



# Hypersomnia and our Heroes: Studying IH and behavioral disorders in the U.S. Veteran Population

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### Sleep: Why Worry?

- Prevalence
  - Sleep problems are experienced by a large segment of the general population
  - at least 4-6% of the population is impacted by hypersomnia<sup>1</sup>
- Persistence
  - Sleep problems often do <u>not</u> resolve spontaneously <u>or</u> by treating comorbidities
- Perniciousness
  - Exacerbate and can even contribute to the development of comorbidities (e.g. depression; cardiovascular disease; diabetes)
- Treatable
  - Effective treatments exist for sleep apnea, nightmares, and insomnia



# Idiopathic Hypersomnia

- Impacts an estimated 1 to 4 individuals out of every 100,000 in the general population<sup>3</sup>
- Represents ~ 1% of patients who seek care at sleep centers<sup>4</sup> and IH is 5 to 10 times less common than narcolepsy<sup>5,6</sup>
- A low base rate and diagnostic challenges have limited the progression of IH research
- Increasing our knowledge of physical and behavioral health correlates will enhance our understanding of IH, its development, and course



3. Bassetti & Dauvilliers (2011); 4. Anderson et al. (2007); 5. Bassetti & Aldrich (1997); 6. Billiard & Dauvilliers (2001)



# Why Veterans? Why Big Data

- Big data allows us to leverage the medical records of millions of individuals, thousands of cases of IH that we would otherwise miss
- The Veteran population frequently suffers from sleep disorders
- The Veterans Health Administration (VHA) maintains the largest electronic medical records in the nation
  - o 9 million Veterans
  - 1200 Treatment Facilities
  - o 170 Medical Centers





### **Overall Project Aims**

**Aim 1:** Development of a validated process for the identification of cases of IH within the VA EMR using diagnostic and pharmacy data

**Aim 2:** The creation of a cohort of VHA users diagnosed with idiopathic hypersomnia between FY09-FY19 based on the validated process

**Aim 3a:** The estimation of a 10 years prevalence of IH diagnosis among VHA users

**Aim 3b:** Exploration of the associations among idiopathic hypersomnia, treatment utilization patterns, and co-occurring psychopathology and physical health conditions



# Idiopathic Hypersomnia within the VHA

#### **Initial Data Pull**

- All patient encounters between October 1, 2009 and September 30, 2019
- Idiopathic Hypersomnia cases = 3,674
- <u>12 new IH cases per 100,000</u> Veterans treated in FY17



Demographics	Ν	%
Male	2,893	78.7
Female	781	21.3
RACE		
White	2,701	73.5
Black	611	16.6
Asian	60	1.6
American Indian/Alaska Native	45	1.0
Native Hawaiian or other PI	23	0.6
Unknown/declined	234	6.3
ETHNICITY		
Hispanic	260	8.0
Non-Hispanic	3,288	89.1



# Idiopathic Hypersomnia within the VHA

#### **Revised Data Pull**

- Added rule out conditions to make a more conservative dataset
- Excluded patients if any of the following diagnoses were present in the EMR in the 6-months following the initial IH diagnosis:
- Revised Sample:
  - Idiopathic Hypersomnia cases = 1,058
  - Average of **98.7** days between initial IH diagnosis and one of these rule out conditions

Exclusion Conditions	Ν	%
Hypersomnia, unspecified	1,178	28.3
Recurrent Hypersomnia- Klein Levin Syndrome	24	0.6
Narcolepsy	585	14
Alcohol-related Hypersomnia	6	0.1
Drug-related Hypersomnia	7	0.2
Hypersomnia due to a mental disorder	16	0.4
Hypersomnia not due to a substance or known physiological condition	31	0.7
Primary Hypersomnia	121	2.9
Sleep Apnea	2,586	62.1



# Correlates of Idiopathic Hypersonnia

#### **IH Final group data:**

- Idiopathic Hypersomnia cases = 1,058
- Mean age of 57.7 years (SD = 15.4)
- Using these conditions as rule outs leaves us with a sample that is slightly older and has a greater proportion of female Veterans.

Demographics (%)	<b>IH</b> (n=3,674)	<b>Final IH</b> (n=1,058)			
Male	78.7	69.9			
Female	21.3	30.1			
RACE					
White	73.5	71.5			
Black	16.6	17.9			
Asian	1.6	2.4			
American Indian/Alaska Native	1.0	0.8			
Native Hawaiian or other PI	0.6	0.6			
Unknown/declined	6.3	6.9			
ETHNICITY					
Hispanic	8.0	6.0			
Non-Hispanic	89.1	91.4			



# Correlates of Idiopathic Hypersonnia

PHYSICAL HEALTH	Ν	%	Brain Tumor	2	0.2
Diabetes (Type 1 or 2)	103	9.7	Dementia	15	1.4
Other specified cardiac arrhythmias	12	1.1	BEHAVIORAL HEALTH	Ν	%
Orthostatic hypotension	7	0.7	Depression/MDD	331	31.3
Hypothyroidism	69	6.5	Substance Use Disorder	82	7.7
Obesity	169	16.0	Posttraumatic Stress Disorder	312	29.5
Lupus	4	0.4	Schizophrenia & Schizoaffective DXs	0	0.0
Fibromyalgia	35	3.3	Bipolar	28	0.9
Other/Unspecified Encephalopathy	4	0.4	Anxiety Disorders	61	5.8
Chronic fatigue syndrome	44	4.2	Personality Disorders	8	0.8
Epilepsy or Recurrent Seizures	11	1.0	Suicide Attempt	3	0.3



#### Veterans with other Hypersonnia DX

• Included:

VA

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- 1. Primary hypersomnia
- 2. Unspecified hypersomnia
- 3. Hypersomnia not due to SUD or physiological condition
- 4. Klein Levin Syndrome
- Excluded: Idiopathic Hypersomnia
- Cases (FY09 FY19) = **110,530**

Demographics (%)	<b>Other</b> <b>Hyper</b> (n=110,530)	<b>IH</b> (n=1,058)
Male	87.7	69.9
Female	12.3	30.1
RACE		
White	69.1	71.5
Black	21.6	17.9
Asian	1.3	2.4
American Indian/Alaska Native	0.8	0.8
Native Hawaiian/other PI	1.0	0.6
Unknown/declined	6.3	6.9
ETHNICITY		
Hispanic	7.7	6.0
Non-Hispanic	89.3	91.4



\*\*\* p < .001

# Correlates: IH vs other Hypersonnia DX

PHYSICAL HEALTH (%)	Other Hyper	IH	Brain Tumor	0.1	0.2
Diabetes (Type 1 or 2)***	24.4	9.7	Dementia	2.0	1.4
Other specified cardiac arrhythmias	1.7	1.1	BEHAVIORAL HEALTH (%)	Other Hyper	н
Orthostatic hypotension	0.5	0.7	Depression/MDD***	23.4	31.3
Hypothyroidism	6.5	6.5	Substance Use Disorder	7.2	7.7
Obesity***	28.3	16	Posttraumatic Stress Disorder***	26.5	29.5
Lupus	0.2	0.4	Schizophrenia & Schizoaffective DXs	0	0
Fibromyalgia	2.7	3.3	Bipolar	0.8	0.9
Other/Unspecified Encephalopathy	0.3	0.4	Anxiety Disorders***	9.5	5.8
Chronic fatigue syndrome***	1.6	4.2	Personality Disorders	1.0	0.8
Epilepsy or Recurrent Seizures	1.8	1	Suicide Attempt	0.4	0.3



# Correlates: IH vs other Hypersomnia DX

PHYSICAL HEALTH (%)	Other Hyper	ІН	Brain Tumor	0.1	0.2
Diabetes (Type 1 or 2)***	24.4	9.7	Dementia	2.0	1.4
Other specified cardiac arrhythmias	1.7	1.1	BEHAVIORAL HEALTH (%)	Other Hyper	IH
Orthostatic hypotension	0.5	0.7	Depression/MDD***	23.4	31.3
hypothyroidism	6.5	6.5	Substance Use Disorder	7.2	7.7
Obesity***	28.3	16	Posttraumatic Stress Disorder***	26.5	29.5
Lupus	0.2	0.4	Schizophrenia & Schizoaffective DXs	0	0
Fibromyalgia	2.7	3.3	Bipolar	0.8	0.9
Other/Unspecified Encephalopathy	0.3	0.4	Anxiety Disorders***	9.5	5.8
chronic fatigue syndrome***	1.6	4.2	Personality Disorders	1.0	0.8
Epilepsy or Recurrent Seizures	1.8	1	Suicide Attempt	0.4	0.3

\*\*\* p < .001

# Disparities in Hypersomnia Diagnosis and Care

- National Institute of Neurological Disorders & Stroke (NINDS)
  - <u>Request for Information</u> (RFI): Seeking to identify gaps in research and health disparities or inequities in neurological disease, treatment, and care
- Response to RFI:

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- CoRDS participants most often identify as White (92.9%) and female (84.5%)
- VHA Veterans, FY16-19, diagnosed with a hypersomnia disorder (n = 72,592)
- Within VHA, hypersomnia disorders are disproportionately *elevated* among individuals identifying as a racial or ethnic minority and females.
- Implications for Sleep Medicine within VHA
  - If trends hold, expect a lot more hypersomnia within VA
    - 50% increase hypersomnia diagnoses between FY00-FY10
    - 51.8% increase in female Veterans using VHA services FY08-FY17 <sup>8</sup>



### Next Steps

- 1. Incorporation of Pharmacy and Treatment Utilization Data
  - Some Anticipated Challenges:
    - Off-label use of medications to treat IH
    - Prescriptions from non-VHA sources
- 2. Development of a Case Ascertainment Algorithm
  - Some Anticipated Challenges:
    - Documentation of MSLT & PSG testing
    - Sleep testing that occurs outside VHA

Documented testing prior to IH						
Any I	H Diagnosis	6				
( <i>n</i>	= 3,674)					
	N	%				
PSG	581	13.9				
HST	7.9					
MSLT 311 7.5						
Actigraphy 28 0.7						
Idiopathic Hypersomnia – Final						
( <i>n</i> = 1,058)						
PSG 141 13.3						
HST 167 15.						
MSLT 78 7.4						
Actigraphy 7 0.7						



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# Thank You



# Chi Square Tests

					Chi-sq	P value
SUD pre	82	7.7	7,934	7.2	0.51	0.47
Depression/MDD pre	331	31.3	25,889	23.4	36.04	<.001
Depression/MDD post	308	29.1	27,228	24.6	11.3	<.001
PTSD pre	312	29.5	28,979	26.2	5.79	0.02
Anxiety pre	61	5.8	10,467	9.5	16.83	<.001
Anxiety post	48	4.5	7,927	7.2	10.96	<.001
Diabetes (Type 1 or 2) pre	103	9.7	27,000	24.4	123.02	<.001
Diabetes (Type 1 or 2) post	93	8.8	27,713	25.1	148.51	<.001
hypothyroidism pre	69	6.5	7,619	6.9	0.22	0.63
hypothyroidism post	63	5.9	7,326	6.6	0.77	0.38
obesity pre	169	16	31,340	28.3	79.27	<.001
Fibromyalgia pre	35	3.3	3,021	2.7	1.3	0.25
chronic fatigue syndrome pre	44	4.2	1,715	1.6	45.91	<.001
chronic fatigue syndrome post	22	2.1	1,380	1.3	5.83	0.02