The Burden of Living With Narcolepsy: Patient Perspectives From In-Depth Qualitative Interviews

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Work or

School

Menta

Health

Instrumental

Activities of

Daily Living

Relationships

Activities of

Daily Living

Functioning

Sports, Fun

Functioning

Planning

Finances

Hazard

Social

Physical

- Narcolepsy is a rare, chronic neurological disorder that affects the brain's ability to regulate sleep-wake cycles,
- · Narcolepsy may be associated with negative impacts to patients' lives, including impaired mental and physical health, increased stigma, and difficulty obtaining an education or maintaining employment⁴⁻⁷
- Previous studies that have identified the burden associated with narcolepsy have largely relied on quantitative methods (eg, surveys), providing limited insights into the patient experience

OBJECTIVE

• The objective of this study was to use qualitative research methods (ie, in-depth interviews and thematic analysis) to understand the experience and burden of narcolepsy directly from patients with NT1 or NT2

METHODS

- o Using a semi-structured interview guide, interviewers used a concept elicitation approach to gather insights into people's experiences with NT1 or NT2
- Adult participants with NT1 or NT2 were recruited from panels of patients, physician referrals, and social media outlets Participants could also refer other participants to this study (ie, snowball sampling)
- Interview transcripts were coded and thematically analyzed using inductive and deductive approaches
- · This study was approved by an institutional review board and all participants provided informed consent

RESULTS

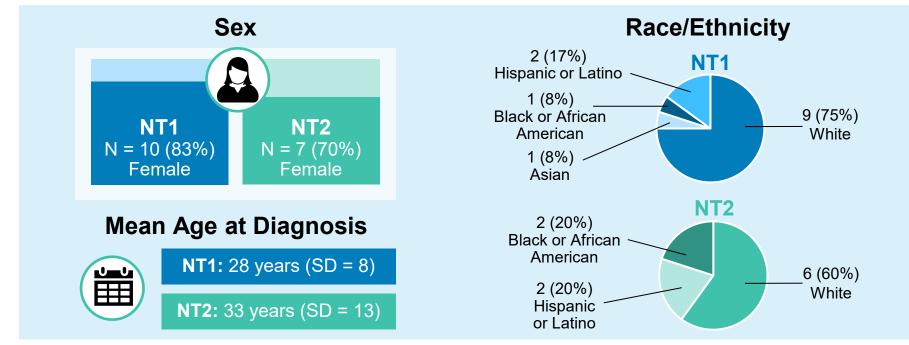
- (Figure 1)

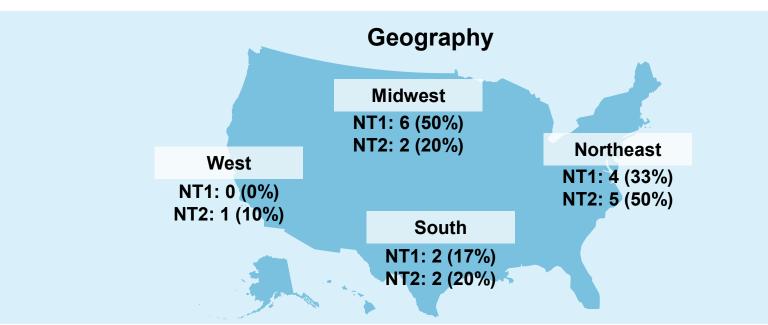
- NT2 = 9, 95%), and instrumental activities of daily living (NT1 = 11, NT2 = 10, 95%) such as home maintenance, cooking/preparing meals, and driving (**Figure 2**)
- activities of daily living (NT1 = 11, NT2 = 6, 77%) such as eating, bathing, dressing/grooming, and toileting, and physical functioning (NT1 = 10, NT2 = 5, 68%) (**Figure 2**)

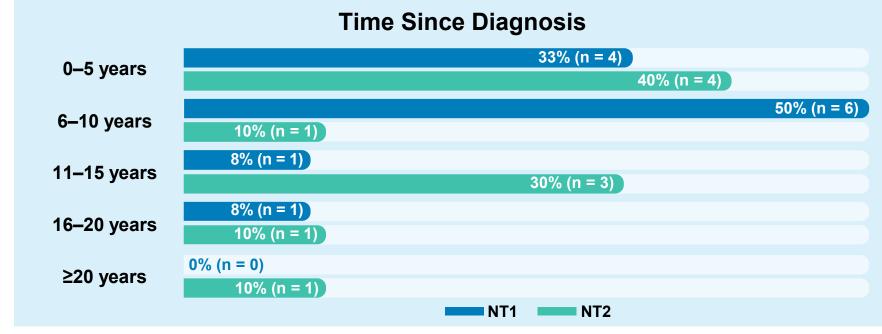
STUDY LIMITATIONS

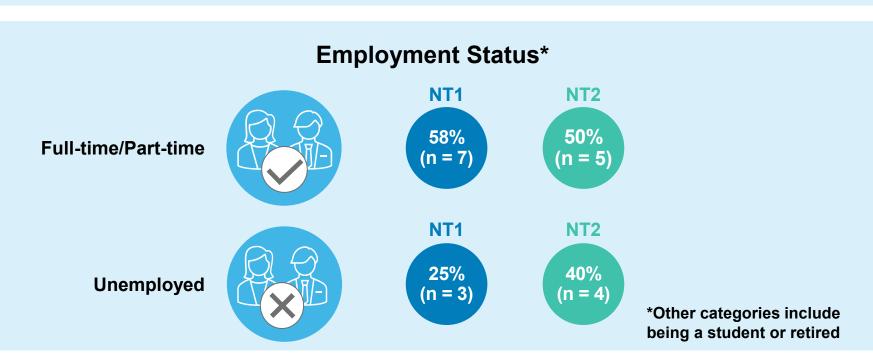
- The rare nature of narcolepsy resulted in difficulty recruiting study participants
- o Participants included in this study were mostly female, White, and under 40 years of age
- o Despite this, a saturation analysis suggested saturation of concepts was reached for NT1 and NT2 participants and additional interviews would likely not have yielded new information
- 8 participants with NT2

FIGURE 1: Demographics and Clinical Characteristics Among Participants









NT1 = narcolepsy type 1; NT2 = narcolepsy type 2.

writing – reviewing and editing, and visualization.

the burden associated with this condition

• Future research should seek to understand predictors of the burden of narcolepsy, including whether burden differs based on type of diagnosis (eg, NT1 or NT2) as well as whether diagnostic delay exacerbates

FIGURE 2: Impact on Quality of Life Among Participants

Female,

47 y/o, NT2

Pt24, Male,

33 y/o, NT1

2

Female,

40 y/o, NT1

40 y/o, NT2

Female,

40 y/o, NT2

• This study demonstrated the many facets of life that are impacted by narcolepsy, straining patients' work/school performances, relationships, and mental health

Yeah, definitely. Uhm,

I work from home. Uhm

that I can do. I mean,

able to hold a job

that's really the only thing

there's no way that I'd be

outside of my home. 99

66 I limit how much I drive. You know,

hours, but now that I know I have

66 Sometimes, I won't eat all day

because I'm asleep all day. And

sometimes, I'll not drink enough, and

I'll get really dehydrated because I'm

asleep or, or it's just easier not to.

infections because of it, because of

or, you know, it's, it's horrendous. 🤊 🤊

not going to the bathroom enough

Because I've gotten urinary tract

narcolepsy I make sure that I have

when I was younger, I could drive for

breaks um if I'm driving a long distance

just because I don't want to risk it. 99

Pt34, Female

23 y/o, NT1

66 It just feels kind of hopeless, I guess. Like most people, if they're tired or worn out, they can go

to sleep or take a nap or take a couple of days off for vacation and feel refreshed and better.

And I just don't ever get to feel better. And that is incredibly hopeless, and daunting. Feeling

like I just, I just have to be like this, and I don't—I can't fix it. I don't get a choice in the matter.

I, I can do everything right and I still have to feel like this and that is very depressing. 🤊 🤊

Yes. Uhm, I was, uh, just, just sleepiness and not being able to take care of things like I

responsible and, and work-driven, and I can't do any of that anymore. 🤊 🤊

should. Uhm, I know my family gets very frustrated, even for family events that I'm late for,

uhm, you know, that's, that's annoying to them. And, uhm, I come from a family that's very

Female,

28 y/o, NT1

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66 I couldn't get through, like, a textbook.

Like, I even tried doing it with the audio,

and it just—like, I would be so tired. I'd be

sitting, trying to get through it. And I would

66 I am able to do a little

period. 99

66 Uhm, and with like shower, like

I have had a lot of like sleep

in the shower. So, it's very

scary. Uhm, I have like a

attacks or cataplexy happening

shower chair now, but I still feel

like showers drain me a lot. It

just takes all the energy away

from me for some reason. ""

housekeeping. It's just

that I have to keep it to a

minimum or a maximum

of about 10 minutes per

be focusing more on staying awake than

I was on the material, and so I had to

drop out. 99

Female

46 y/o, NT1

INTRODUCTION

resulting in excessive daytime sleepiness (EDS)^{1,2}

- There are 2 major types of narcolepsy: narcolepsy type 1 (NT1), which includes cataplexy, and narcolepsy type 2 (NT2), which does not include cataplexy³

- This was a qualitative, cross-sectional, observational study

PARTICIPANT DEMOGRAPHICS AND DISPOSITION

- A total of 22 adults with narcolepsy participated in this study (NT1 = 12; NT2 = 10) (**Figure 1**)
- Overall, over 70% of participants were female and over 60% of participants were White (**Figure 1**)
- 83% of participants with NT1 and 50% of participants with NT2 were diagnosed with narcolepsy within the last 10 years

PATIENT PERSPECTIVE - IMPACT ON QUALITY OF LIFE

- All, or nearly all, participants reported impacts on work or school (NT1 = 12, NT2 = 10, 100%), mental health (NT1 = 12,
- Most participants also described impacts on their relationships with family and friends (NT1 = 10, NT2 = 8, 82%),

- o It is unclear if results would have been different with a more diverse sample with respect to sex, race/ethnicity, and age
- Confirmation of diagnosis was encouraged but not required; confirmation was provided by 4 participants with NT1 and

1. Ruoff C, Rye D. Curr Med Res Opin. 2016;32(10):1611-1622. 2. NINDS. Narcolepsy Fact Sheet. https://www.ninds.nih.gov/narcolepsy-fact-sheet#3201 1 Accessed May 9, 2024. 3. Sateia MJ. Chest. 2014;146(5):1387-1394. 4. Ohayon MM. Sleep Med. 2013;14(6):488-492. 5. Maski K, et al. J Clin Med Sleep. 2017;13(3):419-425. **6.** Ingravallo F, et al. Sleep Med. 2012;13(10):1293-1300. **7.** Barker EC, et al. Nat Sci Sleep. 2020;12:453-466.

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Proportion of Patients

(n = 6)

(n = 8)

(n = 9)

■NT1

■NT2

Results of this study provide a comprehensive description of the patient experience of narcolepsy

(n = 5)

(n = 5)

(n=4)

(n = 5)

NT1 = narcolepsy type 1; NT2 = narcolepsy type 2.

CONCLUSIONS

(n = 5)

(n = 12)

(n = 10)

(n = 12)

(n = 10)

(n=9)

(n = 11)

(n = 11)

(n = 10)

(n = 10)

(n = 10)

(n = 8)