

SCIENTIFIC INVESTIGATIONS

Treatment and care delivery in pediatric narcolepsy: a survey of parents, youth, and sleep physicians

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Study Objectives: To describe the most commonly used treatments in pediatric narcolepsy and their perceived effectiveness, as well as to elicit key stakeholder perspectives on the most optimal manner in which care ought to be delivered to youth with narcolepsy.

Methods: A cross-sectional survey of youth with narcolepsy, parents, and sleep physicians.

Results: Complete survey results were available for 35 youth with narcolepsy, 116 parents, and 30 sleep physicians. Overall there was general agreement among family and physicians regarding most effective treatments, including both pharmacologic (stimulants, sodium oxybate, and modafinil/armodafinil) and nonpharmacologic (sleep schedule, exercise, diet) approaches. There was a stronger interest in cannabidiol oil (CBD) from families compared to physicians. Both families and physicians also endorsed a need for multispecialty care, ideally delivered in a same day setting and including specialists in mental health, social work, and nutrition. Quality measures were felt to be important but are not currently tracked by most sleep physicians. Qualitative responses highlight the value families place on providers who listen well and remain open-minded.

Conclusions: Our results suggest strong support by key stakeholders for an interdisciplinary approach to care for youth with narcolepsy.

Keywords: pediatric narcolepsy, biopsychosocial model, quality of life, sleep

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BRIEF SUMMARY

Current Knowledge/Study Rationale: Narcolepsy in youth affects many domains of psychosocial functioning. We sought to examine key stakeholder perspectives on perceived treatment effectiveness and optimal care delivery.

Study Impact: Youth, parents, and sleep physicians all endorsed the effectiveness of both pharmacologic and nonpharmacologic treatment modalities. There was a strong desire for the development of multispecialty care delivery, auxiliary care services, and quality improvement efforts.

INTRODUCTION

Narcolepsy is a lifelong neurological disorder characterized by excessive daytime sleepiness, cataplexy, sleep-related hallucinations, and sleep paralysis.¹ There is an increasing awareness and recognition of narcolepsy in youth. While several medications are now available that effectively improve our ability to manage symptoms and decrease disease severity, there is almost always some degree of residual sleepiness.² Several recent studies have demonstrated that individuals with narcolepsy have substantial medical and psychological challenges.^{3–6}

Our own recent survey amplified these previous findings within the pediatric population.⁷ Specifically, we found that most of 18 queried psychosocial concerns were endorsed as substantial challenges by both adults and youth, including difficulty focusing and memory, school, worry and anxiety, diet and nutrition, lack of motivation, mood problems, and relationship problems. Physicians recognized some, but not all, of the same challenges in their patients. The same survey identified a high rate of medical comorbidities, such as visual problems, anxiety/depression, allergies, overweight/obesity,

eczema, chronic pain, restless legs syndrome, asthma, attention deficit/hyperactivity disorder, and obstructive sleep apnea. These data suggested a need for a more holistic, structured assessment of impairments in youth with narcolepsy.

Given the significant comorbidities associated with narcolepsy, optimal management might best be achieved through an interdisciplinary approach. In fact, a recent study of patients with hypersomnia found that a substantial proportion of patients' symptoms are not sufficiently managed by medications alone, and over 90% of patients utilize nonpharmacologic therapies.^{8,9} An interdisciplinary approach within a biopsychosocial framework was also advanced by Graef and colleagues,¹⁰ and several areas of future study were posited, such as eliciting key stakeholder input regarding important factors to consider in a biopsychosocial model. Therefore, in the current study we performed a survey of youth and young adults (hereafter referred to as "youth") with narcolepsy, parents of youth with narcolepsy, and sleep physicians as a first step to better understand several aspects of optimal disease management, including therapy options, sleep clinic care delivery, subspecialist care, and quality improvement.

METHODS

Participants

A description of the survey development and distribution is provided in our recent publication.⁷ Invitations to participate in this research study were distributed via the WakeUpNarcolepsy website and social media platforms (ie, Facebook, Twitter) for parents and youth, and via the PedSleep listserv for pediatric sleep physicians. The PedSleep listserv contains approximately 300 participants (including physicians, psychologists, and other pediatric sleep providers/researchers). Individuals were eligible to participate in the survey if they were the parent of a child with narcolepsy between the ages of 1 and 22 years, a patient with narcolepsy between the ages of 12 and 22 years, or a sleep physician who provides care to youth with narcolepsy. The survey was housed in a Research Electronic Data Capture (REDCAP) database and was anonymous, so individual respondents would not be identified. This study was approved by the institutional review board at Children's Mercy Hospital.

Survey

The survey was developed for the current study with the input of a sleep medicine physician (DI), sleep psychologist (SS), and 2 representatives of WakeUpNarcolepsy (CC and LJ). Separate parent, youth, and provider versions of the questionnaire included both multiple-choice and open-ended questions assessing respondent characteristics, narcolepsy symptoms, psychosocial challenges, comorbidities, treatments options, specialist care, and sleep clinic care. Items and responses were developed based on a review of the literature and were then reviewed and revised by the research team.

Multiple choice questions regarding treatment options for youth and parents were assessed via: "Never used, not interested", "Never used, would consider", "Used, and helpful", and "Used, but ineffective". For physicians "Do not discuss, generally not helpful", "Do not discuss, but would be willing to consider", "Discuss, and generally helpful", "Discuss, but generally not helpful". Furthermore, we assessed multiple aspects of care delivery via additional closed-ended and open-ended response items, as detailed in the results section. In order to help preserve anonymity, we did not query or attempt to correlate individual youth and parent survey responses.

Data analysis

Descriptive statistics were used to examine the distribution of responses and are reported as percentages or means and standard deviations. Analyses were performed in IBM SPSS Statistics. Responses to open-ended questions were coded and categorized into representative themes using a grounded theory approach. Grounded theory stipulates that the collected data are systematically examined line by line, and key phrases are identified and coded into categories to uncover overarching themes.¹¹

RESULTS

Survey participation

The survey remained open for 2 months. During that time, 251 individuals opened the survey link and 230 proceeded to the

survey questions. Of the parents, 116 (77%) of 150 completed the entire survey. Of the youth, 35 (76%) of 46 completed the survey. Finally, of the providers, 30 (88%) of 34 completed the entire survey.

Respondent characteristics

Respondent characteristics are detailed in our recent publication.⁷ In summary, most youth respondents were female (74%), and the age at the time of survey completion was a mean of 19.0 (2.6) years. Age of youth respondents ranged from 13 to 22 years, with the following distribution: 13–14 (n = 2), 15–16 (n = 7), 17–18 (n = 5), 19–20 (n = 6), 21–22 (n = 15). Similarly, parent respondents reported that their children were predominantly female (58%), and their age at time of survey completion was 15.4 (3.8) years. Most youth respondents (94% White, 3% Black, 0% Asian, 0% American Indian, 3% prefer not to respond) and parent respondents were White (88% White, 5% Black, 2% Asian, 1% American Indian, 4% prefer not to respond), and the majority of patients had type 1 narcolepsy (80% youth report and 65% parent report). Physician respondents were 93% board-certified in sleep medicine (80% in pediatrics) and were generally very experienced, with 33% having > 15 years of sleep medicine experience, 30% 11–15 years, 23% 5–10 years, and 13% < 5 years. Most (73%) practiced in an academic medical center, and almost all (90%) practiced in a setting that was 75–100% pediatric patients.

Treatment options

Overall responses regarding pharmacologic and non-pharmacologic treatment experiences are presented in **Table 1** and **Table 2**. There was general agreement between youth, parents, and physicians regarding the top 10 rated most effective treatments, as demonstrated in **Figure 1**, which included (in descending order by youth rank): daytime naps, scheduled bedtime/waketime, exercise, diet, stimulants, sodium oxybate, modafinil/armodafinil, caffeine/energy drinks, antidepressants, and temperature manipulation. An exception to this general agreement was a noted discordance in treatment ratings in that parents rated aromatherapy and physicians rated mindfulness high enough to be in the top 10, in lieu of temperature manipulation included by youth.

While there were similarities in the top 10 rated therapies, responses diverged in several areas in lower rated options. The largest differences in youth and parent ratings were that youth had higher ratings for cannabidiol (CBD) oil, nicotine, mindfulness, and temperature manipulation. Similarly, the greatest differences in youth and physician ratings were that youth had higher ratings for CBD oil, aromatherapy, nicotine, diet, temperature manipulation, exercise, and chewing gum. Finally, the largest differences between parent and physician ratings were that parents had higher ratings for aromatherapy, chewing gum, baclofen, CBD oil, and diet. Of note, physicians also judged several therapies, especially pharmacologic, as more frequently helpful compared to youth/parents; for example, 90% of physicians felt stimulants were helpful, compared to only 46% of youth or 49% of parents. Similarly, 90% of physicians felt modafinil/armodafinil were helpful, but only 37% of youth and 30% of parents felt the same.

Table 1—Pharmacologic treatment options rated by youth, parents, and sleep physicians.

	Youth	Parent	Physician
Stimulants			
Never used, not interested/Do not discuss, generally not helpful	5%	7%	0%
Never used, would consider/Do not discuss, but would be willing to consider	11%	4%	0%
Used, and helpful/Discuss, and generally helpful	46%	49%	90%
Used, but ineffective/Discuss, but generally not helpful	37%	40%	10%
Sodium oxybate			
Never used, not interested/Do not discuss, generally not helpful	11%	20%	0%
Never used, would consider/Do not discuss, but would be willing to consider	34%	32%	3%
Used, and helpful/Discuss, and generally helpful	37%	34%	90%
Used, but ineffective/Discuss, but generally not helpful	17%	13%	7%
Modafinil/armodafinil			
Never used, not interested/Do not discuss, generally not helpful	9%	14%	0%
Never used, would consider/Do not discuss, but would be willing to consider	9%	26%	3%
Used, and helpful/Discuss, and generally helpful	37%	30%	90%
Used, but ineffective/Discuss, but generally not helpful	45%	30%	7%
Antidepressants			
Never used, not interested/Do not discuss, generally not helpful	23%	24%	0%
Never used, would consider/Do not discuss, but would be willing to consider	23%	22%	10%
Used, and helpful/Discuss, and generally helpful	34%	36%	80%
Used, but ineffective/Discuss, but generally not helpful	20%	18%	10%
Cannabidiol oil			
Never used, not interested/Do not discuss, generally not helpful	31%	34%	67%
Never used, would consider/Do not discuss, but would be willing to consider	46%	51%	33%
Used, and helpful/Discuss, and generally helpful	20%	4%	0%
Used, but ineffective/Discuss, but generally not helpful	3%	11%	0%
Baclofen			
Never used, not interested/Do not discuss, generally not helpful	43%	34%	33%
Never used, would consider/Do not discuss, but would be willing to consider	40%	52%	60%
Used, and helpful/Discuss, and generally helpful	14%	12%	7%
Used, but ineffective/Discuss, but generally not helpful	3%	2%	0%
Nicotine			
Never used, not interested/Do not discuss, generally not helpful	66%	80%	73%
Never used, would consider/Do not discuss, but would be willing to consider	14%	16%	20%
Used, and helpful/Discuss, and generally helpful	5%	0%	0%
Used, but ineffective/Discuss, but generally not helpful	14%	3%	7%
Pitolisant			
Never used, not interested/Do not discuss, generally not helpful	40%	36%	17%
Never used, would consider/Do not discuss, but would be willing to consider	54%	61%	63%
Used, and helpful/Discuss, and generally helpful	3%	2%	17%
Used, but ineffective/Discuss, but generally not helpful	3%	0%	3%
Atomoxetine			
Never used, not interested/Do not discuss, generally not helpful	40%	44%	10%
Never used, would consider/Do not discuss, but would be willing to consider	48%	44%	67%
Used, and helpful/Discuss, and generally helpful	3%	2%	7%
Used, but ineffective/Discuss, but generally not helpful	8%	8%	17%
Solriamfetol			
Never used, not interested/Do not discuss, generally not helpful	54%	39%	13%
Never used, would consider/Do not discuss, but would be willing to consider	43%	59%	73%

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Table 1—Pharmacologic treatment options rated by youth, parents, and sleep physicians. (continued)

	Youth	Parent	Physician
Used, and helpful/Discuss, and generally helpful	0%	1%	10%
Used, but ineffective/Discuss, but generally not helpful	3%	1%	3%

The first item in the stem applies to youth/parents and the second for physicians.

Specialist care

Youth and parents were asked what medical specialists they have seen. In addition to neurology/pulmonology (which may represent their sleep provider), the most commonly endorsed specialists (currently or previous) were: psychology (43% youth, 62% parents), psychiatry (28% youth, 47% parents), cardiology (31% youth, 32% parents), gastroenterology (17% youth, 23% parents), and endocrinology (11% youth, 22% parents). Of note, although only 10-11% of parents and youth reported ever seeing a weight management specialist, 15-17% reported they thought that they needed such services. Youth and parents were further asked to identify which specialists they felt would be “very important” to see for their care, and the most frequently identified were: psychologist (54% youth, 69% parents), nurse (43% youth, 53% parents), psychiatrist (31% youth, 58% parents), dietician (26% youth, 47% parents), and social worker (14% youth, 32% parents). Although 24% of parents felt an obesity specialist would be “very important”, only 6% of youth shared that view. Physicians identified that these specialty services were available either embedded within their sleep clinic or, more commonly, by referral: nurse (76% in clinic), psychologist (23% in clinic, 67% by referral), social worker (20% in clinic, 47% by referral), dietician (10% in clinic, 63% by referral), psychiatrist (3% in clinic, 73% by referral), and obesity specialist (0% in clinic, 73% by referral).

Sleep clinic care

Participants were asked a series of questions related to the optimal delivery and configuration of sleep clinic care for youth with narcolepsy. In terms of frequency of sleep clinic visits, both parents (45%) and physicians (73%) most commonly felt that every 3–4 months would be ideal, while slightly more youth preferred every 6 months (43%) compared to every 3–4 months (34%). In a scenario in which the youth required care by multiple specialists, the overwhelming preference was that those encounters all take place within the same clinic on the same day (51% youth, 80% parents, 70% physicians). In terms of auxiliary services, only a minority of respondents had attended a local narcolepsy support group (23% youth, 37% parents, 20% physicians), but most that had not expressed an interest in such participation (51% youth, 48% parents, 67% physicians). Similarly, most participants had not previously attended but were interested in participating in a family education day (48% youth, 54% parents, 63% physicians) or a narcolepsy camp (51% youth, 45% parents, 70% physicians).

Quality measures

The majority (59%) of parents felt that quality measures ought to be tracked by sleep clinics/providers and publicly reported,

while 39% felt they should be tracked but not publicly reported. In contrast, while 94% of physicians agreed with tracking quality measures, only 27% wanted to publicly report them. In terms of current practice patterns, approximately one-third of sleep physicians endorsed tracking the quality measures recommended by the American Academy of Sleep Medicine (AASM).¹² Current frequency of tracking for individual quality measures are outlined in [Figure 2](#).

Open-ended responses

Overall themes from open-ended questions are presented in [Table 3](#), [Table 4](#), and [Table 5](#). Multiple themes emerged from analysis of youth, parent, and physician responses. Parents frequently valued physicians who listened well and maintained an open mind regarding therapeutic options for their child. They wished that their sleep clinics and providers had a greater knowledge of issues, research, and information regarding narcolepsy, and there was an overwhelming desire to see a multispecialty team to help manage their child’s narcolepsy. Youth also highly valued physicians who listened well to them and were understanding. They did not like long wait times or travel to clinic visits and had a desire for greater discussion with and encouragement from their sleep team. Youth also expressed an interest for more information regarding auxiliary services such as support groups and educational events. Finally, physicians almost universally expressed a desire for multispecialty delivery of care to youth with narcolepsy.

DISCUSSION

Youth with narcolepsy exhibit a wide array of medical and psychosocial challenges. The results of the current survey demonstrate several important factors for consideration when caring for these youth. We found that while medications are rated as helpful by key stakeholders, nonpharmacologic therapies were many times rated just as effective or more effective by youth and parents. Particularly, sleep schedule interventions, nutrition, and exercise were highly rated by families. Furthermore, our findings amplify the growing literature calling for a more comprehensive approach to pediatric narcolepsy management within a biopsychosocial framework. A substantial number of youth, parents, and physicians felt that multispecialty care would be beneficial for youth with narcolepsy, and there was overwhelming support from key stakeholders regarding the need for multispecialty clinics as a vehicle to deliver that care. Finally, our results suggest that there is an interest from families for pediatric sleep clinics to track and public really report quality measures for youth with narcolepsy.

Table 2—Nonpharmacologic treatment options rated by youth, parents, and sleep physicians.

	Youth	Parent	Physician
Daytime naps			
Never used, not interested/Do not discuss, generally not helpful	0%	2%	0%
Never used, would consider/Do not discuss, but would be willing to consider	6%	1%	0%
Used, and helpful/Discuss, and generally helpful	63%	71%	93%
Used, but ineffective/Discuss, but generally not helpful	31%	27%	7%
Scheduled bedtime/waketime			
Never used, not interested/Do not discuss, generally not helpful	6%	3%	0%
Never used, would consider/Do not discuss, but would be willing to consider	14%	3%	0%
Used, and helpful/Discuss, and generally helpful	60%	67%	97%
Used, but ineffective/Discuss, but generally not helpful	20%	26%	3%
Exercise			
Never used, not interested/Do not discuss, generally not helpful	3%	3%	0%
Never used, would consider/Do not discuss, but would be willing to consider	20%	15%	3%
Used, and helpful/Discuss, and generally helpful	60%	48%	80%
Used, but ineffective/Discuss, but generally not helpful	17%	34%	17%
Diet			
Never used, not interested/Do not discuss, generally not helpful	5%	10%	3%
Never used, would consider/Do not discuss, but would be willing to consider	31%	26%	17%
Used, and helpful/Discuss, and generally helpful	54%	41%	53%
Used, but ineffective/Discuss, but generally not helpful	8%	22%	27%
Caffeine/energy drinks			
Never used, not interested/Do not discuss, generally not helpful	20%	27%	13%
Never used, would consider/Do not discuss, but would be willing to consider	0%	11%	20%
Used, and helpful/Discuss, and generally helpful	37%	28%	30%
Used, but ineffective/Discuss, but generally not helpful	43%	34%	37%
Temperature manipulation			
Never used, not interested/Do not discuss, generally not helpful	31%	32%	37%
Never used, would consider/Do not discuss, but would be willing to consider	49%	53%	50%
Used, and helpful/Discuss, and generally helpful	20%	11%	10%
Used, but ineffective/Discuss, but generally not helpful	0%	3%	3%
Mindfulness			
Never used, not interested/Do not discuss, generally not helpful	11%	26%	20%
Never used, would consider/Do not discuss, but would be willing to consider	49%	52%	37%
Used, and helpful/Discuss, and generally helpful	20%	11%	33%
Used, but ineffective/Discuss, but generally not helpful	20%	11%	10%
Aromatherapy			
Never used, not interested/Do not discuss, generally not helpful	20%	28%	63%
Never used, would consider/Do not discuss, but would be willing to consider	54%	47%	33%
Used, and helpful/Discuss, and generally helpful	17%	15%	0%
Used, but ineffective/Discuss, but generally not helpful	8%	10%	3%
Chewing gum			
Never used, not interested/Do not discuss, generally not helpful	29%	27%	47%
Never used, would consider/Do not discuss, but would be willing to consider	34%	48%	40%
Used, and helpful/Discuss, and generally helpful	11%	14%	3%
Used, but ineffective/Discuss, but generally not helpful	26%	10%	10%
Yoga/Tai Chi			
Never used, not interested/Do not discuss, generally not helpful	26%	32%	27%

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Table 2—Nonpharmacologic treatment options rated by youth, parents, and sleep physicians. (continued)

	Youth	Parent	Physician
Never used, would consider/Do not discuss, but would be willing to consider	60%	59%	60%
Used, and helpful/Discuss, and generally helpful	8%	6%	13%
Used, but ineffective/Discuss, but generally not helpful	5%	3%	0%
Acupuncture			
Never used, not interested/Do not discuss, generally not helpful	34%	35%	43%
Never used, would consider/Do not discuss, but would be willing to consider	63%	59%	53%
Used, and helpful/Discuss, and generally helpful	3%	3%	0%
Used, but ineffective/Discuss, but generally not helpful	0%	3%	3%
Light therapy			
Never used, not interested/Do not discuss, generally not helpful	23%	23%	30%
Never used, would consider/Do not discuss, but would be willing to consider	71%	59%	50%
Used, and helpful/Discuss, and generally helpful	3%	8%	10%
Used, but ineffective/Discuss, but generally not helpful	3%	10%	10%

The first item in the stem applies to youth/parents and the second for physicians.

In terms of specific treatment modalities, there was general agreement on the “top 10” most effective, with an emphasis on nonpharmacologic interventions by families. Not surprisingly, stimulant medications, sodium oxybate, and modafinil/armodafinil were the most commonly rated effective therapies by families and physicians. Nonpharmacologic therapies including scheduled bedtimes and wake times, naps, and fitness and nutrition were highly rated by families and physicians. These findings also suggest that more research is warranted into the effect of dietary manipulation on narcolepsy symptom control; one previous trial in adult patients with narcolepsy did demonstrate a significant reduction in daytime sleepiness scores with a lower carbohydrate diet.¹³ CBD oil was one treatment modality that was much more frequently endorsed as potentially effective or of interest to families compared to physicians and therefore may also warrant further research and evaluation as a potential adjuvant therapy for patients with narcolepsy. Newer medications (pitolisant and solriamfetol) were rated lower, likely due to lack of pediatric experience and limitations on availability; we anticipate this will change as availability increases over time.

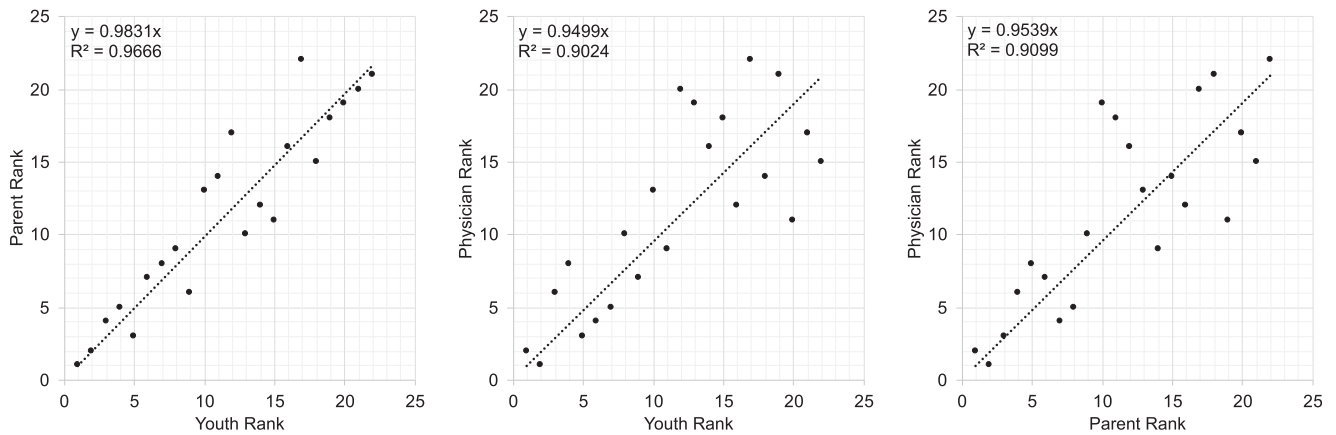
There are several important and practical clinical implications of our findings. First, as discussed above, clinicians and families may want to consider nonpharmacologic therapies in addition to medications used to manage narcolepsy. Specifically, exercise, diet, and sleep schedule management may be particularly salient. Second, our data strongly support a multispecialty and comprehensive care approach for youth with narcolepsy. Both families and physicians endorsed a desire for an interdisciplinary care model (with an emphasis on providers spanning sleep medicine, mental health, social work, and nutrition), with multiple specialists seen in the same day, and with regular follow up every 3–6 months. Third, tracking care quality over time was also of value to both families and physicians, supporting the quality metrics devised by the AASM; publicly

reporting such metrics was more of interest to families than physicians. Fourth, our data demonstrate a large interest and greater need for promotion of auxiliary services such as narcolepsy support groups, family education days, and narcolepsy camp. Fifth, analysis of open-ended responses also identified key attributes that families value in their treating physicians, including talking directly to the youth with narcolepsy during visits, a willingness and openness to consider new or alternative treatment modalities, and a desire by families for their treating physician to be up to date on the latest research and treatments for narcolepsy in youth. Physicians almost universally discussed the importance and desire to provide interdisciplinary care for their patients with narcolepsy.

The current study has several strengths. First, our results were obtained via a wide variety of viewpoints, including the perspectives of parents, youth with narcolepsy, and physicians. Second, although to preserve anonymity we did not query respondents regarding geographic location, the fact that the survey was distributed via a worldwide patient advocacy organization (WakeUpNarcolepsy) suggests that our findings may apply to a wide array of settings. Third, our inclusion of open-ended responses allowed for a richer appreciation of family and physician experiences.

Our study does have several important limitations. First, the survey nature of our study is inherently subjective and at risk for response bias. Specifically, treatment efficacy was judged by respondents using self-reported answers to survey questions rather than objective metrics such as maintenance of wakefulness testing or standardized questionnaires. That said, the nature of our survey responses likely reflects information that is of practical utility for clinicians caring for youth with narcolepsy. Second, several of the treatment options queried, pitolisant and solriamfetol in particular, are relatively novel with limited experience reported. Only a handful of youth or parent respondents endorsed experience with solriamfetol or pitolisant. Although these medications have been approved for use

Figure 1—Comparison of respondent relative ratings of treatment modality effectiveness.



Each queried treatment modality was ranked according to the percentage of respondents saying it was “Used, and helpful” (youth/parents) or “Discuss, and generally helpful” (physicians).

Figure 2—Percentage of sleep physician respondents who reported currently tracking the listed individual quality measures published by the American Academy of Sleep Medicine.

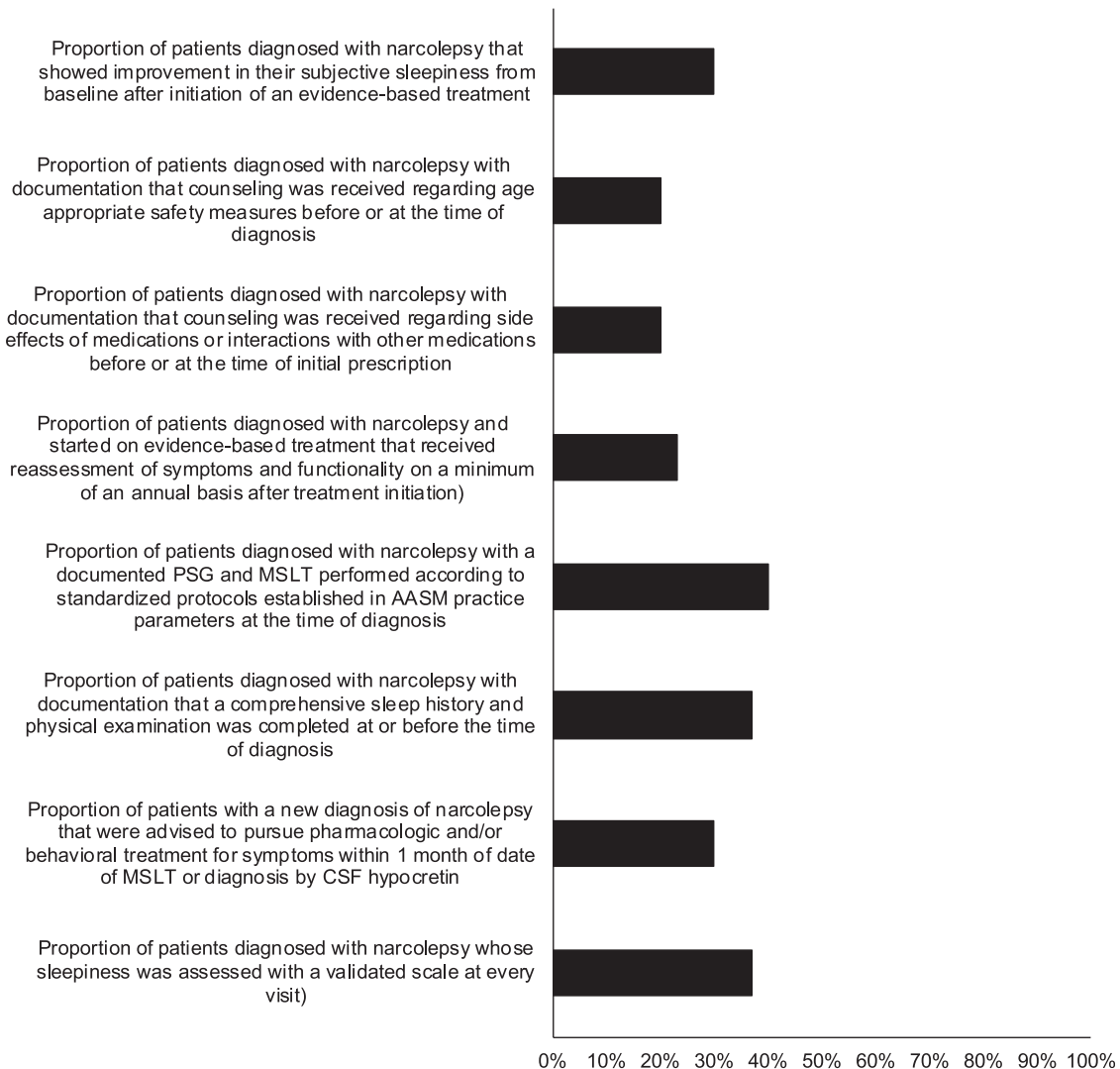


Table 3—Parent responses to open-ended questions.

Question	Themes
What is most valuable or helpful about the care provided by your sleep clinic?	• Willingness (n = 13)
	• Listening (to patient and family) (n = 20)
	• Encouragement/Understanding/ Support (n = 18)
	• Prescribing Medications (n = 20)
	• Providing Knowledge or Information (n = 18)
	• Spending ample Time with patient (n = 7)
	• Access to Multiple Providers (n = 4)
What do you wish was part of the care provided by your sleep clinic/provider that is currently absent?	• Greater Knowledge of issues, research, and information (n = 25)
	• Support group access/patient organization Resources (n = 12)
	• Willingness to try something different/new meds/think outside of the box (n = 10)
	• Being Understanding of the needs (n = 4)
What would the ideal sleep clinic visit look like for your child's narcolepsy?	• Access to other providers (Multi-Disciplinary Team) (n = 28)
	• Would have multiple specialists/ Multi-Disciplinary Team (n = 32)
	• The doctor would be educated/ Knowledgeable regarding narcolepsy, treat, research, etc. (n = 8)
	• Appointments would not be rushed, Ample Time to discuss patient, ask questions, and share information (n = 9)
Are there any issues that your child's sleep doctor is not currently addressing that you wish they would?	• Listening/Discussion (n = 9)
	• Social/Emotional Impact (n = 11)
	• School Issues (n = 6)
	• Symptom Issues understanding symptoms and managing them (n = 17)
	• Medication Issues (n = 8)

Themes are in bold. n Values represent the frequency of responses coded to the theme.

Table 4—Youth responses to open ended questions.

Question	Themes
What is most valuable or helpful about the care provided by your sleep clinic?	• They Listen to me (n = 8)
	• They are Understanding (n = 5)
	• Medication aspects (n = 11)
	• They are Knowledgeable/Informative (n = 9)
What do you like least about going to your sleep clinic appointment?	• Long Wait Times (n = 8)
	• Distance to travel to get to clinic (n = 8)
	• Talking about Problems (n = 2)
	• Recommendations/ Outcomes (n = 7)
What do you wish was a part of the care provided by your sleep clinic/provider that is currently missing?	• Therapy sessions/ Support Groups (n = 4)
	• More Information and discussions (n = 6)
	• Other providers (Multi-Disciplinary Team) (n = 5)
What would the ideal sleep clinic look like for your narcolepsy?	• Greater engagement and Discussion (n = 11)
	• Holistic/multiple provider supports (Multi-Disciplinary Team) (n = 3)
What suggestions do you have for sleep doctors to improve the care of children and adolescents with narcolepsy in the future?	• Listen to your patients (n = 4)
	• Provide Information for events/supports (n = 11)
	• Educate and Advocate (Both Patients and the Community) (n = 5)
	• Believe Patient (children) (n = 2)
	• Holistic Approach (Multi-Disciplinary Team) (n = 2)

Themes are in bold. n Values represent the frequency of responses coded to the theme.

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Table 5—Physician responses to open ended questions.

Question	Themes
What do you wish was different about the way you deliver care to your patients with narcolepsy?	• Multi-Disciplinary Team approach (n = 17)
	• Diagnosis Time (n = 4)
	• More Time for appointments (n = 3)
If you could design the ideal pediatric narcolepsy clinic, what would it look like?	• Additional services/Multi-Disciplinary Team approach (n = 20)

Themes are in bold. n Values represent the frequency of responses coded to the theme.

in adult patients with narcolepsy, neither currently has a pediatric indication. We chose to include these medications on the survey despite their novelty, as it is common for medications to be prescribed for pediatric narcolepsy without explicit pediatric indication; in fact, at the time of writing, only 1 medication (sodium oxybate) actually has an indication for pediatric narcolepsy. Without a priori knowledge of prescribing practices of pediatric sleep physicians at the time of survey development, we chose to include all possible medications rather than limit choices. Third, the respondent sample was predominantly White with a lack of respondents from minority groups. This is an important limitation, as some previous investigations have found differential symptom expression in minority groups.^{14,15} The reason for the lack of participants with minority status is unclear but may be due to either a lack of participation in the channels used for survey invitation or a differential preference for those individuals choosing not to participate in the survey itself. Certainly this would be an area worthy of future investigation. Fourth, no youth with narcolepsy were included in the survey development phase, which in retrospect would have been ideal. That said, all authors were included in survey development, with representation for pediatric sleep physician (DGI), pediatric sleep psychologist (SLS), and parents of children with narcolepsy (LJ and CC). Another limitation related to survey development was that the survey response choices of “ineffective” and “not helpful” may not necessarily be interchangeable. Fifth, more detailed queries regarding formulations, dosages, and detailed responses with respect to efficacy and side effects would have been ideal and an area worthy of future investigation. We limited our response categories as written in an effort to reduce survey fatigue for our respondents, as the survey was quite long even without asking for those desired details.

In conclusion, results from this study add to the growing literature supporting a biopsychosocial model for the management of narcolepsy in youth. A more holistic care approach might better be delivered via an interdisciplinary vehicle with consideration of both pharmacological and nonpharmacological therapies. Our results highlight both family and physician desire for such a treatment model, as well as the value of auxiliary services for family support and the tracking of quality metrics. Finally, this study highlights the need for additional research into the relative effectiveness and safety of a wide variety of treatment modalities including dietary therapy, newly developed medications for narcolepsy, and CBD oil.

ABBREVIATIONS

AASM, American Academy of Sleep Medicine
 CBD, cannabidiol oil

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