

SCIENTIFIC INVESTIGATIONS

# The impact of narcolepsy on social relationships in young adults

Ryan D. Davidson, PhD<sup>1,2</sup>; Kelsey Biddle, BA<sup>2</sup>; Malik Nassan, MD<sup>2,3,4</sup>; Thomas E. Scammell, MD<sup>2,3</sup>; Eric S. Zhou, PhD<sup>1,2,3,5</sup>

<sup>1</sup>Boston Children's Hospital, Boston, Massachusetts; <sup>2</sup>Harvard Medical School, Boston, Massachusetts; <sup>3</sup>Beth Israel Deaconess Medical Center, Boston, Massachusetts; <sup>4</sup>Northwestern University, Evanston, Illinois; <sup>5</sup>Dana-Farber Cancer Institute, Boston, Massachusetts

**Study Objectives:** Narcolepsy often begins during adolescence and young adulthood, which are crucial periods for social development. The symptoms of narcolepsy likely impact social interactions, but little research has assessed the effects of narcolepsy on social relationships. The current study investigated the impact of narcolepsy on friendships and romantic and sexual relationships.

**Methods:** Young adults (18–39 years) with narcolepsy were recruited through national narcolepsy patient organizations. Participants (n = 254) completed an online survey assessing their friendships and romantic and sexual relationships, including communication about their social relationships with medical providers.

**Results:** All participants (mean age = 28.8 years; 87% female, 92% White/Caucasian) reported that narcolepsy made their social life more challenging. They reported receiving more support from significant others, compared to family or friends ( $P < .05$ ). Most (80%) indicated that narcolepsy currently impacted their sex life. Only a few participants reported that their providers asked about their social and sex lives, though they wanted providers to ask.

**Conclusions:** Narcolepsy impacts social functioning in young adults. Many individuals with narcolepsy prioritize single, meaningful, romantic relationships as developing and sustaining new relationships may be challenging. In addition, narcolepsy symptoms impact sexual functioning. Though many participants wanted to discuss their social and sex lives with providers, only a few providers ask. Treatment of narcolepsy in young adulthood should include supporting individuals regarding the impact on social, romantic, and sexual health.

**Keywords:** narcolepsy, social functioning, romantic relationships, patient–provider communication

**Citation:** Davidson RD, Biddle K, Nassan M, Scammell TE, Zhou ES. The impact of narcolepsy on social relationships in young adults. *J Clin Sleep Med*. 2022;18(12):2751–2761.

## BRIEF SUMMARY

**Current Knowledge/Study Rationale:** Narcolepsy often begins in adolescence or young adulthood and is associated with excessive daytime sleepiness, among other symptoms. Given the timing of onset and side effects of both symptoms and treatment, narcolepsy can significantly impact social and romantic functioning.

**Study Impact:** The current study is one of the first to assess the impact of narcolepsy on social functioning during a critical time for social development, young adulthood. Social functioning, including friendships and romantic and sexual relationships, is an important area of assessment when providing care to patients with narcolepsy.

## INTRODUCTION

Narcolepsy is a chronic neurological sleep disorder characterized by excessive daytime sleepiness, disrupted nighttime sleep, abnormal rapid eye movement sleep, cataplexy, sleep paralysis, and hypnagogic hallucinations.<sup>1</sup> Narcolepsy affects approximately 3 in 4,000 people in the United States,<sup>2</sup> and symptoms usually begin in adolescence or young adulthood.<sup>3,4</sup> This is a critical developmental period during which individuals explore and establish significant social relationships, setting the stage for the development of lifelong partnerships, such as a spouse/partner.<sup>5</sup> Although medical interventions can address some symptoms, many people with narcolepsy (PWN) continue to report that narcolepsy substantially impairs many aspects of their daily life, especially close relationships and social life.<sup>6,7</sup>

In the general population, social relationship health is critical to one's well-being. For example, loneliness is associated with a 26% increase in premature death.<sup>8</sup> Evidence suggests that infrequent social contact is associated with loneliness across

young adulthood and into adulthood,<sup>9</sup> and recent findings indicate that young adulthood is a period of increased loneliness.<sup>10,11</sup> Early research on the importance of social relationships focused on relationship status (single vs married). Recent research indicates that positive relationship quality and stability are more important predictors of positive physical and psychological outcomes.<sup>12,13</sup> It is important to understand the impact of relationship quality, and not just status, for young adults as they transition away from adolescence, especially as young adults have been delaying marriage.<sup>14,15</sup> In addition, growing evidence indicates that young adults may be especially impacted as lack of social contact increases loneliness,<sup>9</sup> increasing the importance of understanding factors which can impact social relationships in this age group.

Little is known about how narcolepsy impacts the social relationships of PWN, and most studies have been limited in their breadth of understanding these relationships. Two previous studies of adults with narcolepsy showed that between 19 and 27% report fewer opportunities to meet partners, and about 1 in

4 PWN reported that their narcolepsy was the reason a dating relationship ended.<sup>16,17</sup> Another study demonstrated that PWN had lower marriage rates than the general population.<sup>18</sup> In fact, these studies suggest that the impact of narcolepsy on social relationships is greater than the impact on both education and employment. Ingravallo et al noted: “It would be interesting to understand why [narcolepsy with cataplexy] had a greater impact on social lives of patients than their education and employment ... we hypothesize that difficulties in relationships are an integral part of the disease.”<sup>18</sup>

Prior studies of social relationships in PWN have several key limitations. First, they typically included only a few broad questions regarding social functioning as a part of larger surveys investigating overall quality of life. There are many forms of social relationships (eg, friendships, romantic relationships), and these studies did not specifically assess the ways in which different social relationships may be impacted. Second, many included PWN across the adult lifespan (18–89 years). This “one-size-fits-all” study approach may obscure the developmental changes to social relationships that occur with age.<sup>19,20</sup> Finally, existing research was often conducted in relatively small samples. Given the importance of social relationships and their impact on quality of life, it is essential to understand how narcolepsy impacts social functioning, especially at the crucial juncture of young adulthood. To address this crucial knowledge gap, we studied the impact of narcolepsy on a range of social relationships in young adults, their choices around disclosing their narcolepsy diagnosis in the context of these relationships, and their communication with medical providers on this subject. Ultimately, the goal of this exploratory study is to develop further insight into how PWN, their support network, and their clinical providers can collaborate to better manage their symptoms in the context of improving social relationship health.

## METHODS

### Study design

PWN were recruited through national nonprofit narcolepsy patient organizations via emails sent out by the organizations to their members. Organizations which sent emails were Wake Up Narcolepsy, Narcolepsy Network, Hypersomnia Foundation, and Project Sleep. Study procedures were approved by the Institutional Review Board of Beth Israel Deaconess Medical Center.

### Participants

Individuals were eligible to participate in the study if they (1) had received a diagnosis of narcolepsy from a medical provider, (2) were between 18 and 39 years old, (3) lived in the United States, and (4) were fluent in English. Participants were excluded if they did not complete all survey-related questions (n = 87). As many of our survey questions touched on delicate subjects, we used anonymous online survey procedures because participants answer sensitive questions more honestly when asked in this manner.<sup>21</sup> To increase the likelihood that the participant’s self-report of narcolepsy was accurate, we reviewed

study data and excluded participants who reported a diagnosis of narcolepsy type 2 along with symptoms of cataplexy (n = 8) or indicated they had idiopathic hypersomnia (n = 1). All participants completed the survey in June 2020.

### Procedure

The link to the online questionnaire was contained within an email that narcolepsy patient organizations distributed to their members. The anonymous online questionnaire was administered through REDCap (Research Electronic Data Capture), hosted at Beth Israel Deaconess Medical Center. REDCap is a secure, web-based software platform designed to support data capture for research studies. When participants clicked the link for the survey, they completed a series of screening questions to ensure eligibility. Subsequently, they reviewed a prospective agreement indicating that they were agreeing to participate in the study by continuing with the survey. After completing the survey, participants were asked to choose a nonprofit narcolepsy patient organization that would receive a \$25 donation per completed questionnaire. Responses were nonidentifiable due to the sensitive nature of some questions.

### Measures

The survey was developed through an iterative process by a group of relevant stakeholders (a young adult with narcolepsy, a sleep physician with expertise in narcolepsy, a sleep psychologist with expertise in narcolepsy, and a health psychologist), guided by feedback from a panel of four young adults with narcolepsy. A list of related narcolepsy and social functioning survey questions are provided in **Appendix A** in the supplemental material.

#### **Narcolepsy and medical history**

Participants were asked about their narcolepsy history (age of symptom onset, age of diagnosis, and symptoms), medical and psychiatric comorbidities, and medical management of their narcolepsy disorder. As the goal was to measure the impact on social relationships, participants were only asked to self-report their diagnosis and narcolepsy type (as provided by a medical provider; type 1 [NT1] or type 2 [NT2]).

#### **Social/romantic relationships**

We adapted several items from the National Longitudinal Study of Adolescent and Adult Health (Add Health)<sup>22</sup> study, a national cohort study, including current friendship information, history of romantic relationships, history of sexual activity, current relationship status, and relationship satisfaction.

#### **Narcolepsy and social/romantic relationships**

The survey included questions on the impact of narcolepsy on social relationship health generated through an iterative process with stakeholders. Question themes included which symptoms bothered participants in the context of social functioning, whether participants had fallen asleep or had cataplexy during sex, and whether this had a significant impact on their sex life.

### Multidimensional Scale of Perceived Support (MSPSS).

The MSPSS is a 12-item questionnaire with a 7-item Likert scale (1 = very strongly disagree, 7 = very strongly agree) designed to assess perceived social support.<sup>23</sup> The MSPSS has been used in other studies of adolescents and young adults with chronic illnesses,<sup>24</sup> including cerebral palsy,<sup>25</sup> and has been implemented in a range of adolescent and young adult clinics for a variety of chronic illnesses.<sup>26</sup> The MSPSS includes three subscales, including perceived social support from friends, family, and significant others, and it demonstrates strong internal reliability (coefficient alphas for both subscales and total scale ranges from .85 to .91)<sup>23</sup> as well as stability (test–retest ranging from .72 to .85).<sup>23</sup> Increased social support from friends and family has been associated with decreased symptom severity in other populations, including young adults with posttraumatic stress disorder,<sup>27</sup> anxiety, and depression.<sup>28</sup>

### Communication with others regarding narcolepsy

Participants were asked several questions regarding whether they are open about their narcolepsy diagnosis, to whom they disclose their diagnosis, and when they disclose to friends, romantic partners, and sexual partners. In addition, participants were asked whether the medical providers who treat their narcolepsy have asked about their social and sex life, as well as whether they would like their providers to ask these questions.

### Qualitative responses

There were opportunities for participants to provide additional thoughts about their social relationships in the form of open-ended questions in the survey.

### Data analysis

We conducted descriptive analyses, including frequencies, means, and standard deviations for most variables of interest. Chi-square tests and unpaired two-sample Wilcoxon tests using Bonferroni corrections were used to examine differences in demographics, clinical presentations, and social, romantic, and sexual relationships between individuals with NT1 and NT2. A Wilcoxon signed-rank test with continuity correction was used to compare differences in perceived support provided by significant others, friends, and family on the MSPSS. A chi-square test was used to determine significant differences in timing of narcolepsy disclosures for friendships compared to romantic relationships. Illustrative quotes were used from the open-ended responses, but full mixed-methods analyses were outside of the scope of the current paper.

## RESULTS

### Demographics

A total of 350 individuals viewed the survey landing page, with 254 ultimately completing the survey, meeting inclusion criteria, and data cleaning/exclusion standards. The average participant age was 28.8 years (standard deviation = 5.6; range = 18 to 39), and the majority were female (87.4%) and identified as

White (92.1%). Most participants were working full- or part-time (77.1%).

### Narcolepsy characteristics

More participants had NT1 (59.4%) than NT2 (40.6%). Most were diagnosed with narcolepsy many years after symptom onset (mean = 7.8 years, standard deviation = 6.2). Almost all participants (93.3%) reported they were taking at least 1 medication, with about a third taking 3 or more medications (34.3%). Demographic and narcolepsy characteristics did not differ between those with NT1 and NT2 (chi-square tests with Bonferroni corrections). See **Table 1** for more demographic and narcolepsy diagnosis information. See **Table S1** for information regarding reports of narcolepsy symptoms across participants with NT1 and NT2. The symptoms with the greatest impact on social functioning were reported to be excessive daytime sleepiness, depression, and brain fog (see **Table S2** for information regarding impact of narcolepsy symptoms on social functioning).

### Social life and romantic relationships

#### Friendships

Overall, friendships were challenging as 98.4% of respondents indicated that narcolepsy made their social life harder (**Table 2**). Almost half indicated they felt they had too few friends (49.6%), and approximately 1 in 5 participants (19.7%) reported they had not spent any time with friends at all over the past week. Chi-square tests with Bonferroni corrections were conducted comparing characteristics of friendships between participants with NT1 and NT2 and there were no significant differences identified. An example of how PWN described narcolepsy impacting their friendships is exemplified in the following response to an open-ended question regarding symptom management:

I limit the amount of social gatherings that I attend per week. I typically can only attend one social gathering per weekend. I leave when I'm sleepy. I honor my limitations and remind others I can't stay out past a certain time. I'm very aware of what worsens my symptoms and essentially avoid them or limit them through careful planning, transparent boundaries, and engaging in activities that improve my symptoms.

Another exemplar quote indicates the choices a person with narcolepsy makes with respect to their social behavior in the context of medications for their narcolepsy:

I've stopped going out and drinking because of my medications and have since lost a lot of friendships.

#### Romantic relationships

In terms of entering romantic relationships, 88.1% of participants indicated that their narcolepsy made it somewhat or a lot harder (**Table 3**). Despite this, nearly all participants had previously been in a romantic relationship (94.5%), with over three quarters of participants currently in a romantic relationship (76.3%). A sizable minority were currently married (42.1%). For those currently in a relationship, most reported feeling satisfied in their relationship (87.9% indicating they were at least "Mostly Satisfied"). For those who were not actively in a

**Table 1**—Demographic characteristics and narcolepsy characteristics.

Demographics	NT1 (n = 151)	NT2 (n = 103)	Corrected P	Total (n = 254)
Age, y, mean (SD)	28.8 (5.85)	28.2 (5.09)	1.0	28.6 (5.55)
Sex, n (%)			1.0	
Male	15 (9.9)	5 (4.9)		20 (7.87)
Female	127 (84.1)	95 (92.2)		222 (87.4)
Other (transgender/nonbinary)	8 (5.3)	3 (2.9)		11 (4.3)
Race, n (%)				
White	140 (92.7)	94 (91.3)	1.0	234 (92.1)
Hispanic	10 (6.6)	6 (5.8)	1.0	16 (6.3)
Black	5 (3.3)	5 (4.8)	1.0	10 (3.9)
Other	7 (4.6)	4 (3.9)	1.0	11 (4.3)
Employment, n (%)				
Working full-time	81 (53.6)	70 (68.0)	1.0	151 (59.4)
Working part-time	30 (19.9)	15 (9.9)	1.0	45 (17.7)
Student	28 (18.5)	20 (19.4)	1.0	48 (18.9)
Other – unemployed	34 (22.5)	17 (16.5)	1.0	51 (20.1)
Narcolepsy characteristics				
Age at symptom onset, y, mean (SD)	15.1 (5.39)	15.4 (5.04)	1.0	15.2 (5.24)
Age at diagnosis, y, mean (SD)	22.7 (6.1)	23.6 (4.68)	1.0	23 (5.57)
Years between symptom onset and diagnosis, mean (SD)	7.6 (6.28)	8.2 (6.14)	1.0	7.8 (6.22)
Narcolepsy-specific medication use, n (%)				
No medications	10 (6.6)	7 (6.8)	1.0	17 (6.7)
1+ medications	141 (93.4)	96 (93.2)	1.0	237 (93.3)
2+ medications	110 (72.8)	71 (68.9)	1.0	181 (71.3)
3+ medications	59 (39.1)	28 (27.2)	1.0	87 (34.3)
Tricyclic or SSRI medication use, n (%)**			.005	
No	117 (77.5)	98 (96.1)		215 (84.9)
Yes	34 (22.5)	4 (3.9)		8 (15.1)

Participant demographics and characteristics of narcolepsy diagnosis and treatment, separated by narcolepsy type. Chi-square tests with Bonferroni corrections conducted to compare responses for individuals with NT1 vs NT2. Individuals with NT1 were more likely to take tricyclic or SSRI medications ( $\chi^2 [1, n = 253] = 15.067, P = .005$ ) than those with NT2. NT1 = narcolepsy type 1, NT2 = narcolepsy type 2, SD = standard deviation, SSRI = selective serotonin reuptake inhibitor. \*\* $P < .01$ .

relationship, equal number of participants (57.9%; 12.9% of total sample) reported they were not looking to be in one as those looking to be in a relationship, with the remainder seeking other types of noncommitted partnerships (eg, “Friends with benefits”). Chi-square tests with Bonferroni corrections were conducted and no significant differences between relationship characteristics or quality were noted between those with NT1 and NT2. One example of how PWN prioritized their romantic relationships is evidenced in the following quote:

I do not go out and socialize at all, but spend all my time at home nurturing my romantic relationship because it's the most important to me.

### Sexual relationships

Most participants indicated that their narcolepsy impacts their sex life (81.1%; [Table 4](#)). Despite this, many participants had

previously engaged in sexual activity of some form (89.0% reported a history of engaging in oral sex, 87.4% in vaginal sex, and 39.4% in anal sex). Almost 1 in 3 (32.6%) participants had experienced cataplexy during sex, and 53.2% had fallen asleep during sex. For participants with NT1, use of medications which are known to impact sexual functioning (selective serotonin reuptake inhibitors/tricyclics) was not associated with differences in impact on sex lives ( $\chi^2 [1, n = 144] = .014, P = .9$ ). Out of the participants who indicated they had cataplexy or had fallen asleep during sex, many currently felt that these symptoms were still impacting their sex life (36.6%). The only significant difference in response rates for individuals with NT1 and NT2 across all social functioning variables was whether or not they had experienced cataplexy during sex ( $\chi^2 [2, n = 239] = 81.8, P < .001$ ). One participant described the frustration of the impact of narcolepsy on their sex life:



**Table 2**—Characteristics of friendships.

	NT1 (n = 151)		NT2 (n = 103)		Corrected P	Total (n = 254)	
	n	%	n	%		n	%
Narcolepsy impact on social life					1.0		
Makes it a lot harder	80	53.0	56	54.4		136	53.5
Makes it somewhat harder	71	47.0	43	41.7		114	44.9
Has no impact	0	0.0	4	3.9		4	1.6
Makes it a lot easier	0	0.0	0	0.0		0	0.0
Makes it somewhat easier	0	0.0	0	0.0		0	0.0
Number of friends					1.0		
Too few	77	51.0	49	47.6		126	49.6
Just right	74	49.0	53	51.5		127	50.0
Too many	0	0.0	1	0.9		1	0.4
Time spent with friends the past week					1.0		
Not at all	27	17.9	23	22.3		50	19.7
1 or 2 times	74	49.0	51	49.5		125	49.2
3 or 4 times	32	21.2	20	19.4		52	20.5
5+ times	18	11.9	9	8.7		27	10.6

Descriptive characteristics of friendships reported by participants, separated by narcolepsy type. Chi-square tests with Bonferroni corrections conducted to compare responses for individuals with narcolepsy type 1 vs narcolepsy type 2. NT1 = narcolepsy type 1, NT2 = narcolepsy type 2.

Having sex is harder because it has to be when I'm actually awake in the middle of the night, assuming I am actually awake.

### Perceived social support

There were no significant differences in perceived social support between participants with NT1 and those with NT2. Across the full sample, participants reported significant differences in perceived social support from different social connections (Table 5). Perceived social support from significant others was significantly higher than both perceived social support from friends ( $V = 19,112, P < .001$ ) and perceived support from family ( $V = 19,746, P < .001$ ). There was not a significant difference between perceived social support from friends or from family ( $V = 11,296, P = .062$ ).

### Narcolepsy disclosure

#### Relationships

Most participants indicated that they were mostly or very open about their diagnosis (83.8%). All participants reported they had told at least 1 other person about their diagnosis, and almost all participants told their close family and friends (Table 6). They were least likely to disclose to acquaintances (52.4%), new dating partners (36.7%), and casual sexual partners (20.1%). Very few participants immediately disclosed their diagnosis to friends (16.2%), but most disclosed within the first 6 months of their friendship (80.2%). Participants reported disclosing the diagnosis to romantic partners immediately (33.3%), and most disclosed within the first 6 months of starting a romantic relationship (80.9%). Participants disclosed at different times when comparing disclosures to friendships

compared to romantic relationships ( $\chi^2 [6, n = 254] = 40.6, P < .001$ ). Specifically, they were more likely to disclose to romantic partners immediately compared to disclosing to friends and were more likely to disclose to friends during the 6 months to a year time frame. A number of participants reported that they always tell their sexual partners (41.3%), though many still either only disclose sometimes (20.4%) or not at all (19.6%). The disclosure of their narcolepsy in the context of social relationships is captured by participant quotes related to friendships and sexual relationships:

I try to explain narcolepsy to my friends so that they understand why I may fall asleep when I am with them.

I disclose my diagnosis to sexual partners because my cataplexy almost always flares up during sex and it can be alarming to people who don't know to expect it.

#### Providers

Most participants (69.3%) indicated that their primary narcolepsy-treating provider had never asked them about the impact of narcolepsy on their social life (Table 7). Most PWN wanted their medical provider to ask about the impact of narcolepsy on social life (72.8%). Only 9.8% of medical providers had asked about the impact of narcolepsy on the sex life of the participant, yet 44.9% of participants reported that they wanted their providers to ask about how narcolepsy impacts their sex life.

## DISCUSSION

Narcolepsy usually begins during adolescence and young adulthood, a developmental period when many individuals are forming

**Table 3**—Characteristics of romantic relationships.

	n	%	n	%	Corrected P	n	%
Narcolepsy impact on entering a relationship	<b>NT1 (n = 151)</b>		<b>NT2 (n = 103)</b>		1.0	<b>Total (n = 254)</b>	
Makes it a lot harder	57	37.7	32	31.1		89	35.0
Makes it somewhat harder	77	51.0	58	56.3		135	53.1
Has no impact	17	11.3	13	12.6		30	11.8
Makes it somewhat easier	0	0.0	0	0.0		0	0
Makes it a lot easier	0	0.0	0	0.0		0	0
Ever in a relationship					1.0		
Yes	145	96.0	95	92.2		240	94.5
No	6	4.0	8	7.8		14	5.5
Currently in a relationship	<b>NT1 (n = 145)</b>		<b>NT2 (n = 95)</b>		1.0	<b>Total (n = 240)</b>	
Yes	103	71.0	80	84.2		183	76.3
No	42	29.0	15	15.8		57	23.4
Current relationship status	<b>NT1 (n = 103)</b>		<b>NT2 (n = 80)</b>		1.0	<b>Total (n = 183)</b>	
Married	47	45.6	30	37.5		77	42.1
Cohabiting/living together (> 1 month)	24	23.3	26	32.5		50	27.3
Engaged to be married	8	7.8	4	5.0		12	6.6
Currently dating	23	22.3	20	25.0		43	23.5
Childbearing/pregnancy	1	1.0	0	0.0		1	0.5
Current relationship satisfaction					1.0		
Completely satisfied	34	33.0	30	37.5		64	34.9
Almost completely satisfied	32	31.1	27	23.8		59	32.2
Mostly satisfied	22	21.4	16	20.0		38	20.8
Somewhat satisfied	6	5.8	4	5.0		10	5.5
A little satisfied	8	7.8	3	3.8		11	6.0
Not at all satisfied	0	0.0	0	0.0		0	0.0
If not in a relationship, are you ...	<b>NT1 (n = 42)</b>		<b>NT2 (n = 15)</b>			<b>Total (n = 57)</b>	
Not looking	23	54.8	10	66.7	1.0	33	57.9
Looking	22	52.4	11	73.3	1.0	33	57.9
Friends with benefits	7	16.7	3	20.0	1.0	10	17.5
Hooking up	6	14.3	1	6.7	1.0	7	12.3
Other	4	9.5	3	26.7	1.0	7	12.3

Descriptive characteristics of romantic relationships reported by participants, separated by narcolepsy type. Participants were able to check all that apply if not in a relationship. Chi-square tests with Bonferroni corrections conducted to compare responses for individuals with NT1 vs NT2. NT1 = narcolepsy type 1, NT2 = narcolepsy type 2.

critical lifelong relationships, yet there is scant research on the impact of narcolepsy on social relationships. In a national survey, we found that young adults with narcolepsy overwhelmingly report their disease makes the development and maintenance of their social relationships more difficult. Most PWN want their medical team to be more actively involved in helping them navigate the impact of narcolepsy on their social relationships, but this rarely occurs in clinical practice. The impact of narcolepsy diagnosis and symptoms on social functioning was independent of the type of narcolepsy (NT1 vs NT2), and excessive daytime sleepiness was most impactful symptom on social functioning. Perceived social support was generally lower than in some other populations of young adults, such as those with

posttraumatic stress disorder (mean total scores of 19 compared to 14 and 15 for family and friends scales in our current sample, respectively),<sup>27</sup> though greater than others, including young adult cancer survivors (mean scale scores of 3.0–3.1 compared to 3.6–4.5 in the current sample).<sup>29</sup> These findings will hopefully serve as a wake-up call for health care clinicians treating young adults with narcolepsy: Their social health needs are intrinsic to their well-being and require more attention than currently provided.

Young adults with narcolepsy often feel limited in how much time and energy they can commit to their social relationships. Consequently, it appears that they often choose to prioritize a single romantic partnership. Over three quarters of our

**Table 4**—Characteristics of sexual relationships.

	n	%	n	%	Corrected P	n	%
Does narcolepsy currently impact your sex life?	<b>NT1 (n = 144)</b>		<b>NT2 (n = 94)</b>		1.0	<b>Total (n = 238)</b>	
Yes	119	82.6	74	78.7		193	81.1
No	25	17.4	20	21.3		45	18.9
Have you ever engaged in following sexual activities?	<b>NT1 (n = 151)</b>		<b>NT2 (n = 103)</b>			<b>Total (n = 254)</b>	
Oral sex	134	88.7	92	89.3	1.0	226	89.0
Vaginal sex	133	88.1	88	85.4	1.0	222	87.4
Anal sex	64	42.4	36	40.0	1.0	100	39.4
Have you ever experienced cataplexy during sex?***	<b>NT1 (n = 145)</b>		<b>NT2 (n = 94)</b>		<.001	<b>Total (n = 239)</b>	
Yes	77	53.1	1	1.0		78	32.6
No	42	29.0	79	84.0		121	50.6
Not sure	26	17.9	14	14.9		40	16.7
Have you ever fallen asleep during sex?	<b>NT1 (n = 145)</b>		<b>NT2 (n = 94)</b>		.094	<b>Total (n = 239)</b>	
Yes	87	60.0	40	42.5		127	53.2
No	43	29.7	49	52.1		92	38.5
Not sure	15	17.9	5	5.3		20	8.4
Does cataplexy or falling asleep currently impact your sex life?	<b>NT1 (n = 121)</b>		<b>NT2 (n = 50)</b>		1.0	<b>Total (n = 171)</b>	
Yes	49	40.5	13	26.0		62	36.3
No	55	45.5	30	60.0		85	49.7
Not sure	17	14.0	7	14.0		24	14.0

Descriptive characteristics of sexual relationships reported by participants, separated by narcolepsy type. Participants were able to check all that apply for sexual activities they have engaged in. Chi-square tests with Bonferroni corrections conducted to compare responses for individuals with NT1 vs NT2. Only significant difference was a history of experiencing cataplexy during sex ( $\chi^2 [2, n = 239] = 81.81, P < .001$ ). \*\*\* $P < .001$ . NT1 = narcolepsy type 1, NT2 = narcolepsy type 2.

participants were currently in a romantic relationship, and almost all reported that they were at least mostly satisfied with their romantic relationships. Marriage rates within the current sample were also similar to general population rates (42% vs 44% in the national National Longitudinal Study of Adolescent and Adult Health sample), while cohabitation rates were

slightly higher than in the general population (27% in current sample vs 19% in the National Longitudinal Study of Adolescent and Adult Health).<sup>30</sup> Our MSPSS findings support the hypothesis that most young adults with narcolepsy dedicate their energy to a romantic relationship, with respondents perceiving significantly higher levels of support from their

**Table 5**—Multidimensional Scale of Perceived Social Support.

	NT1 (n = 151)	NT2 (n = 103)	Corrected P	Total Scale Score n = 254	Total Sum Score
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)
Significant other	4.5	4.5	1.0	4.5***	18.0 (5.6)
Family	3.6	3.7	1.0	3.7	14.6 (6.0)
Friends	3.9	3.9	1.0	3.9	15.5 (5.7)
Total	4.0	4.0	1.0	4.0	48.1 (13.2)

Scale scores of perceived support received from significant others, family, and friends. Wilcoxon signed-ranks test for nonparametric mean comparison of perceived social support by social connections. There were no significant differences in perceived social support based on type of narcolepsy. Perceived support was significantly higher from significant others compared to family ( $V = 19,746, P < .001$ ) and friends ( $V = 19,112, P < .001$ ). There was no significant difference between friends and family ( $V = 11,296, P = .062$ ). Lower scores indicate less perceived support. \*\*\* $P < .001$ , continuity-corrected.

**Table 6**—Narcolepsy disorder disclosures: social relationships.

	n	%
How open are you about your narcolepsy diagnosis (n = 253)		
Very open	77	30.4
Mostly open	135	53.4
Somewhat open	35	13.8
Not at all open	6	2.4
Who have you told about your narcolepsy diagnosis? (n = 254)		
Close family	253	99.6
Close friends	248	97.6
Romantic partners	179	70.5
Extended family	169	66.5
Sexual partner, exclusive	141	55.5
Acquaintances	133	52.4
Newly dating	93	36.7
Sexual partner, casual	51	20.1
None	0	0.0
When do you tell friendships about diagnosis? (n = 253)		
Immediately	41	16.2
Less than 1 month	95	37.5
1–6 months	67	26.5
6 months–1 year	22	8.7
More than a year	6	2.4
I generally don't disclose	5	2.0
Other	17	6.7
When do you tell relationships about diagnosis (n = 237)		
Immediately	79	33.3
Less than 1 month	75	31.6
1–6 months	38	16.0
6 months–1 year	5	2.1
More than a year	3	1.3
I generally don't disclose	3	1.3
Other	34	14.3
Do you tell sexual partners? (n = 230)		
Yes, always	95	41.3
Most of the time	43	18.7
Sometimes	47	20.4
Never	45	19.6

Descriptive characteristics of disclosure around narcolepsy diagnosis across social relationships. Chi-square tests of independence with Bonferroni corrections were conducted and showed differences in timing of disclosure for friends compared to romantic relationships ( $\chi^2 [6, n = 254] = 40.594, P < .001$ ).

significant others in comparison to friends or even their family, different from findings of perceived social support in other populations.<sup>27,29</sup> This leads us to believe that their commitment to nurturing their romantic relationships was reciprocated.

Although romantic relationships are prioritized by young adults with narcolepsy, they experience struggles with respect to sexual functioning. The majority of participants reported that narcolepsy as a whole currently impacts their sex life. Prior studies have reported sexual activity and orgasm can trigger

cataplexy.<sup>31,32</sup> The current study highlights that most young adults with NT1 have had cataplexy during sex. For some, it was described as something they have come to expect. Further, PWN are often exhausted in the evening, and over half of respondents reported that they had fallen asleep during sex, with no difference between those with NT1 and those with NT2. This can be a risky situation for PWN as there have been reports of women being sexually abused during cataplexy or in drowsy periods when they are in between sleep and wake.<sup>33</sup>



**Table 7**—Narcolepsy disorder disclosures: provider relationships (n = 254).

	n	%
Has your doctor asked about your social life?		
No	176	69.3
Yes	78	30.7
Has your doctor asked about your sex life?		
No	229	90.2
Yes	25	9.8
Do you want your doctor to ask about your social life?		
No	18	7.1
Yes	185	72.8
Don't know	50	19.7
Do you want your doctor to ask about your sex life?		
No	60	23.6
Yes	114	44.9
Don't know	80	31.5

Descriptive characteristics of provider communication around social and sex life.

There are also reports of sexual dysfunction, including erectile dysfunction,<sup>34</sup> which may be exacerbated by medications used to treat symptoms of narcolepsy.<sup>35</sup> It is noteworthy that less than a quarter of participants with NT1 were using medications with may adversely impact sexual functioning (tricyclic agents or selective serotonin reuptake inhibitors) for the treatment of cataplexy, indicating that sexual functioning is likely impacted by more than just medication side effects. Further there was no difference in frequency of reported impact on sex lives between those with NT1 who were taking these medications and those who were not.

Though participants indicated that others might not understand their symptoms, most participants disclose their diagnosis at some point in their relationship. Relatively few participants tell friends or romantic partners about their diagnosis immediately, but most disclose within the first 6 months of meeting a friend or romantic partner. This openness was unexpected as prior studies reported that PWN have significant concerns with disclosing their health information as disclosure is associated with fear of consequences.<sup>36,37</sup> This difference could be due to the relatively young age of our participants and greater access to information online about narcolepsy disorder. There may also be differences in disclosure with social relationships as compared to coworkers or employers. Researchers hypothesize that in adolescents with chronic illnesses one of the driving factors for disclosing their diagnosis is practical need.<sup>38</sup> In support of this perspective, some participants stated that they disclosed for safety and planning reasons as well as to minimize judgement.

One domain in which PWN are clear in wanting more open conversation is with their narcolepsy medical provider. Almost

3 out of 4 PWN want their doctor to ask about how narcolepsy impacts their social life, and almost half would like to be asked about the impact of narcolepsy on their sexual relationships. Though often viewed as too sensitive a subject to raise, these discussions are crucial as PWN want to understand more about how their medications and behavioral efforts to cope with the disorder can be balanced with their need for social connectedness. For example, several participants stated that they had to limit the number of social activities they engaged in due to side effects from medications they were taking for narcolepsy. One especially notable limitation is that PWN are instructed to avoid drinking alcohol if they take an oxybate or other sedatives. This can impact social functioning, especially in young adulthood, when drinking alcohol is part of the social fabric of developing and building social relationships.<sup>39,40</sup> For those who implemented behavioral recommendations to manage their narcolepsy, the need to set aside time for scheduled naps, have consistent bedtimes, and obtain adequate sleep was an impediment to evening (and early morning) events that contribute to developing and maintaining many young adult relationships.

Though there are a few studies indicating that social functioning may be impacted by narcolepsy diagnosis and symptoms, previous research has only included a few questions or variables as part of larger studies. The current findings provide more depth in understanding how social functioning across various social domains is impacted. This is the first study to indicate that there may be differential effects on friendships compared to romantic relationships. Further, the current study notes similar findings across those individuals diagnosed with NT1 and NT2, indicating that social functioning (friendships, romantic, and sexual) is not solely impacted by cataplexy but that social functioning is impacted by various symptoms of NT1 and NT2 and intervention strategies as a whole.

## Limitations

We believe this study is the first to focus in depth on the social impact of narcolepsy across multiple social relationship domains. However, there are some limitations that should be addressed in future research. First, there were limitations regarding data collection. Data collection occurred during the beginning of the COVID-19 pandemic, which may have contributed to the respondents' sense of social disconnection. To fully understand the impact of narcolepsy on social functioning, it will be important to reexamine this topic when social lives are closer to normal. However, our survey specifically asked participants to respond regarding their life prior to the pandemic, and the surveys were completed in June 2020, only 3 months into the pandemic. To provide anonymity for participants answering questions about sensitive subject matter (eg, sexual behavior), the surveys were conducted without the ability to confirm that each entry was independent. However, participant responses were visually inspected to verify that no two individual datasets were duplicates. Further, qualitative responses were included solely as anecdotal and illustrative examples of the impacts of diagnosis and symptoms on social functioning. This can lead to bias in selection of provided quotations and further research

should include more robust qualitative methods to assess for themes as this was outside the scope of this paper.

Second, due to our anonymous data collection, the diagnosis of narcolepsy was self-reported with no linkage to participants' medical records, identification of specific providers, or details of their diagnostic medical workup. Though there are limitations that come with lack of medical records, similar procedures with self-reported diagnosis have been used in prior studies of PWN.<sup>16,41</sup> Still, we believe it is likely that nearly all participants had narcolepsy as all participants reported daytime sleepiness, their symptoms usually began in adolescence, and many were prescribed medications used to treat narcolepsy. About 40% of participants self-reported a NT2 diagnosis, which is greater than prevalence rates identified in European settings,<sup>42,43</sup> but these rates are similar to those reported in prior studies of PWN in the United States.<sup>44,45</sup> Further, cataplexy and use of anti-cataplexy medications were limited to participants reporting NT1 and other symptoms such as sleep paralysis were more common in the NT1 participants, further supporting validity of self-reported diagnosis. Future research should expand on themes identified within the current paper with further confirmation of narcolepsy diagnosis and type.

Third, sample selection bias may limit the generalizability of this study. Participants were recruited from narcolepsy patient organizations, and individuals connected with these organizations may differ from those who are not connected. For example, they may have more severe symptoms, be more comfortable with disclosing their diagnosis, and may receive social support through the organization. Even in this context, many participants still reported a large impact of narcolepsy on their social functioning. Regarding generalizability, the sample was predominantly White and female, with many of the participants indicating they were working part- or full-time. Narcolepsy occurs at similar rates in men and women and across races,<sup>46</sup> so this is not fully representative of young adults with narcolepsy. Given typical differences in access to social support, resources, and utilization of social connections across genders, these findings may not be generalizable for men or transgender and non-binary PWN. However, the impact of narcolepsy on social functioning was clear. We suspect that more diverse samples would demonstrate a greater impact of the disorder on their social health because they may have less equitable access to health care. Future studies should include more diverse populations to gain additional perspectives of men and people of diverse ethnicities and levels of functioning.

## CONCLUSIONS

These findings have key implications for clinical practice and future research and are the first to truly investigate the impact of narcolepsy diagnosis and symptoms on social functioning, in depth, across multiple domains of social relationships (friendships, romantic relationships, and sexual relationships) as well as investigate rates of disclosure and provider communication preferences. First, it is essential to improve provider awareness of the many ways in which narcolepsy impacts social

relationships. One approach will be to screen for these issues during medical visits. These topics can be viewed as sensitive, and some providers may hesitate to raise these questions as many are not trained in how to effectively respond. In general, physicians rarely ask about sensitive topics such as sexual health or ask only if it seems directly related to the presenting problem.<sup>47</sup> We suggest that when asking about social health challenges providers ask clear, concrete, and direct questions while maintaining a nonjudgmental demeanor. It may be helpful to refer patients to health psychologists, especially those with knowledge and experience working with PWN.<sup>48</sup> Second, there is a growing interest in developing behavioral interventions to improve quality of life for PWN.<sup>48</sup> Our data demonstrate that the inclusion of components focused on addressing their difficulties with social relationships and providing patients with the skills to better manage these relationships is important. Helping young adults with narcolepsy better understand their individual barriers to developing and nurturing positive social relationships should be viewed as an essential component of treating the whole patient.

## ABBREVIATIONS

MSPSS, Multidimensional Scale of Perceived Support  
 NT1, narcolepsy type 1  
 NT2, narcolepsy type 2  
 PWN, people with narcolepsy

## REFERENCES

1. Dauvilliers Y, Arnulf I, Mignot E. Narcolepsy with cataplexy. *Lancet*. 2007; 369(9560):499–511.
2. Scheer D, Schwartz SW, Parr M, Zgibor J, Sanchez-Anguiano A, Rajaram L. Prevalence and incidence of narcolepsy in a US health care claims database, 2008–2010. *Sleep*. 2019;42(7):zsz091.
3. Dauvilliers Y, Montplaisir J, Molinari N, et al. Age at onset of narcolepsy in two large populations of patients in France and Quebec. *Neurology*. 2001;57(11): 2029–2033.
4. Nevsimalova S. Narcolepsy in childhood. *Sleep Med Rev*. 2009;13(2):169–180.
5. Fraley RC, Davis KE. Attachment formation and transfer in young adults' close friendships and romantic relationships. *Pers Relatsh*. 1997;4(2):131–144.
6. Ozaki A, Inoue Y, Hayashida K, et al. Quality of life in patients with narcolepsy with cataplexy, narcolepsy without cataplexy, and idiopathic hypersomnia without long sleep time: comparison between patients on psychostimulants, drug-naïve patients and the general Japanese population. *Sleep Med*. 2012;13(2):200–206.
7. Kotagal S. Hypersomnia in children: interface with psychiatric disorders. *Child Adolesc Psychiatr Clin N Am*. 2009;18(4):967–977.
8. Cacioppo JT, Cacioppo S. The growing problem of loneliness. *Lancet*. 2018; 391(10119):426.
9. Nyqvist F, Victor CR, Forsman AK, Cattan M. The association between social capital and loneliness in different age groups: a population-based study in Western Finland. *BMC Public Health*. 2016;16(1):542.
10. Hawkey LC, Buecker S, Kaiser T, Luhmann M. Loneliness from young adulthood to old age: explaining age differences in loneliness. *Int J Behav Dev*. 2022;46(1):39–49.
11. Bu F, Steptoe A, Fancourt D. Who is lonely in lockdown? Cross-cohort analyses of predictors of loneliness before and during the COVID-19 pandemic. *Public Health*. 2020;186:31–34.

12. Barr AB, Culatta E, Simons RL. Romantic relationships and health among African American young adults: linking patterns of relationship quality over time to changes in physical and mental health. *J Health Soc Behav.* 2013;54(3):369–385.
13. Kershaw KN, Hankinson AL, Liu K, et al. Social relationships and longitudinal changes in body mass index and waist circumference: the coronary artery risk development in young adults study. *Am J Epidemiol.* 2014;179(5):567–575.
14. Sassler S. Partnering across the life course: sex, relationships, and mate selection. *J Marriage Fam.* 2010;72(3):557–575.
15. Furstenberg FF Jr. On a new schedule: transitions to adulthood and family change. *Future Child.* 2010;20(1):67–87.
16. Daniels E, King MA, Smith IE, Shneerson JM. Health-related quality of life in narcolepsy. *J Sleep Res.* 2001;10(1):75–81.
17. Teixeira VG, Faccenda JF, Douglas NJ. Functional status in patients with narcolepsy. *Sleep Med.* 2004;5(5):477–483.
18. Ingravallo F, Gnucci V, Pizza F, et al. The burden of narcolepsy with cataplexy: how disease history and clinical features influence socio-economic outcomes. *Sleep Med.* 2012;13(10):1293–1300.
19. Laursen B, Hartl AC. Understanding loneliness during adolescence: developmental changes that increase the risk of perceived social isolation. *J Adolesc.* 2013;36(6):1261–1268.
20. Luong G, Charles ST, Fingerhut KL. Better with age: social relationships across adulthood. *J Soc Pers Relat.* 2011;28(1):9–23.
21. Bartell AL, Spyridakis JH. Managing risk in internet-based survey research. In: *2012 IEEE International Professional Communication Conference.* IEEE;2012:1–6.
22. Harris KM, Udry JR. National Longitudinal Study of Adolescent to Adult Health (Add Health), 1994–2018 [Public Use]: Version 23. Published online 2008.
23. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Perceived Social Support. *J Pers Assess.* 1988;52(1):30–41.
24. Nearchou F, Davies A, Hennessy E. Psychometric evaluation of the Multi-Dimensional Scale of Perceived Social Support in young adults with chronic health conditions. *Ir J Psychol Med.* 2019:1–5.
25. Magill-Evans J, Darrah J, Pain K, Adkins R, Kratochvil M. Are families with adolescents and young adults with cerebral palsy the same as other families? *Dev Med Child Neurol.* 2001;43(7):466–472.
26. d'Emden H, McDermott B, Poulson K, McGahan G. Protocol for psychosocial screening of adolescents and young adults with chronic illness. *Intern Med J.* 2019;49(9):1138–1145.
27. Haden SC, Scarpa A, Jones RT, Ollendick TH. Posttraumatic stress disorder symptoms and injury: the moderating role of perceived social support and coping for young adults. *Pers Individ Dif.* 2007;42(7):1187–1198.
28. Grey I, Arora T, Thomas J, Saneh A, Tohme P, Abi-Habib R. The role of perceived social support on depression and sleep during the COVID-19 pandemic. *Psychiatry Res.* 2020;293:113452.
29. Tremolada M, Bonichini S, Basso G, Pillon M. Perceived social support and health-related quality of life in AYA cancer survivors and controls. *Psychooncology.* 2016;25(12):1408–1417.
30. Sorgi A, Chen P, Dean SC, Halpern CT, Harris KM. Characteristics of young adult relationships: the National Longitudinal Study of Adolescent to Adult Health.
31. Poryazova R, Khatami R, Werth E, Bassetti CL. Weak with sex: sexual intercourse as a trigger for cataplexy. *J Sex Med.* 2009;6(8):2271–2277.
32. Reinert AE, Simon JA. "Did you climax or are you just laughing at me?" Rare phenomena associated with orgasm. *Sex Med Rev.* 2017;5(3):275–281.
33. Schenck CH, Arnulf I, Mahowald MW. Sleep and sex: what can go wrong? A review of the literature on sleep related disorders and abnormal sexual behaviors and experiences. *Sleep.* 2007;30(6):683–702.
34. Karacan I. Erectile dysfunction in narcoleptic patients. *Sleep.* 1986;9(1 Pt 2): 227–231.
35. Lindsley G. Narcolepsy, Intimacy, and Sexuality. In: Goswami M, Thorpy MJ, Pandi-Perumal SR, eds. *Narcolepsy.* New York: Springer International Publishing; 2016: 217–231.
36. Broughton WA, Broughton RJ. Psychosocial impact of narcolepsy. *Sleep.* 1994; 17(Suppl 8):S45–S49.
37. Kapella MC, Berger BE, Vern BA, Vispute S, Prasad B, Carley DW. Health-related stigma as a determinant of functioning in young adults with narcolepsy. *PLoS ONE.* 2015;10(4):e0122478.
38. Kaushansky D, Cox J, Dodson C, McNeely M, Kumar S, Iverson E. Living a secret: disclosure among adolescents and young adults with chronic illnesses. *Chronic Illn.* 2017;13(1):49–61.
39. Patrick ME, Terry-McElrath YM, Lee CM, Schulenberg JE. Simultaneous alcohol and marijuana use among underage young adults in the United States. *Addict Behav.* 2019;88:77–81.
40. MacLean S. Alcohol and the constitution of friendship for young adults. *Sociology.* 2016;50(1):93–108.
41. Hershner S, Kakkar R, Chung F, Singh M, Wong J, Auckley D. Narcolepsy, anesthesia, and sedation: a survey of the perioperative experience of patients with narcolepsy. *Anesth Analg.* 2019;129(5):1374–1380.
42. Baumann-Vogel H, Schreckenbauer L, Valko PO, Werth E, Baumann CR. Narcolepsy type 2: a rare, yet existing entity. *J Sleep Res.* 2021;30(3):e13203.
43. Zhang Z, Mayer G, Dauvilliers Y, et al. Exploring the clinical features of narcolepsy type 1 versus narcolepsy type 2 from European Narcolepsy Network database with machine learning. *Sci Rep.* 2018;8(1):10628.
44. Silber MH, Krahn LE, Olson EJ, Pankratz VS. The epidemiology of narcolepsy in Olmsted County, Minnesota: a population-based study. *Sleep.* 2002;25(2): 197–202.
45. Ohayon MM, Thorpy MJ, Carls G, et al. The Nexus Narcolepsy Registry: methodology, study population characteristics, and patterns and predictors of narcolepsy diagnosis. *Sleep Med.* 2021;84:405–414.
46. Okun ML, Lin L, Pelin Z, Hong S, Mignot E. Clinical aspects of narcolepsy-cataplexy across ethnic groups. *Sleep.* 2002;25(1):27–35.
47. Wimberly YH, Hogben M, Moore-Ruffin J, Moore SE, Fry-Johnson Y. Sexual history-taking among primary care physicians. *J Natl Med Assoc.* 2006;98(12): 1924–1929.
48. Ong JC, Fox RS, Brower RF, Mazurek S, Moore C. How does narcolepsy impact health-related quality of life? A mixed-methods study. *Behav Sleep Med.* 2021;19(2):145–158.

## SUBMISSION & CORRESPONDENCE INFORMATION

Submitted for publication February 25, 2022

Submitted in final revised form July 12, 2022

Accepted for publication July 12, 2022

Address correspondence to: Ryan D. Davidson, PhD, Boston Children's Hospital, 300 Longwood Avenue, Boston, Massachusetts, United States 02115; Email: Ryan.davidson@childrens.harvard.edu

## DISCLOSURE STATEMENT

All authors have seen and approved the manuscript. This study was funded by a grant from Jazz Pharmaceuticals to E.S.Z. and T.E.S. R.D.D. has received consulting fees from Jazz Pharmaceuticals; T.E.S. has received consulting fees from Avadel, Consynance, Harmony Biosciences, Idorsia, Jazz Pharmaceuticals, Merck, Eisai, and Takeda and has received research grants from Merck, Harmony Biosciences, and Takeda; K.B. has received consulting fees from Jazz Pharmaceuticals and Takeda. All other authors report no conflicts of interest.