Understanding the Lexicon and Experience of "Brain Fog" in Online Narcolepsy and Idiopathic Hypersomnia Communities: A Social Listening Analysis

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INTRODUCTION

- Narcolepsy and idiopathic hypersomnia (IH) are rare, chronic central disorders of hypersomnolence (CDoH)[1]
- People with CDoH often report "brain fog" among the most burdensome daily symptoms, which has been associated with impaired cognitive function and interferes with daily life, work/school, emotional well-being, and social functioning[2-5]
- Brain fog has been described as a cluster of cognitive symptoms, including fatigue, impaired memory, and reduced attention or concentration, but there is no consensus on a formal definition[5-7]
- Online conversations from digital platforms can provide valuable, firsthand insights to better understand the lexicon and experience of brain fog in people with CDoH

OBJECTIVE

- To better understand the lexicon and experience of brain fog in people with narcolepsy and IH using conversations from online sleep communities

METHODS

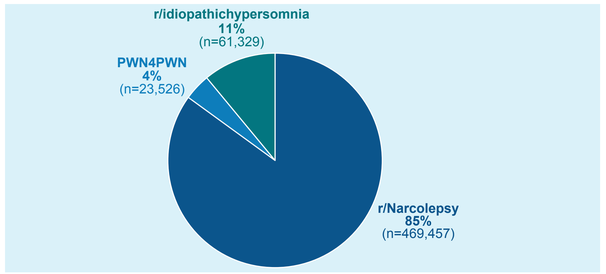
- This social listening analysis used data from 3 online sleep disorder communities of people with narcolepsy and/or IH and their family members or supporters, including
  - The r/Narcolepsy subreddit[8]
  - The r/idiopathichypersomnia subreddit[9]
  - The PWN4PWN Facebook group[10]
- The r/Narcolepsy and PWN4PWN communities are for people with narcolepsy or IH and their family members, and the r/idiopathichypersomnia community is for people with and supporters of people with IH
- Posts/comments that were made in these communities from August 2011 to September 2025 were analyzed
- A lexicon analysis was conducted to infer the collective meaning of brain fog among people with narcolepsy and IH based on
  - The association of brain fog with words used in its immediate context (ie, contextual words) over time
  - The occurrence of used terms with a semantic meaning most similar to brain fog based on the community's use of language (ie, similar terms) over time
  - The emergence of the term brain fog in 4 preselected time periods (ie, 2011-2017, 2018-2020, 2021-2023, and 2024-2025)
    - Time periods were chosen to yield roughly equal posts/comments counts in each period, except for the 2011-2017 period during which the term brain fog was first being adopted
- Semantic similarity between brain fog and other terms was calculated using cosine similarity
- Monotonic trends of yearly proportions of posts/comments for terms most semantically similar to brain fog were calculated using the Mann–Kendall test
- Clinical experience associated with brain fog mentions were determined using proprietary clinical span recognition and clinical span linking models (TREND Community, PBC)
- To assess the meaning of brain fog based on frequency of experiencing fatigue or sleepiness, Reddit authors mentioning fatigue and/or sleepiness in addition to brain fog were divided into 4 cohorts using Jenks natural breaks method
  - Fatigue/sleepiness-balanced (ie, authors whose proportions of posts/comments mentioning fatigue and sleepiness were roughly equal)
  - Fatigue-dominant (ie, authors whose proportion of posts/comments mentioning fatigue exceeded the proportion mentioning sleepiness)
  - Sleepiness-dominant (ie, authors whose proportion of posts/comments mentioning sleepiness exceeded the proportion mentioning fatigue, but by <7.5%)
  - Very sleepiness-dominant (ie, authors whose proportion of posts/comments mentioning sleepiness exceeded the proportion mentioning fatigue by ≥7.5%)

RESULTS

DATASET OVERVIEW

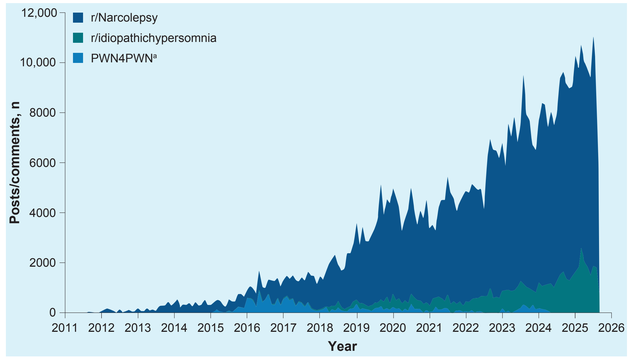
- During the study period, a total of 554,312 posts/comments were identified
- The majority (85%) of posts/comments were from r/Narcolepsy, followed by r/idiopathichypersomnia and PWN4PWN (**Figure 1**)

FIGURE 1: Proportion of All Posts/Comments by Online Sleep Community



- Over time, the number of monthly posts/comments by online sleep community increased in the r/Narcolepsy and r/idiopathichypersomnia subreddits, with the most prominent increase observed in the r/Narcolepsy sleep community (**Figure 2**)

FIGURE 2: Monthly Number of All Posts/Comments by Online Sleep Communities Over Time



[a]Facebook data limitations implemented after April 2024 restricted access to the PWN4PWN online sleep community.

BRAIN FOG MEANING

- The top 5 most common contextual words associated with brain fog that were unrelated to symptom alleviation were "forgetfulness," "memory," "fatigue," "drunkenness," and "dissociation" (**Table 1**)
  - Among the top 15 most common contextual words associated with brain fog, those that were related to symptom alleviation included "clears," "lifted," "lifts," and "clearing"
- The top 5 terms with the highest similarity scores to brain fog that were not synonyms, shorthand, or spelling variations of brain fog included "tiredness," "difficulty concentrating," "inability to focus," "poor memory," and "memory issues"
  - Among the top 15 terms with the highest similarity scores to brain fog, those that appeared to be brain fog synonyms, shorthand, or spelling variations included "fog," "mental fog," "fog etc," "brain fog etc," "fogginess," "foggy brain," and "brainfog"

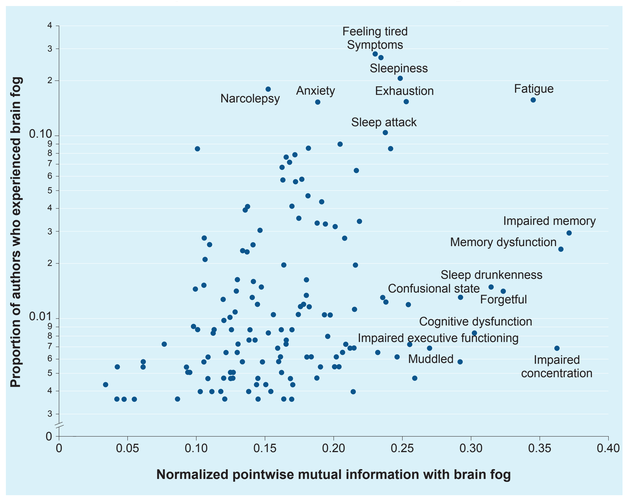
TABLE 1: Contextual Words Most Associated With Brain Fog and Terms With Meanings Most Similar to Brain Fog

Rank	Most common words used in the immediate context of brain fog	Terms with meanings most similar to brain fog
1	Clears[a]	Fog[b]
2	Forgetfulness	Tiredness
3	Lifted[a]	Mental fog[b]
4	Memory	Fog etc[b]
5	Fatigue	Difficulty concentrating
6	Drunkenness	Inability to focus
7	Dissociation	Brain fog etc[b]
8	Concentration	Fogginess[b]
9	Cognitive	Poor memory
10	Constant	Memory issues
11	Confusion	Foggy brain[b]
12	Lifts[a]	Brainfog[b]
13	Inertia	Memory loss
14	Derealization	Forgetfulness
15	Clearing[a]	Fatigue brain

[a]Context words related to symptom alleviation.
[b]Similar terms that are synonyms, shorthand, or spelling variations of brain fog.

- The top 5 symptoms related to clinical experiences most highly associated with brain fog were memory-related and included "impaired memory," "memory dysfunction," "impaired concentration," "fatigue," and "forgetful" (**Figure 3**)

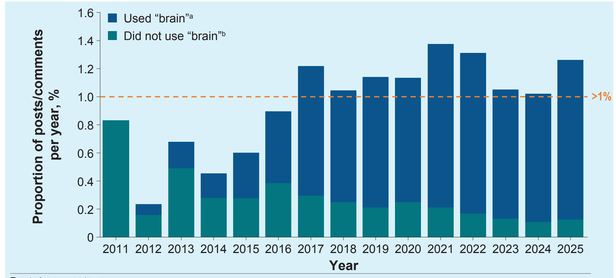
FIGURE 3: Clinical Experiences Associated With Brain Fog



BRAIN FOG MEANING OVER TIME

- Mentions of brain fog and similar terms, which included those that are synonyms, shorthand, or spelling variations of brain fog, increased in frequency each year from 2011 to 2017 and was consistently used in >1% of posts/comments thereafter (**Figure 4**)
  - Frequency of mentions of terms that used "brain" (ie, brain fog, foggy brain, and brainfog) increased over the study period

FIGURE 4: Yearly Counts and Proportions of Posts/Comments Mentioning Brain Fog and Similar Terms



Posts/comments, n	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Used "brain"[a]	0	1	5	8	20	72	157	191	408	446	601	761	807	927	957
Did not use "brain"[b]	1	2	13	13	17	54	50	60	93	125	109	110	116	110	104
Total	1	3	18	21	37	126	207	251	501	571	710	871	923	1037	1061

Only similar terms that are synonyms, shorthand, or spelling variations of brain fog were included. Orange dashed line indicates the frequency of brain fog mentions used in >1% of posts/comments.
[a]Includes brain fog and the similar terms foggy brain and brainfog.
[b]Includes the similar terms fog, mental fog, fogginess.

- Use of brain fog significantly increased from 2014 to 2025 (**Table 2**)
  - Terms most semantically similar to brain fog with the greatest use increase were "fatigue brain," "fog fatigue," and "fatigue brain fog"
  - Terms most semantically similar to brain fog with the greatest use decrease were "mental fog," "poor memory," "memory," "concentration issues," "memory loss," "tiredness," and "memory problems"

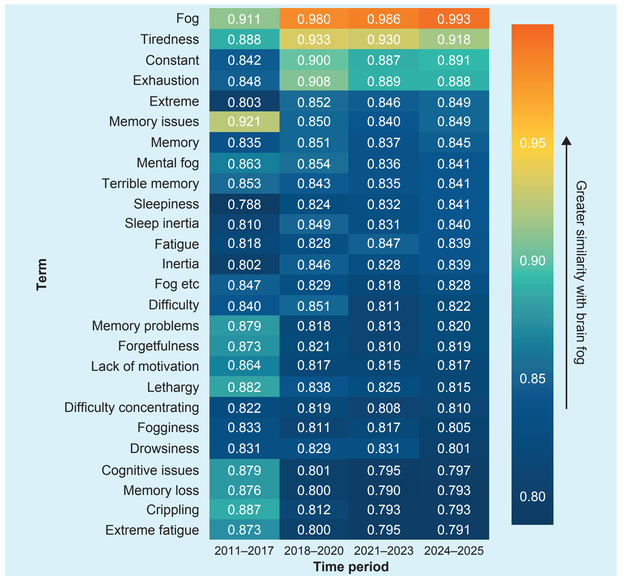
TABLE 2: Yearly Trends in Mentions of Brain Fog and Related Terms From 2014 to 2025[a]

Trend	Term	Z-score	*P* value
↑ Increased	Brain fog	2.95	0.003
	Fatigue brain	2.19	0.029
	Fog fatigue	2.07	0.039
	Fatigue brain fog	1.98	0.048
↓ Decreased	Mental fog[b]	−3.36	0.001
	Poor memory	−3.22	0.001
	Memory	−2.81	0.005
	Concentration issues	−2.67	0.008
	Memory loss	−2.67	0.008
	Tiredness	−2.67	0.008
	Memory problems	−2.40	0.016

Results from the Mann–Kendall test for monotonic trend of the yearly proportions of posts/comments using brain fog and terms most semantically similar to brain fog. Only statistically significant results are shown.
[a]Trends were assessed from 2014 onward as high variance of proportional term usage, attributed to smaller post/comment sample sizes, was observed in prior years.
[b]Similar term that is a synonym of brain fog.

- The meaning of brain fog in relation to similar terms displayed subtle changes over time, with the largest change observed between 2011-2017 and 2018-2020 when it shifted away from memory-related terms and toward terms related to exhaustion/tiredness (**Figure 5**)
  - Its meaning remained fairly consistent from approximately 2018 to 2025

FIGURE 5: Cosine Similarity Scores of Brain Fog With Other Terms Over Time

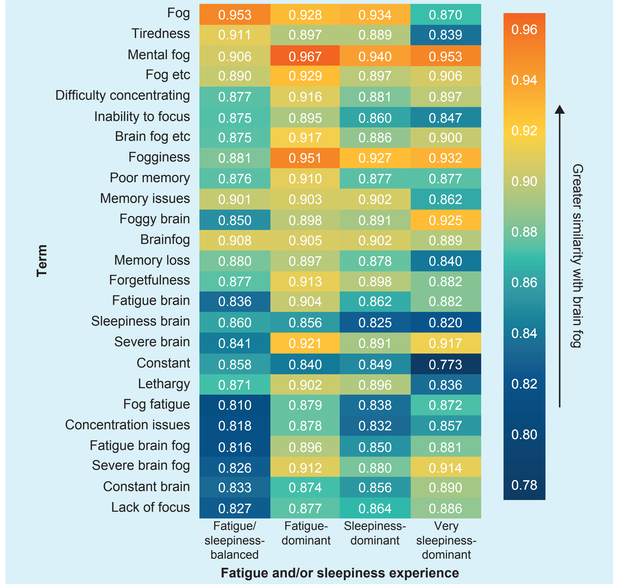


Higher scores indicate a greater similarity of the term with brain fog.

BRAIN FOG MEANING BY EXPERIENCE OF FATIGUE AND/OR SLEEPINESS

- Across cohorts based on their frequency of experiencing fatigue and/or sleepiness, the greatest discrepancy in the meaning of brain fog was observed between the fatigue/sleepiness-balanced and very sleepiness-dominant cohorts (**Figure 6**)
  - The fatigue/sleepiness-balanced cohort had a memory and focus connotation
  - The very sleepiness-dominant cohort signaled a relationship with energy/motivation and an association with time/intensity qualifiers (eg, "constant," "intense," "severe")

FIGURE 6: Cosine Similarity Scores of Brain Fog With Other Terms by Reddit Authors' Experience of Fatigue and/or Sleepiness



Only Reddit authors with ≥100 posts/comments and ≥3 mentions of experiencing either fatigue or sleepiness were included. Higher scores indicate a greater similarity of the term with brain fog.

STUDY LIMITATIONS

- Data for this analysis were obtained over a >14-year period; thus, social media patterns may have shifted over time, making it difficult to isolate the observed changes from platform use effects
- People with narcolepsy and IH who participate in online sleep communities may not fully represent broader patient populations
- Given that posts/comments were verbatim, the authors' ability to articulate symptoms and their interpretation of the meaning of brain fog may vary
- Manifestations of brain fog symptoms may vary across CDoH and, therefore, results combining narcolepsy type 1, narcolepsy type 2, and IH data could be challenging to interpret
- Moreover, brain fog symptoms may be confounded by primary or comorbid CDoH symptoms

CONCLUSIONS

- In online narcolepsy and IH communities, brain fog was primarily associated with memory impairment, while also describing difficulty concentrating and forgetfulness
- Further, brain fog was semantically distinguishable from fatigue and sleepiness
- The meaning of brain fog remained stable since 2018 and was distinguishable from fatigue and sleepiness, suggesting a mature, shared vocabulary suitable for research applications, such as development of patient-reported outcome measures and clinical endpoints
- Clinicians should consider the independent nature of patients' perception of brain fog when addressing their overall symptomatology

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DISCLOSURES

AMM has served as an investigator, consultant, speaker, and/or on advisory boards for Alkermes, Inc., Apnimed, Avadel Pharmaceuticals, Axsome Therapeutics, Eisai, Harmony Biosciences, Jazz Pharmaceuticals, Lilly, Lundbeck, Noble Pharmaceuticals, Novartis, and Takeda Pharmaceutical Co.; has received grant funding from the National Institutes of Health, UCB Pharmaceuticals, ResMed Foundation, Coverys Community Healthcare Foundation, Harmony Biosciences, and Geisinger Health Plan; is the Chief Executive Officer of DAMM Good Sleep, LLC; is the chairman of the clinical advisory board for NanoMosaic; and serves as an adviser for Neura Health, OpenEvidence, Pulse Infoframe, and FloraWorks. **AM** has received grant funding from the National Institutes of Health; has received income related to medical education from LivaNova, Powell Mansfield, Sunrise Pharmaceutical, Zoll Medical, and Lilly; and his institution has received a philanthropic donation from ResMed Foundation, but AM has not received personal income from ResMed Foundation or medXcloud. **LB** has served as a consult for Bioprojet, Idorsia, and Takeda Pharmaceutical Co. **DTP** has served as a consultant or advisory board member for Addum Bio LLC, Alkermes, Inc., Centessa Pharmaceuticals, Harmony Biosciences, Jazz Pharmaceuticals, Takeda Pharmaceutical Co., and Teva Pharmaceuticals (Australia). **ZC** is an employee of TREND Community. Clients of TREND Community are pharmaceutical biotechnology companies including, but not limited to, Amgen, Harmony Biosciences, Acadia, Soleno Therapeutics, and Avadel Pharmaceuticals. **CD** and **MP** are owners of and own stock options in TREND Community. Clients of TREND Community are pharmaceutical and biotechnology companies including, but not limited to, Horizon Therapeutics, Chiesi Global Rare Disease, Novartis, Harmony Biosciences, and Avadel Pharmaceuticals. **JB** is an employee of Alkermes, Inc.

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