

Idiopathic Hypersomnia and Narcolepsy 2: Subjective Experiences of Stimulant Use



Savannah Santos

Supervised by Sarah Butler, Ph.D.
Associate Professor of Psychology

Supported by a grant from the Honors
Council of the Illinois Region

Idiopathic Hypersomnia (IH)

- “Idiopathic hypersomnia is an uncommon sleep disorder that causes you to be excessively sleepy during the day even after a good night's sleep. It also often causes difficulty waking up after you've been asleep at night or for a nap. Naps generally aren't refreshing.” (Mayo Clinic, 2017)
- Estimated to affect around 1 in 50 million (National Sleep Foundation, 2020)
- 5-10% less common than narcolepsy (National Sleep Foundation, 2020).
- No FDA approved treatment (Genetic and Rare Diseases Information Center, 2018)



Informal Inquiry - Experiences of IH and treatments

In 2019, I asked an IH support group “When taking stimulants, does anyone else feel like their mind is foggy/sleepy, but their body is awake?”

- “Yes. I feel like they just give me massive anxiety, but I’m still sleepy and cloudy but can’t sleep. I don’t take meds anymore.”
- “Yes. I hate it. Im physically awake but my brain isnt working.”
- “Yep. Always battling. It’s like you’re wrapped in a sheet.”
- “No. I have the opposite problem. I built a tolerance to my dose and so it still clears my brain fog and gets my mind going and wanting to do stuff, but my body will not wake up. I try to will myself to physically get up for ages and I often still can’t do it. Just lay in bed wanting to do all these things, and I can’t physically move.”

Connections between IH and Narcolepsy Type 2 (N2)

- “Narcolepsy is a chronic sleep disorder characterized by overwhelming daytime drowsiness and sudden attacks of sleep. People with narcolepsy often find it difficult to stay awake for long periods of time, regardless of the circumstances.” (Mayo Clinic, 2017)
- In the general population, N2 affects 1 and 65.4 per 100,000 (Slowik, Collen, Yow 2019)
- Treatment for IH is based off of N2, but some very limited research has been done on how the conditions may actually be different (Billiard & Sonka, 2016; Genetic and Rare Diseases, 2018).
- Difference is measured through the number of of REM periods during sleep, so there does seem to be differences in brain function (Hypersomnia Foundation, 2016).

Research on IH and N2 grouped together

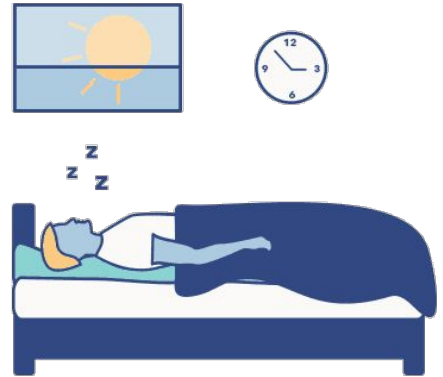
- IH and N2 together - study of dosage and side effects - grouped together (Auger, Goodman, Silber, Krahn, Pankratz, & Slocumb, 2005)
- Mental Health of people with hypersomnia - grouped together (Dauvilliers, Paquereau, Bastuji, Drouot, Weil, & Viot-Blanc, 2009)
- No research could be found that compares the rates of psychological disorders between IH and N2

Research on comorbidity in IH

- Some research has looked at hypersomnia disorders and autoimmune disease (Barateau, Lopez, Arnulf, Lecendreux, Franco, Drouot, Leu-Semenescu, Jaussent, & Dauvilliers, 2017).
- Some research has studied hypersomnia disorders and ADHD (Ito, et. al. 2018).
- Some research has studied only IH and ADHD (Oosterloo, Lammers, Overeem, Noord, & Kooij, 2006)
- No research could be found that compares the rates of Comorbidity for IH and N2

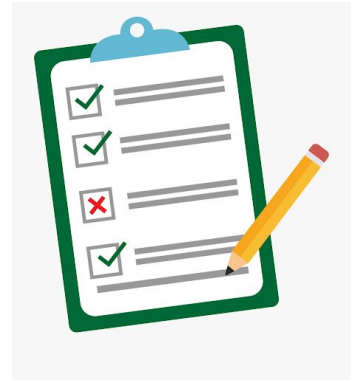
Research Questions

- Are experiences of people with IH and N2 different?
- Are there differences in perceptions of stimulant effectiveness and side effects?
- Are there differences in rates of Comorbid disorders?



Survey Details

- Conducted through a honors psychology independent study course at the College of Dupage
- Received IRB approval
- Approximately 10-15 minutes for completion
- Participants recruited through IH/Narcolepsy groups on Reddit and Facebook
- Entirely anonymous, participants must be diagnosed with IH or N2
- Participants had the option of entering in a drawing for 1 of 20 \$30 Amazon gift cards



Survey Questions

- Demographics
 - Gender, Age, Race/Ethnicity, Country of Residence, Primary Language
- Diagnosis
 - IH, N2, or Neither
 - If answered neither, taken to a thank you page.
- Age of Diagnosis
- Family members with diagnosis
 - Y/N



Survey Questions

- Current Medication:
 - Are you currently prescribed and taking medication for your IH/N2?
 - Y/N
 - What medication?
 - provided with a list of common treatments and an “other” option
- Medication effectiveness
 - All used 5 point bipolar scales
 - After taking my medication I feel... (Exhausted to Wide Awake)
 - If I don't take my medication I feel... (Exhausted to Wide Awake)
 - My medication addresses my daytime sleepiness. (Not at all to Entirely)
 - How satisfied are you with your current medication (Not at all to Entirely)

Survey Questions

Switched/Stopped Medications:

- Have you ever **switched** Medications? - Y/N
- How often?
 - 1, 2, 3, 4, 5 or more times
- Why did you **switch** medications? -
 - List of options, with “other” option
- Have you ever **stopped** taking medication entirely? - Y/N
- Why did you stop?
 - List of options, with “other” option

Side Effects:

- Have you ever suffered negative side effects...?
 - Y/N
- What side effects?
 - List provided, with “other” options
- To what extent do you feel able to prevent side effects...
 - 5 point scale, Entirely to not at all

Survey Questions

Comorbidity:

- Have you ever been diagnosed with...? (All responses were Y/N)
 - Attention Deficit Hyperactivity Disorder (ADHD)
 - Depression or a Depressive Disorder (e.g. Major Depressive Disorder, Persistent Depressive Disorder)
 - Anxiety or an Anxiety Disorder
 - Immune Disorder
 - Another Sleep Disorder
 - Which sleep disorder specifically?
 - List provided and “other” option

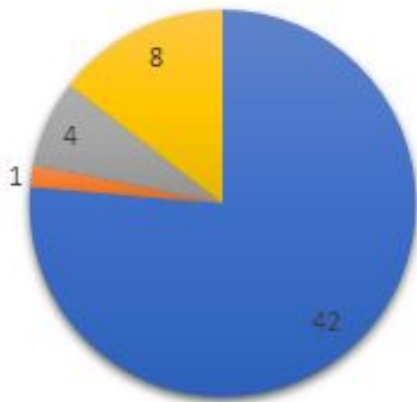


Survey Questions

- Over-the-Counter stimulant use - Caffeine
 - In your opinion how much caffeine do you ingest compared to the average person?
 - 5 point likert type scale
 - a lot less - a lot more
 - After consuming 150-200 mg of caffeine (i.e a Bang energy or large 20oz coffee) I feel...
 - After consuming 300 mg of caffeine (i.e a 12oz Red Bull or medium 14oz coffee) I feel...
 - 5 point scale
 - 1 - No different, 3 - moderately more alert, 5 - significantly more alert
 - Included separately With and Without medication for those on medication

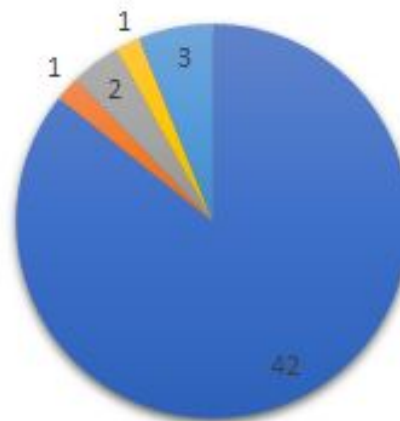
Preliminary demographics (n=55)

Where participants are from



■ United States ■ Australia ■ Canada ■ Declined to answer

Participant Race



■ White ■ Latino/a ■ Black ■ Asian ■ Multiracial

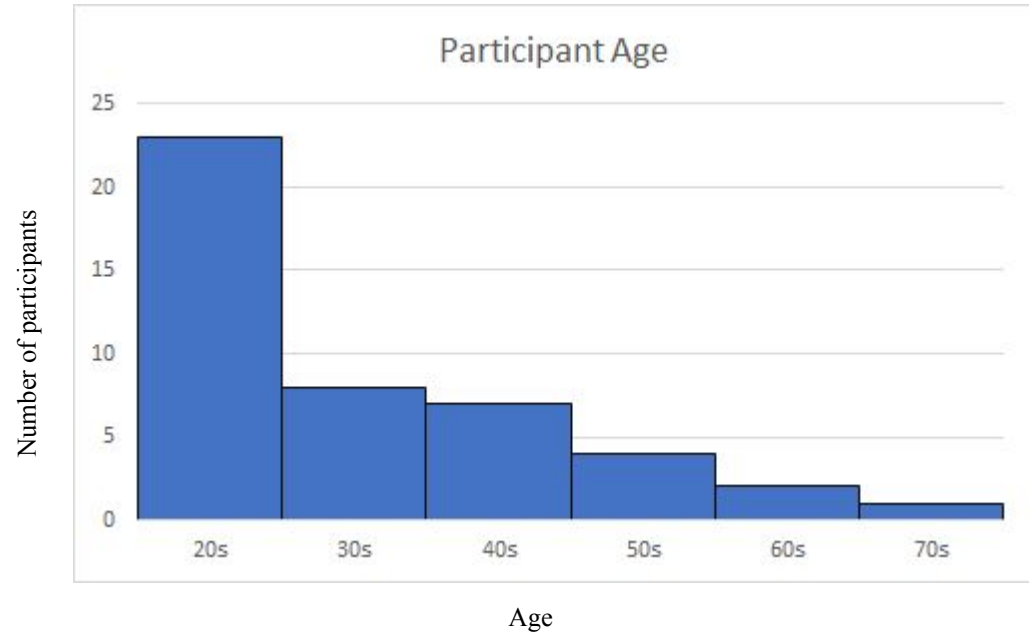
Preliminary Demographics - Age

Mean - 34.4

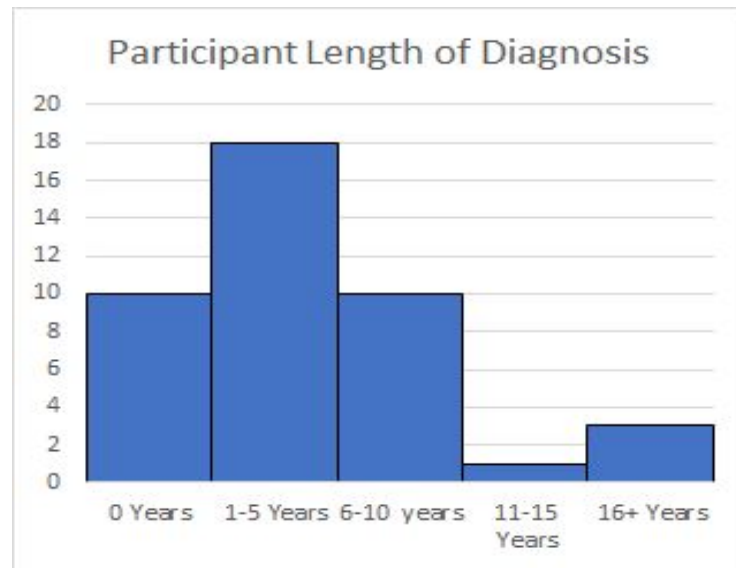
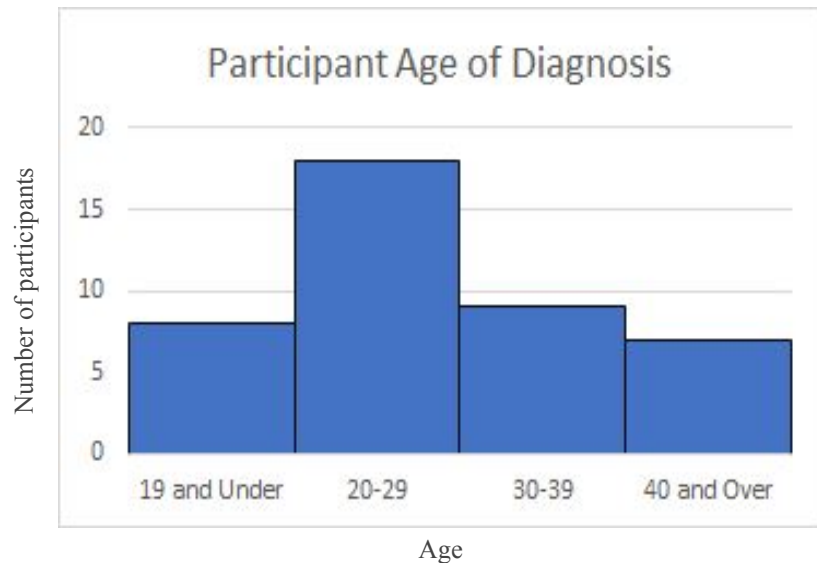
Median - 29.0

Minimum - 21

Maximum - 71



Preliminary Demographics - Age of diagnosis

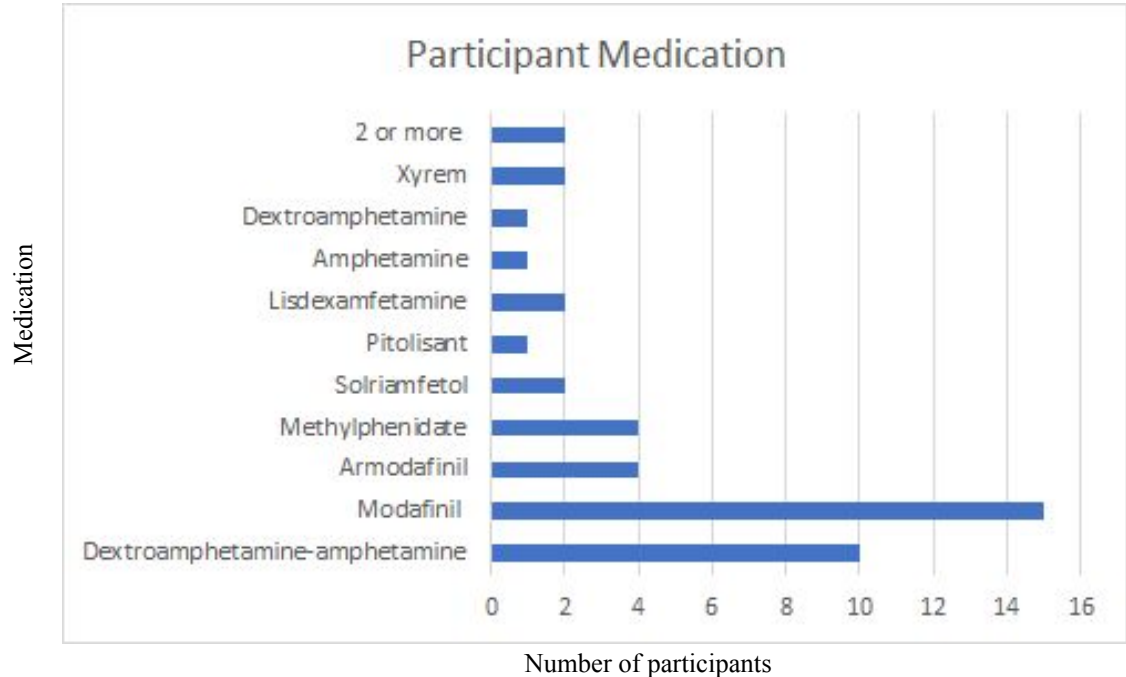


Preliminary Demographics - Diagnosis and Medication

Idiopathic Hypersomnia - 39

Narcolepsy 2 - 13

Neither - 3 (only answered initial demographics questions)



Proposed Analyses

- Contrasting IH and N2
 - Medication effectiveness
 - Medication satisfaction
 - Caffeine effectiveness
 - Rates of comorbidities - autoimmune, ADHD, and psychological diagnoses
 - How many times medication has been switched
- Other Exploratory Analyses

Limitations & Considerations for Future Research

- No control group surveyed
- Didn't define autoimmune disease in survey
- Didn't ask participants the dosage of medication



Thank you!

