 (46%) responded that they were uncertain whether their state mandated reporting. Most (75%) respondents did not know if their state provided any legal protection to reporting physicians. Factors most impacting current practice patterns of respondents were as follows: learned practice from sleep fellowship training (25%), local sleep practice group standard (13%), understanding of legal obligation (13%), professional ethical obligations (36%), and continuing medical education (11%).

Physicians with < 10 years in practice rated "learned practice from sleep fellowship training" as the most common factor influencing practice patterns, whereas those with ≥ 10 years in practice rated professional ethical obligations most commonly. Physicians practicing in states that do not mandate reporting of unsafe drivers were more likely to respond that they would not report a driver under any circumstance (54% vs 0%, $p = 0.006$). Similarly, those physicians practicing in mandatory reporting states were more likely to agree that clinicians have a duty to inform the DMV if they feel their patients is unsafe to drive (70% vs 9%, $p = 0.001$), and were more likely to have previously reported a patient to the DMV (40% vs 0%, $p = 0.002$). No other responses were significantly associated with years in practice, number of narcolepsy patients seen per month, board certification in pediatrics, or practicing in a State mandating reporting.

Discussion

This is the first study to our knowledge that characterizes practice patterns for evaluating readiness to drive of adolescents with narcolepsy. Overall, we found that an overwhelming majority of pediatric sleep physicians routinely assess for driving readiness in this population. That said, the importance given to various factors in their assessment of driving readiness varied tremendously as did the likelihood of reporting any results to driving or health authorities. There was general agreement in the high importance of the following: history of previous fall-asleep crash or near miss, sleepiness (either patient or parent-reported), and cataplexy (either patient or parent-reported). In contrast, about half of respondents felt that MWT played an important role in their evaluation; if employed, a result of 30 min was felt to be minimally acceptable. Interestingly, providers seeing greater volumes of patients with narcolepsy were less concerned with MSLT results, which may reflect the relatively lower correlation of MSLT results with simulated driving parameters compared to MWT [7]. Similarly, there was substantial variability in how physicians weighed their duties to their patients and society as a whole; few physicians had ever contacted the department of motor vehicles or health department regarding an adolescent with narcolepsy they felt was unsafe to drive.

Reasonable approach to assessing driving readiness

There are currently no evidenced-based recommendations or practice parameters for assessing readiness to drive in the

adolescent with narcolepsy. It is therefore not surprising that our survey found substantial variability in current practice patterns among pediatric sleep physicians. Despite the lack of evidence or guidelines, sleep clinicians are faced with the challenge of assessing and counseling children and their families regarding this issue in clinic on a daily basis. Some have suggested that patients with narcolepsy ought to do a self-assessment of their alertness during driving, solicit feedback from family and friends, and discuss this with their treating physician [8] who may choose to do an MWT. They also suggest practical precautions when driving, including limiting trip length, taking medications before driving, breaking up longer drives, or taking turns with a friend [8].

That said, what constitutes a reasonable and prudent approach for the evaluation to be performed by a sleep physician remains unclear. The results of our survey suggest that by far the factors that physicians feel are most important to assess are a history of previous fall-asleep crash or near miss and self/parent-reported residual symptoms of daytime sleepiness and/or cataplexy. Interestingly, there was much less agreement on the importance of MWT or sleepiness score from structured questionnaires. This means that all dimensions of this problem: when to test, how to test, and whether to report produced highly variable self-reported clinical practice data.

The clinical utility of MWT testing among pediatric narcolepsy patients remains to be shown. Prior research has demonstrated that MWT testing may result in management changes for children with narcolepsy [9]; those authors took a mean latency of > 20 min to indicate adequate control on medications. Research in adults has found that MWT testing results significantly correlates with mean number of inappropriate line crossings [5, 10]. While structured questionnaires for subjective sleepiness can be useful to assess pathologic sleepiness, they have low correlation with MWT suggesting that they are measuring distinct features of alertness versus sleep propensity in adults [11]. In a real-life driving situations of adults with sleep apnea, MWT results < 34 min identify patients who have more inappropriate line crossings [12]. In the current study, about a third of respondents never utilize the MWT, a third do so if there is reported residual sleepiness, and a third always use an MWT regardless of patient symptoms. If used, the median minimally acceptable result on an MWT indicating that an adolescent is adequately alert to drive was 30 min. Clinician ambivalence over MWT testing may be influenced by the lack of a tight functional fit between the MWT test alone and driving safety.

While there is a great need for evidence-based practice parameters, our results in conjunction with what is known from adult literature suggest that a reasonably prudent approach to the evaluation of driving readiness in adolescents with narcolepsy would include inquiring regarding residual subjective sleepiness/cataplexy from both parent and child, asking about a history of near miss or actual drowsy driving accidents, and performing an MWT. Given that almost all children with narcolepsy continue to have some degree of subjective daytime sleepiness (although much improved from baseline) even with effective pharmacologic therapy [13], we suggest the routine use of MWT testing as a part of evaluation with a minimally acceptable result of 30 min. Another important consideration when interpreting the results of an MWT is how they relate to drive duration; for instance, while a 30-min result may be minimally acceptable for short drives, it may not provide the same level of reassurance regarding propensity to fall asleep for long drives lasting > 1–2 h. The above represent largely author opinion combined with survey results, but given the overall variability observed in practice patterns from respondents, it is likely that a substantial number of survey participants would have alternative recommendations. The pediatric sleep medicine community would benefit greatly from the development of expert guidance and recommendations from the academy on this topic.

Role of the sleep physician

The sleep physician embodies at least two roles in the safe driving determination encounter: that of clinical provider to a given patient, genuinely interested in maximizing human development and quality of life for a given patient and that of public welfare guardian with some, variable responsibility to advise government authorities of safe driving risk. The balance between these two roles is sometimes left to the practitioner, sometimes left to the government, and sometimes left to the patient. Provider confusion over where the balance has been struck in a given jurisdiction may reflect the fact that most sleep physicians rely heavily on information learned in medical training that may have taken place in a state with rules and statutes different from the one in which they now practice. It is noteworthy that in the current study practicing in a mandated reporting state had no impact on differential ratings of factor importance, and may indicate providers are unaware of their jurisdictions reporting requirements.

All states require drivers license applicants of license renewal applicants to self-report on medical diagnoses that may result in lapse of consciousness. This illustrates that the traditional approach of self-reporting of such potential driving safety concerns is intact.

Six states, however, also have mandatory reporting laws for drivers who have medical impairment that may result in loss of lapse of consciousness. The mandated reporter in each of these six states is the clinician, not the patient. The providers in these jurisdictions (California, Delaware, Nevada, New Jersey, Oregon, and Pennsylvania) are not mandated to determine driver's license eligibility but, rather, to report lapse of consciousness patients (defined to include those with sleep apnea and narcolepsy by statute, regulation, official policy, or case ruling) to licensing or public health authorities who

screen these drivers or would-be drivers more closely under duly promulgated regulations or official procedures, often developed in concert with sleep physicians. It is significant that all of these statutes operate differently, with some allowing medical professionals to communicate directly with licensing authorities and others not allowing it. In these last states, physicians report to health authorities who review reports and then, themselves, forward selected reports to driving authorities. This last approach is designed to address the physician dual agency problem as well as to create a record as clean of conflict of interest as possible in light of possible appeal.

The remaining states work off of a variety of approaches incorporating elements of self-reporting, reporting by law enforcement authorities and citizens that activates a higher level of driving fitness scrutiny, and statutory regimes that increase frequency of in-person renewal of driver's licenses as individuals advance in age.

Liability considerations

Sleep physicians also appear to be unaware of any liability concerns that may attach to reporting as well as to failure to report in a given jurisdiction. There are always three parts to the answer about the legal liability of a licensed health provider in any situation: by whom, for what, and likelihood of success.

Third party claims against an individual non-reporter

The statutory and regulatory systems of the states may leave a non-reporter open to law suit by a private individual injured by a non-reported drowsy driver in a mandated reporting statute jurisdiction, unless immunity is explicitly offered. Mandated reporting statutes typically offer immunity from suit for reporting but not for the failure to report. If, however, the standard for licensed health provider reporting is anything other than a strict clear mandate, a suit might be very difficult to fashion because subjective judgment is usually clearly built into the determination. In addition, tort law does not ordinarily allow tort defendants (drowsy drivers, in this case) to try to drag in other "bad actors" (arguably non-reporting licensed health professionals) with ease. Causation for an accident or wreck must be fairly direct and not highly speculative. In short, "you let me drive by not reporting me and so I drove drowsy and caused the wreck" represents quite a stretch on the causation element of tort liability (see Richard W. Wright, Causation in Tort Law, December 1985).

State licensing board actions against non-reporting licensed health care providers

We know of no state health care licensing board actions against sleep physicians for failure to report in either mandated or voluntary reporting jurisdictions.

Potential state liability for failure to follow up on physician reports

The doctrine of sovereign immunity makes it difficult to sue a governmental entity operating in the ordinary course of government business. Unless state health and driving authorities have waived or abrogated such immunity, regulating safe driving standards is clearly a core function of the state (See Frank J. Kane v. State of New Jersey, U.S. 1916). Alternatively, a private citizen is always free to seek a court order to require the government to perform a constitutional or statutory duty but the procedural tools for such an approach, including the writ of mandamus, typically allow for no attorneys fees even for the successful obtaining of such a writ, drastically limiting the attractiveness of these tools.

Limitations

First, a major limitation of this study is the relatively small sample size of participants. That said, 52 providers represent a significant proportion of pediatric sleep providers in the country. In addition, half of states in the USA were represented in the current sample. Second, we did not include questions regarding adherence with medication regimen or sleep duration in our survey; in hindsight, these are clearly important factors affecting overall symptom control and therefore driving readiness. Third, while our data are informative regarding expert opinion on acceptable results from an MWT, there was substantial variability in responses. There are no well-established normative data regarding MWT results in the pediatric population, an area requiring future research. Furthermore, long-term outcome studies are sorely needed to better elucidate any predictive abilities of the MWT for motor vehicle collisions within this population and develop evidence-based guidelines for its interpretation. Until such evidence is available, our results may help inform clinicians who are caring for patients at present.

Conclusions

In conclusion, these results demonstrate substantial variability in current practice patterns for assessing driving readiness in adolescents with narcolepsy. Based on the results of this survey and prior literature, we posit that a reasonably prudent approach would include inquiring regarding residual subjective sleepiness/cataplexy from both parent and child, asking about a history of near miss or actual drowsy driving accidents, and performing an MWT with a minimally acceptable result of 30 min. Further research and practice parameters are needed.

Compliance with ethical standards

Conflict of interest Dr. Ingram has served as a consultant and is on the speaker's bureau for Jazz Pharmaceuticals. All other authors decline any potential conflict of interest.

Ethical approval This study was approved by the IRB at Children's Mercy Hospital, #17120726, and was determined to be exempt under category 2—Research involving the use of educational tests, survey procedures, interview procedures or observations of public behavior. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Abbreviations *MWT,* Maintenance of Wakefulness Test; *MSLT,* Multiple Sleep Latency Test

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