

Appendix A

Related Narcolepsy and Social Functioning Survey Questions

- How old are you in years? _____
- What is your gender?
 - Male Female Transgender Non-Binary Other
- What is your employment status? [check all that apply]
 - Working, full time Working, part time College student
 - Homemaker Graduate student On disability (full or partial)
 - Unemployed, looking for work
 - Unemployed, not looking for work
- What is your race? [check all that apply]
 - White/Caucasian Black/African American Hispanic/Latino(a) Asian
 - Native American Other _____
- How many children do you have? _____
- Have you been diagnosed with narcolepsy by a healthcare professional?
 - Yes No

If yes to “Have you been diagnosed with narcolepsy by a healthcare professional?”: Do you have type 1 or type 2 narcolepsy?

 - Type 1 Narcolepsy (with cataplexy) Type 2 Narcolepsy (without cataplexy)
 - Not sure Other _____
- At what age did you start having symptoms of narcolepsy? _____
- At what age were you officially diagnosed with narcolepsy? _____
- What medications do you currently take for your narcolepsy? (check all that apply)
 - Stimulants (e.g. methylphenidate [Ritalin], amphetamine/dextroamphetamine [Adderall])
 - Modafinil (Provigil) or Armodafinil (Nuvigil) Atomoxetine (Strattera)
 - Sodium oxybate (Xyrem)
 - Cataplexy suppressing medication such as fluoxetine, venlafaxine (Prozac, Effexor)
 - Baclofen
 - Pitolisant (Wakix) Solriamfetol (Sunosi)
 - Caffeinated drinks (soda/pop, coffee, energy drinks)
 - Nicotine
 - None
 - Other
- Which narcolepsy symptoms have you ever experienced? (check all that apply)
 - Excessive sleepiness Sleep attacks Disrupted nighttime sleep Cataplexy
 - Brain fog
 - Hallucinations when falling asleep or waking up
 - Sleep paralysis when falling asleep or waking up

- Medication side effects
 - Depression or other mood challenges
 - Automatic behaviors (doing things such as taking notes or driving without full awareness)
- Have you been diagnosed or treated for the following by a medical professional? (check all that apply)
 - None of the below
 - Depression
 - Anxiety
 - Post-Traumatic Stress Disorder (PTSD)
 - Substance Abuse
 - Obesity
 - Hypertension
 - Migraines
- MSPSS: Please indicate how you feel about each statement? +
- The number of close friends I have are...
 - Too few
 - Just right
 - Too many
- To what extent does your narcolepsy impact your social life (friendship and/or romantic)?
 - Makes it a lot better
 - Makes it somewhat better
 - Has no impact
 - Makes it somewhat worse
 - Makes it a lot worse
- What strategies do you use to maintain your social and romantic life with narcolepsy (including strategies related to alcohol use, dating culture, etc) ?
- During the past week, how many times did you just hang out or talk with friends?
 - Not at all
 - 1 or 2 times
 - 3 or 4 times
- How does narcolepsy impact your ability to enter/maintain a new relationship (friendship and/or romantic)?
 - Makes it a lot easier
 - Makes it somewhat easier
 - Has no impact
 - Makes it somewhat harder
 - Makes it a lot easier
- In general, how open are you about having narcolepsy?
 - Not at all open – I prefer that very few people know/ it's private
 - Somewhat open – Only my family and my closest friends know
 - Mostly open – People in my daily life know, and if someone asks specifically, I'd tell them
 - Very open – pretty much everyone knows and I often discuss it
- Who have you told you have narcolepsy? (check all that apply)
 - None of the below
 - Close family members
 - Extended family
 - Close friends
 - Acquaintances
 - Person you're newly dating
 - Romantic Partner (>3 months)
 - Sexual Partners (Casual)
 - Sexual Partners (Exclusive)
- What are the reasons you choose to disclose your narcolepsy diagnosis?

_____ -
- At what point in a new friendship do you generally tell your friend that you have narcolepsy? (check one)

- I told him/her immediately
 - Less than one month
 - 1 to 6 months
 - 6 months to a year
 - More than a year
 - I still haven't disclosed
 - Other _____
- Have you ever been in a sexual or romantic relationship?
 - No Yes
- Have you ever engaged in the following sexual activities? (check all that apply)
 - Holding hands
 - Kissing
 - Touching under shirt
 - Touching genitals
 - Oral sex
 - Sexual intercourse (Vaginal sex)
 - Sexual intercourse (Anal sex)
- If yes to "Have you ever been in a sexual or romantic relationship": at what point in a new relationship do you generally tell your partner that you have narcolepsy? (check one)
 - I told him/her immediately
 - Less than one month
 - 1 to 6 months
 - 6 months to a year
 - More than a year
 - I still haven't disclosed
 - Other
- If yes to "Have you ever been in a sexual or romantic relationship": Does narcolepsy impact your sex life?
 - No
 - Yes
- If yes to "Have you ever been in a sexual or romantic relationship": Do you tell someone you have narcolepsy before you decide to have sex?
 - Yes, always
 - Most of the time
 - Sometimes
 - No, never
- If yes to "Have you ever been in a sexual or romantic relationship": Have you ever experienced cataplexy during sexual activities (including foreplay, oral sex, or sexual intercourse (vaginal or anal))?
 - No
 - Yes
 - Not sure
- If yes to "Have you ever been in a sexual or romantic relationship": Have you ever fallen asleep during sexual activities (including foreplay, oral sex, or sexual intercourse (vaginal or anal))?
 - No
 - Yes
 - Not sure
- If yes to "Have you ever been in a sexual or romantic relationship" and "Have you ever experienced cataplexy during sexual activities" or "Have you ever fallen asleep during sexual activities", does it currently affect your sex life?
 - No
 - Yes
 - Not sure
- Are you currently in a sexual or romantic relationship?
 - No
 - Yes
- If yes to "Are you are currently in a relationship": Describe the type of sexual or romantic relationship you are currently in:
 - Currently dating
 - Cohabiting/living together in a marriage-like way for greater than one month
 - Childbearing/pregnancy
 - Engaged to be married
 - Married

- If yes to “Are you currently in a relationship”: In general, how satisfied are you with your relationship?
 Not at all A little Somewhat Mostly Almost Completely
 Completely
- If no to “Are you currently in a relationship”: How much would you like to have a romantic relationship in the next year?
 Not at all Very little Somewhat Quite a bit Very much Don't know
- If no to “Are you currently in a relationship”: are you currently (check all)...
 Not looking for a relationship Looking for a relationship Hooking up
 In a friends with benefits situation Other
- Has your doctor or medical professional who primarily treats your narcolepsy ever asked you about how narcolepsy impacts your social life?
 No Yes
- Has your doctor or medical professional who primarily treats your narcolepsy ever asked you about how narcolepsy impacts your sex life?
 No Yes
- Would you want your doctor or medical professional who primarily treats your narcolepsy to ask you about how narcolepsy impacts your social life?
 No Yes Not sure
- Would you want your doctor or medical professional who primarily treats your narcolepsy to ask you about how narcolepsy impacts your sex life?
 No Yes Not sure
- We know that narcolepsy can have an impact in multiple aspects of your personal life including social and sexual functioning as well as other domains. What information have we not asked about that you think is important for us to know?

Appendix B

Supplementary Tables

Table S1: Narcolepsy Symptoms by Self-Reported Diagnostic Type							
Symptom	NT1 (N = 151)		NT2 (N = 103)		Corrected p-value	Total (N = 254)	
	N	%	N	%		N	%
Excessive sleepiness	150	99.3	103	100.0	1.0	253	99.6
Brain fog	141	93.3	98	95.1	1.0	239	94.1
Disrupted nighttime sleep	142	94.0	90	87.4	1.0	232	91.3
Automatic behaviors	141	93.3	88	85.4	1.0	229	90.2
Sleep attacks	141	93.3	86	83.5	0.99	227	89.4
Depression	129	85.4	84	81.5	1.0	213	83.9
Hallucinations	133	88.1	77	74.8	0.46	210	82.7
Medication side effects	126	83.4	71	68.9	0.48	197	77.6
Sleep paralysis**	128	84.8	64	62.1	0.003	192	75.6
Cataplexy***	148	98.0	0	0.0	<.001	148	58.3

Note: Frequencies of self-reported history of experiencing symptoms of narcolepsy, separated by narcolepsy type. Chi-square tests with Bonferroni corrections were conducted to compare rates of symptoms between participants with NT1 compared to NT2. Individuals with NT1 were more likely to experience sleep paralysis ($\chi^2 (1, N = 254) = 15.79, p = .003$) and cataplexy ($\chi^2 (1, N = 254) = 237.89, p < .001$) than those with NT2. **p<.01; ***p<.001

Table S2: Narcolepsy Symptoms by Impact on Social Functioning

Symptom	Impact		
	n	Mean	SD
Excessive sleepiness	244	82.25	18.55
Depression	204	78.24	23.68
Brain fog	233	74.25	24.8
Disrupted nighttime sleep	219	62.85	28.16
Sleep attacks	210	60.47	25.64
Medication side effects	192	53.85	31.31
Cataplexy	139	52.29	30.57
Automatic behaviors	220	50.67	28.67
Hallucinations	201	28.75	24.22
Sleep paralysis	188	27.52	27.41

Note: Mean and standard deviations of the impact of specific symptoms on social functioning. Questions utilized visual analog scale with range from 0-100.