

SCIENTIFIC INVESTIGATIONS

Building a deeper understanding of social relationship health in adolescents with narcolepsy disorder

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Study Objectives: Common symptoms for patients with narcolepsy can have a significant impact on social health. As one peak for symptom onset is adolescence, these symptoms impact social relationships during a critical developmental period. Much of the existing literature in this domain has relied on broad questionnaires, with less insight into the nuances of patients' potential social struggles.

Methods: Adolescents (aged 12–17 years) with narcolepsy and their parents individually completed a semistructured interview (n = 14 dyads). Interview transcripts were analyzed using a multistage thematic analysis.

Results: An overarching theme was the difficulty adolescents experienced trying to balance narcolepsy symptom management with engaging in social activities in a meaningful way. Narcolepsy affected social relationships in 3 primary domains: mood, physical activities, and driving. Adolescents reported that they were frustrated with feeling as though narcolepsy sometimes defined their social lives. Adolescents and parents expressed a desire for medical providers to better understand their evolving priorities, to validate their social limitations, and to provide more information around the social implications of narcolepsy and its treatment.

Conclusions: Narcolepsy has a significant impact on social relationships in adolescents, one that is not adequately managed in current clinical care models. A routine, structured assessment of social health is a vital first step for providers treating adolescents with narcolepsy. Medical centers and patient organizations can play an important role in facilitating social opportunities for this underserved population.

Keywords: narcolepsy disorder, social relationship health, adolescent, qualitative interview

Citation: Zhou ES, Revette A, Heckler GK, Worhach J, Maski K, Owens JA. Building a deeper understanding of social relationship health in adolescents with narcolepsy disorder. *J Clin Sleep Med.* 2023;19(3):491–498.

BRIEF SUMMARY

Current Knowledge/Study Rationale: Common narcolepsy symptoms (eg, cataplexy, daytime sleepiness) can have a significant impact on social health. As narcolepsy symptom onset often occurs during adolescence, a key developmental period for social relationships, we sought to develop a richer understanding of this issue for adolescents with narcolepsy.

Study Impact: Social relationship health has been a largely overlooked quality-of-life domain for adolescents with narcolepsy. It is critical for providers to discuss the unmet social needs of their patients and to support adolescents as they navigate the complicated tasks of developing and maintaining friendships/romantic relationships with a chronic medical condition.

INTRODUCTION

Narcolepsy is a lifelong sleep disorder characterized by sleep paralysis, hypnagogic hallucinations, disrupted and nonrestorative sleep, excessive daytime sleepiness, and/or cataplexy.¹ It is well known that narcolepsy disorder has a considerable impact on day-to-day functioning, with consistent data showing its negative impact on quality of life.^{2,3} At a critical stage in their development, pediatric patients' narcolepsy impairs their cognitive function,^{4–7} disrupts everyday life,^{8–10} and is associated with psychological comorbidities.¹¹ In combination with the symptoms of narcolepsy (eg, daytime sleepiness and cataplexy), this sequelae profile has been hypothesized to have "important implications for social relations."¹²

One subpopulation for which this hypothesis is highly relevant are adolescents. The burden of narcolepsy disorder

disproportionately affects the lives of adolescents because one peak for symptom onset occurs at approximately 15 years of age.^{13,14} Close to half of patients with narcolepsy begin to experience symptoms before 20 years of age.¹⁵ Developmentally, adolescence is a seminal period during which individuals develop many core relationships that can last their whole lives.¹⁶ During this period, healthy adolescents explore and begin to establish their adult identity through these friendships and romantic relationships,^{17,18} many of which form part of the foundation of their sense of well-being.¹⁹

Prior literature has shown that 45% of children with narcolepsy (aged 7–16 years) experience social impairments, with severe social impairments 17 times more likely than in an age- and sex-matched healthy control population.²⁰ In another study, children with narcolepsy (also aged 7–16 years) scored significantly worse than children with idiopathic epilepsy and healthy

control patients on multiple social health subscales of a parent-reported measure of child behavior.⁵ Finally, a survey of youth with narcolepsy (between 12 and 22 years of age) revealed that 60% of patients and parents rated social awkwardness/isolation as either a “medium” or a “big” problem.²¹ For sexually active adolescents, there are further complexities to consider. For example, teenage girls taking modafinil/armodafinil must be more cautious about unwanted pregnancy, and cataplexy may occur in conjunction with sexual excitement/orgasm for boys and girls. In addition, social stigma may accompany a narcolepsy diagnosis.²²

While this prior research has successfully identified that social relationship health is likely to be disturbed in adolescents with narcolepsy, this work has mostly relied on single-item queries or social subscales of general quality-of-life measures. These nonspecific instruments provide minimal insight into the depth and nuances of the social struggles for this population. Further, a recent review proposing a biopsychosocial model for clinical management of pediatric narcolepsy noted that there is a lack of input from key stakeholders.²³ In this study, we report on our efforts to build a deeper understanding of social relationship health in adolescents with narcolepsy. We conducted semistructured interviews with both the adolescent and a parent, seeking to gather greater insight into the entire family’s experience. A richer understanding of the impact of narcolepsy on social relationships for adolescents with narcolepsy is a fundamental first step toward better clinical care.

METHODS

Sample

Study participants were dyads, including an adolescent between 12 and 17 years of age (as defined by the Centers for Disease Control and Prevention’s “Young Teens” and “Adolescence” categories) and one parent/primary caregiver. To be considered eligible for study participation, the adolescent had to have a physician-confirmed diagnosis of narcolepsy type 1 or type 2 using polysomnography/Multiple Sleep Latency Test data or cerebrospinal fluid orexin testing. Further, the adolescent had to possess English fluency and not present with a psychiatric or developmental disorder that would interfere with the ability to participate in an interview. Data were abstracted from the patient’s medical record regarding the narcolepsy medication plan and Epworth Sleepiness Scale²⁴ score if we had documentation of a medical appointment that occurred within 3 months of the patient’s interview date. The data were acquired through the medical record of patients at Boston Children’s Hospital or a medical history form from patients not at Boston Children’s Hospital. We did not include additional eligibility criteria, in an effort to capture the diversity of adolescents with narcolepsy.

Procedure

Our sampling strategy was purposeful in nature, aimed to include sufficient, information-rich materials on patients across the study’s age range. Study recruitment occurred through one of two pathways. First, direct referrals were made by the patient’s sleep medicine physician at Boston Children’s Hospital. Appropriate patients

were provided with a study flyer at the time of a medical appointment. If the family members expressed study interest, then they were contacted by a research coordinator. Second, support groups for patients with narcolepsy (eg, Wake Up Narcolepsy) shared a link to the study flyer on their website. Interested participants were directed to contact study staff, at which point they were instructed to have their sleep physician send our team a verification that they had been diagnosed with narcolepsy disorder. Once participants confirmed their interest in study enrollment, the dyad was instructed on the completion of online assent (adolescent) and consent (parent/caregiver). Participant dyads were thanked for their time with a \$100 gift card. Data collection ceased when thematic code saturation was reached.²⁵ Study procedures were approved by the Institutional Review Board of Boston Children’s Hospital.

Study interview

Semistructured interview guides for the adolescent and the parent/caregiver were developed in an iterative process with the core stakeholders. Stakeholders included an adolescent with narcolepsy, a parent/caregiver of an adolescent with narcolepsy, and study investigators with expertise in pediatric narcolepsy, pediatric sleep medicine, pediatric behavioral sleep medicine, and qualitative research methodology. The interview guide explored several key content areas, including the patient’s narcolepsy history and management (medication and nonmedication), friendships and romantic relationships, and perception of the impact of narcolepsy symptoms on social relationships (Appendix A in the supplemental material). Given the potentially sensitive nature of the content discussed, adolescents and their parent/caregiver were interviewed separately to ensure confidentiality and to increase the probability of gathering honest perspectives. All study interviews were conducted via Zoom audio.

Analytic plan

The primary aim of this study was exploratory. Study interviews were conducted by a study author (AR) with doctoral-level expertise in qualitative research and extensive experience with adolescent patient populations, but no prior relationship with the participants. All interviews were recorded and transcribed, with interview transcripts analyzed using a multistage thematic analysis.^{26–28} A codebook for each population (adolescents and parents) was collaboratively and iteratively developed by investigators (ESZ and AR). ESZ and AR read and reviewed all transcripts before drafting the codebook, which then included prefigured codes that aligned with domains of interest from the interview guide and emergent codes identified in the data. The finalized comprehensive codebook was then applied to all applicable transcripts. Systematic coding was followed by code summarization, in which each individual code was reviewed and summarized. Through an extensive review of the coded data, the team identified overarching connections between the most salient codes. The final steps of the analysis focused on identifying key patterns, concepts, contexts, and themes within and across patient and parent groups to characterize the key symptoms of narcolepsy and the impact of narcolepsy on social relationships during adolescence. Each stage of the coding and analysis was shared and discussed with the research team.

These methods were enhanced using the NVIVO qualitative data management software program (QSR International, Burlington, MA) and followed Consolidated criteria for reporting qualitative research (COREQ) guidelines (Appendix B in the supplemental material).

RESULTS

Between July and December 2021, 18 dyads consented, of which 14 ultimately completed the study interviews. As interviews were completed, transcripts were reviewed and discussed with the team. Recruitment ended when the team concurred that new interviews were no longer introducing new and meaningful domains or topics of interest. Of these 14 dyads, 3 patients were seen outside of Boston Children’s Hospital. All adolescents had been diagnosed with either narcolepsy type 1 (12; 85.7%) or narcolepsy type 2 (2; 14.3%). Further, all adolescents used one or more medications to suppress their narcolepsy symptoms. The adolescent participants were between ages 12 and 17 years (\bar{x} = 15.1 years; standard deviation = 1.6). Among them, 4 females were enrolled (28.6%) and the majority were non-Hispanic White (8; 57.1%). The parent/guardian participants were mostly the adolescents’ mothers (13; 92.9%). See **Table 1** for additional study demographics.

Table 1—Study demographics and adolescent medical characteristics.

	n (%) or Mean (SD)
Narcolepsy diagnosis (n = 14)	
Type 1	12 (85.7)
Type 2	2 (14.3)
Sex (n = 14)	
Male	10 (71.4)
Female	4 (28.6)
Age (n = 14)	15.1 (1.6)
Race (n = 14)	
White	8 (57.1)
Black	5 (35.7)
Other	1 (7.1)
Ethnicity (n = 14)	
Non-Hispanic White	13 (92.9)
Hispanic	1 (7.1)
Narcolepsy medication (n = 11)	
Sodium oxybate	4 (45.5)
Wake-promoting	11 (100.0)
SSRIs/SNRIs	8 (72.7)
Epworth Sleepiness Scale (n = 11)	11.2 (2.5)

Medication and Epworth Sleepiness Scale data were not accessible for the 3 patients recruited from outside of Boston Children’s Hospital. SD = standard deviation, SNRIs = selective norepinephrine reuptake inhibitors, SSRIs = selective serotonin reuptake inhibitors.

Overall themes

The overarching theme for both adolescents with narcolepsy and their parents highlighted the difficulty of balancing the benefits of maintaining a strict “narcolepsy schedule” to manage their symptoms while still trying to engage with peers and friends in a meaningful way. This theme was underscored in the convergence of experience discussed by parents and adolescents along two key symptoms and three primary social impact domains. Across adolescents and parents, symptoms of daytime fatigue and cataplexy were the most commonly discussed and were characterized as having an impact on social relationships. There were crosscutting social impacts of narcolepsy in three domains: mood, physical activities, and driving. As a result of these challenges, adolescents reported that they were frustrated with feeling as though narcolepsy sometimes defined their social lives due to their consistent efforts to having to find ways to cope with narcolepsy symptoms in the context of social engagements. Adolescents and parents expressed a desire for medical providers to better understand the evolving priorities of adolescents with narcolepsy, to validate their social limitations, and to provide more information around the social implications of narcolepsy and its treatment during adolescence. The findings below are organized along key impact domains, and exemplar quotes are provided in **Table 2**.

Adolescents with narcolepsy disorder

Overall

Most adolescents noted that they did not have a lot of friends. Some characterized their current friendship situation as lonely, hard, and uncomfortable, while others noted that they had a few close/good friends. Even for those who reported having good friends, they wished that they had more friends and spent time with people more often, or they noted that they would be open to making new friends. They partially attributed their social relationship limitations on constantly needing to plan ahead, prioritizing a specific schedule to navigate the tiredness associated with narcolepsy, such as going to bed early. When planning ahead was not feasible or unexpected plans arose, adolescents described having to leave early, cancelling plans altogether, and even needing to be cautious with the individuals they spent time with. One example of how adolescents coped with their challenges was prioritizing time with friends who were understanding and supportive of their narcolepsy symptoms.

All adolescents noted specific ways that their relationships were affected by narcolepsy symptoms. They discussed the cognitive impact of feeling tired throughout the day, including not being able to focus on a conversation, which had negative consequences on their relationships. One adolescent even reported “sleeping through” grade 7, resulting in the loss of friendships and social confidence. The effects of cataplexy ranged from being characterized as a minor inconvenience to the biggest issue that adolescents faced. Cataplexy was described as most often brought on by laughter. For some the cataplexy severity was linked to medication management, with one participant noting that before taking a drug targeting the cataplexy,

Table 2—Exemplar quotes from adolescents with narcolepsy and their parents regarding the impact that narcolepsy disorder has on their social relationships.

Domain	Subdomain	Representative Quotes Adolescent	Representative Quotes Parent
Overall		<p>“When my narcolepsy was at its worst, I’d say, and I couldn’t function very well ... I didn’t really have my best friend anymore and like I wasn’t as close to people and I kind of lost all of my confidence.” (ID #5C)</p> <p>“A lot of times I won’t text them back I won’t answer them because I just don’t have energy in me ... I’ll make plans with them, and then the time comes I’ll feel too tired, or I just won’t be feeling it, and then I’ll just cancel on them last minute.” (ID #20C)</p>	<p>“I’ve heard him say things like, I don’t have any friends or only have one friend. And I think he wishes he could have more friends and that people liked him more and more likable. He doesn’t believe that he’s likable. But I also know that he just believes that he’s completely different. He has narcolepsy. People look at him differently. He really feels pretty strongly about that.” (ID #9P)</p> <p>“What he just tends to do is just avoid those situations or not go at all. Or leave early. Which has an impact over time when you feel like you’re the one that’s leaving all the time.” (ID #3P)</p> <p>“It takes too much energy to engage with groups of people, and I think he just doesn’t—didn’t have it to do it, so it was better—it’s easier for him to withdraw than to try and engage with large groups of people.” (ID #2P)</p>
Impact	Mood	<p>“With having narcolepsy, it gives [my mood] a boost in a bad way, I guess. So in the morning I’ll be sort of moody towards my parents and my brothers just because I just woke up and I don’t really want to wake up.” (ID #3C)</p> <p>“The drowsiness of it, it really gets me sometimes. I’ll just be fully negative, not really caring about anything else. And I try my best not to be, but it’s tough.” (ID #9C)</p>	<p>“When you’re just losing all of your friends and not keeping up with the people around you, it was kinda like she had a breakdown, almost ... it lasted, I don’t know, 6 months to a year, I mean, she was definitely emotional—she would just fall apart ... she really lost everything.” (ID #5P)</p> <p>“She struggles a lot with anxiety and depression ... truthfully, at the beginning when it was undiagnosed, I couldn’t handle it. I could not handle the pressure of being the person that she was always crying with. She’d get that look on her face, and then she would tell me how bad her life was.” (ID #21P)</p>
	Physical activities	<p>“It really just—it lowers my, I guess, willingness to do those things when usually I would love to do them ... I really can’t play basketball for long periods of time without needing a nap. And sometimes that can get in the way.” (ID #2C)</p>	<p>“When the winter sport times came for him to sign up for basketball again, he did play, but he just couldn’t—like he needed a lot of breaks. He was just tired all the time. And he didn’t really—like when the kids would like high-five or like cheer together, he was kind of like on the outside, like sitting down resting, like not in the middle of all the hustle and bustle.” (ID #2P)</p>
	Driving	<p>“Sometimes me and my friends we go out later at night ‘til 10 PM or 10:15 PM, so I never drive. And I’m like, oh, OK, someone else can drive. Because normally I’m going to bed at this time, so I just rather not take any chances and y’all can drive.” (ID #1C)</p>	<p>“I do think him not having his license and doing those kind of things, those kind of teen rites of passage that he’s missing out a little bit is a bummer for him. When everyone’s getting their license and going to driver’s ed and he’s not at that point.” (ID #3P)</p>
Suggestions for medical providers		<p>“I feel like since most doctors are older and don’t have to deal with high school, they don’t understand how some people are really involved in school and don’t want to miss anything, so taking naps in school could disrupt their learning process.” (ID #3C)</p> <p>“[The doctor has to make] sure that my mental health is in check. Because narcolepsy, its symptoms can be a bit isolating. So, making sure that if you are isolating, and making sure that you are mentally doing OK. Because if you’re in a depression, it’s a bit harder to make friends or be social.” (ID #21C)</p> <p>“They’d focus on a lot of medication ... and not how it’s affecting you mentally or like not kind of physically. Because you know, that’s important especially for a teenager or even a middle schooler.” (ID #13C)</p>	<p>“What I would want is for our experience to be replicated, for people to understand that having a provider who really gives a kid a lot of good information to work with—and even let the parent know, yeah, no, this is not regular parenting, this is hard—you know, those things are really valuable.” (ID #1P)</p> <p>“I think that there should be mandatory counseling ... there needs to be emotional support. There needs to be counseling groups. And doctors don’t even know. Last time I went into the doctor’s office, I had a brief talk about [patient]. And she didn’t even know. Our family GP didn’t even know that narcolepsy is caused by the loss of orexins in the lateral hypothalamus. That was the first she heard of it was when I was telling her about it.” (ID #21P)</p>

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this symptom would take over. For those whose social lives were impacted by cataplexy, the effects were characterized significant. One participant noted avoiding the deep end of swimming pools because the participant feared drowning if he or she laughed.

Mood

Adolescents discussed feeling negative, annoyed easily, grumpy, stressed out, and depressed and having low mental energy. These emotional impacts were most often associated with them feeling physically tired/fatigued because of their narcolepsy disorder. Participants described how their mood could then make their friends back off or stay away, be upset, or even reciprocate their lack of engagement. However, some noted that friends would be understanding and just give the participant space.

Physical activities

Physical activities, including organized sports and nonorganized activities (eg, walks) were discussed by adolescent participants as something in which they could engage with their friends outside of school. While participants were generally able to participate in physical activities, most noted at least some level of limitation regarding their ability to engage the way they would like to. Daytime fatigue was described as reducing their willingness to participate, limiting the amount of time they could spend playing or requiring a break during the activity.

Driving

Driving was discussed by many adolescents, some of whom were not yet of age to legally drive. Of the two participants who were currently driving and raised the issue, one did not drive after 10:00 PM and the other felt an increased responsibility with friends in the car. For those who were not driving, one participant was hoping to be cleared to drive soon but would not be permitted to drive with friends in the car. Two other participants were not yet old enough to drive, but one participant saw the future inability to drive as a potential limitation around dating.

What medical providers can do better

Adolescents emphasized the importance of having their social challenges validated as they did not want their peers to define them as “that person with narcolepsy,” and they did not want to believe that narcolepsy would be the “be-all, end-all” of their life. They focused on dynamics that were lacking in the care they were currently receiving and asserted that providers should do a better job of trying to understand what was important for their younger patients, noting that these needs can change year to year as they develop. For example, one participant wished that the provider acknowledged the difficulty of incorporating daytime naps into the participant’s schedule as a high school student. Participants also expressed a desire for more thorough information pertaining to how their mental health (eg, anxiety, depression) could influence their social relationships. In addition, they advised setting aside appointment time without their parents as a way to speak privately about drug and alcohol use and the impact of their narcolepsy medications on other sensitive subjects.

Parent

Overall

The parents’ perception of their children’s level of happiness or satisfaction with the quality and quantity of their social relationships ranged widely. For those who characterized their children as satisfied/happy with their social relationships, parents often emphasized the quality of the children’s relationships over quantity, describing their children as having a few core relationships that sometimes included family members. For those who characterized their children as unhappy with their current relationships, parents explained how their children had no friends or very few friends, had lost their friends, did not have close friendships, felt unlikable, and/or desired to have more or better friendships. Overall, parents noted that their children’s narcolepsy caused them to miss out on social opportunities, become less outgoing, and be invited out with friends less.

Parent participants were more likely than the patient to identify the “tremendous” impact that narcolepsy had on social relationships. Parents described their children as socially vulnerable, experiencing difficulty making friends, and lacking the drive to do things socially. Tiredness/fatigue and cataplexy were again key symptoms that impacted various domains of their child’s life including sports, driving, and mental health. Parents identified many situations in which their children would fall asleep, show up late or leave early to facilitate naps, be embarrassed about naps, avoid sleepovers, avoid spending time with friends, avoid after-school activities, and avoid engaging with friends because of the effort it took. Parents also associated cataplexy with laughter, but the perceived impact varied across parent. For example, some described situations in which friends would recognize or be aware of the issue and maybe make some light fun of their child but would be generally supportive and helpful. Others described a more significant impact from cataplexy, including being afraid to interact with friends due to fear of cataplexy, being unable to relax with friends, and cataplexy causing anxiety and self-consciousness. These situations were seen as carrying a significant social impact. To help the adolescent cope, parents emphasized the importance of keeping a consistent schedule for sleep and daily activities, along with constant communication with the children as well as other important figures (eg, a teacher). Parents were active in trying to increase the opportunities for social interactions, such as encouraging their adolescents to join clubs or sports or to go see friends.

Mood

Nearly all parent participants identified emotional dynamics associated with their children’s narcolepsy. However, the perceived impacts on their social relationships fell across a wide range, from moodiness or grumpiness compared to serious suicide concerns. Feelings of anxiety and depression were the most commonly discussed emotional aspects of narcolepsy, with some parents struggling to understand if some of the relationship issues faced by their children were driven by narcolepsy or another factor. Participants also discussed their children feeling unlikable, isolated, irritable, easily overwhelmed, and hypersensitive. These feelings were exacerbated when their children were physically tired/fatigued.

Physical activities

Similar to the adolescent conversations, parents noted limitations in their children's ability to participate or perform in both organized and nonorganized physical activities because of narcolepsy. These limitations included lack of energy, tiredness/need for breaks, and inconsistent and reduced skill in athletic performance. Parents also described negative emotional impacts of these limitations (emotional breakdowns, outbursts, sensitivity) and having to limit the type or number of activities they participated in.

Driving

Parents also discussed driving; most described limitations on their children's ability or comfort driving because of narcolepsy. Some parents expressed concerns that their children could not get their license or were delayed in getting their license, or general fears about their children driving in the future. For those children who were not able to drive/get their license, parents described how this was difficult as the children were missing out on experiences that their peers were able to have.

What medical providers can do better

Parents did not want their children defined by their narcolepsy, hoping for more tools to be able to support their social development. Specifically, it was noted that many pediatricians and primary care providers lacked narcolepsy-specific knowledge. Optimizing medications with a knowledgeable physician was identified as a helpful element associated with better social relationships by some parents. Parents wanted their medical providers to provide resources that connected their children with other children with narcolepsy disorder. A few parents also suggested that physicians should provide mental health referrals, with some going so far as to suggest mandatory counseling for adolescents with narcolepsy. Like the adolescents, parents also emphasized the importance of having their children's social struggles validated by the sleep physician.

DISCUSSION

Our current treatment model for pediatric narcolepsy disorder focuses on the pharmacologic management of physical symptoms such as excessive daytime sleepiness and cataplexy and not on psychosocial health. In recent American Academy of Sleep Medicine clinical practice guidelines for the treatment of central disorders of hypersomnolence (including pediatric narcolepsy), it was acknowledged that even though addressing nonmedical health needs is "often needed to optimally treat patients," there was not enough research in this domain to make any recommendations.²⁹ During a critical juncture in their social development, the whole-patient needs of adolescents with narcolepsy are simply not being adequately met.

Our data indicate that the social impact of narcolepsy is pervasive. Almost every adolescent and parent in our study reported some version of the story of the need to constantly balance what was best for the narcolepsy disorder symptom control vs what would be best for social relationships. This finding is consistent

with prior research in which every single one of 254 young adults with narcolepsy responding to an online survey reported that their sleep disorder made social life more difficult.³⁰ Further, the persistent need to make decisions that typically developing adolescents do not have to concern themselves with was exhausting. In the literature, adolescents with chronic medical illnesses report fatigue or burnout when they must constantly think about how to manage their health, resulting in poorer mental health and quality of life.^{31,32} As increased rates of mental health disorders among pediatric patients with narcolepsy have already been shown,^{33,34} the ongoing social struggles for adolescents add another layer of complexity in our efforts to address their emotional well-being.

There is cause for optimism in that we revealed specific domains in which proper management may mitigate some of the effects of narcolepsy disorder. The fatigue that adolescents with narcolepsy often struggle with plays a key role in creating poorer overall mood, which in turn results in the adolescents not engaging in or disconnecting from their social network. This fatigue also causes clear limitations for their ability to participate in recreational pursuits such as team sports or bike rides with friends. These opportunities are some of the most important for the development of an adolescent's social network,³⁵ and engagement in these pursuits is associated with decreased risk for depression.³⁶ Thus, it is vital that medical providers are vigilant about ensuring that daytime fatigue is adequately managed. Next, the ability to drive is at the forefront of the adolescent's mind, with multiple teens who are not yet of legal driving age already cognizant of the impact that driving limitations due to their narcolepsy may have on their social relationships. A car is central to an adolescent's social life—a relationship that has held true across multiple decades of research.^{37,38} It would be wise for physicians to proactively discuss the narcolepsy-related metrics that an adolescent is expected to meet before they will sign off on a driver's license (eg, medication adherence, control of daytime sleepiness), and target treatment toward improving those metrics.

Health providers caring for adolescents with narcolepsy, including primary care and specialty physicians, nurse practitioners, and mental health providers, need to provide these patients with an open and respectful environment that invites and validates discussion and dialogue regarding their concerns. As with all adolescent patients with a chronic medical disorder, the profound developmental changes across this time span (eg, maturation of executive functions, emergence of sexual preferences and orientation, increasing need for autonomy and independence) need to be appreciated and incorporated into treatment recommendations. This also requires some degree of acceptance on the part of both the adolescent (and family) and the provider that strict adherence to the intervention strategies that help manage the narcolepsy disorder may pose a direct conflict with these developmental goals and are likely to meet with resistance. The theme of mood changes as expressed by both patients and parents underscores the critical need for medical providers to routinely screen adolescents with narcolepsy for depression and anxiety and to appreciate that symptoms may not be "just the narcolepsy." Recommendations have already been made to implement behavioral health screenings in pediatric primary care settings to improve the detection and treatment of mental health disorders.³⁹ In adolescents with

narcolepsy, those who are high achievers may be particularly vulnerable to feelings of frustration and disappointment, as well as lowered self-esteem, when confronted with limitations imposed by their narcolepsy symptoms.

Study limitations and future directions

There are study limitations that warrant further efforts to better understand this important domain in adolescents with narcolepsy. First, we did not systematically collect data on symptom severity in the context of this study. It is possible that those with more difficult-to-treat symptoms experience greater impacts of the disorder on their social relationship health. Second, the terms *fatigue* and *sleepiness* were often used interchangeably by participants during study interviews, even though clinicians recognize that the two are unique symptoms (fatigue describes a state of overall tiredness, whereas sleepiness is characterized by the inability to stay awake during normal daytime hours). Health care providers should consider using separate assessment tools for fatigue and sleepiness in clinical visits to ensure a clearer understanding of the severity of each symptom and its contribution to functional limits. It may also be that patients and families would benefit from education on distinguishing these common narcolepsy symptoms. Next, most participants were non-Hispanic White males with narcolepsy type 1. The experiences captured in our research may not be generalizable to a more diverse population, including those with narcolepsy type 2. Future studies should prioritize the inclusion of a more varied sample. In addition, most of our families were identified via direct referrals from a sleep medicine physician. Although this may have increased study engagement, the sample could have been biased and future research should endeavor to recruit participants via different mechanisms. Further, while our study did have the strength of capturing the dual perspectives of adolescents and parents, a future study might benefit from the triangulation of participant data by including other key social stakeholders, such as teachers, coaches, and peers. Finally, as there have been recent efforts to develop nonpharmacological interventions to improve outcomes in patients with hypersomnia disorder,⁴⁰ additional focus on social support may be a relevant consideration for future program iterations. In trials studying these behavioral health interventions, the addition of patient-reported outcomes, such as quality of life, is an important next step to determine whether better psychosocial management of social relationship health can improve overall patient outcomes.

CONCLUSIONS

Helping adolescents to anticipate and negotiate situations in which they might need to explain their disorder to new acquaintances or curtail social activities with peers due to fatigue not only can provide concrete support but also serves to build trust and strengthen the provider–patient relationship. Too often, the sole treatment emphasis is on pharmacologic interventions. While clearly beneficial for many patients, disease management that includes coping skills, adherence strategies, and lifestyle

accommodations may be equally impactful. For all these reasons, it would be ideal to refer all newly diagnosed adolescents with narcolepsy to a mental health provider familiar with the challenges of the disease to screen for psychosocial comorbidities, offer behavioral management recommendations, provide an entree to the mental health system, and emphasize the availability of these services should they become necessary.

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ACKNOWLEDGMENTS

The authors gratefully acknowledge the families who agreed to participate in the study.

SUBMISSION & CORRESPONDENCE INFORMATION

Submitted for publication July 11, 2022

Submitted in final revised form October 26, 2022

Accepted for publication October 26, 2022

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DISCLOSURE STATEMENT

All authors have seen and approved the manuscript. Work for this study was performed at Boston Children's Hospital and Dana-Farber Cancer Institute. This study was funded by Harmony Biosciences. Dr. Zhou has received grant funding from Harmony Biosciences and Jazz Pharmaceuticals and consulting fees from Samsung and MindUP. Dr. Maski has received grant funding from Harmony Biosciences and Jazz Pharmaceuticals and consulting fees from Jazz Pharmaceuticals, Harmony Biosciences, Takeda, KemPharm, and Alkermes and serves on the Data Safety Monitoring Board for Idorsia Pharmaceuticals. Dr. Owens has received consulting fees from Harmony Biosciences. The remaining authors report no conflicts of interest.