

# EXPLORING THE PATTERNS OF COGNITIVE SYMPTOMS TRACKED BY CAREGIVERS AND PATIENTS IN ONLINE SYMPTOM PROFILES

CTAD 2019

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<sup>3</sup>Nutricia, Amsterdam, Netherlands



# DISCLOSURES

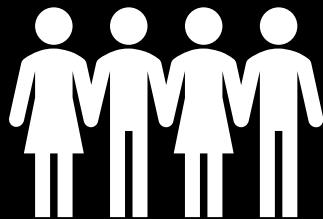
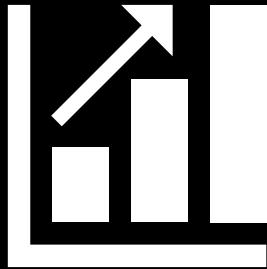
KR founded and has shares in **DGI Clinical**, a company that has contracts with pharma for individualized outcome measure and advanced data analytics in Alzheimer disease, Parkinson disease, and other disorders.

The data were supplied by **DGI Clinical** from its **SymptomGuide®** platform, and the analyses were commissioned as part of contract work with **Nutricia**.



# BACKGROUND

- Existing **mild cognitive impairment (MCI)** guidelines suggest no treatment, possibly beyond lifestyle modification.
- This evidence reflects performance on standardized tests, whereas **patients/carers report heterogenous symptoms** that challenge current measurement and treatment approaches.
- In contrast, the **SymptomGuide® Dementia app (SG-D)**, which allows patient and/or caregiver users to identify, describe, and track their most important symptoms.



## OBJECTIVE

To better understand MCI symptoms, we used a **novel supervised staging algorithm** to explore, in the **SG-D database**, how symptom characteristics and patterns varied across degrees of cognitive impairment.

We were specifically interested in the **nature** of **frequency** and **importance** varied by degree of cognitive impairment.

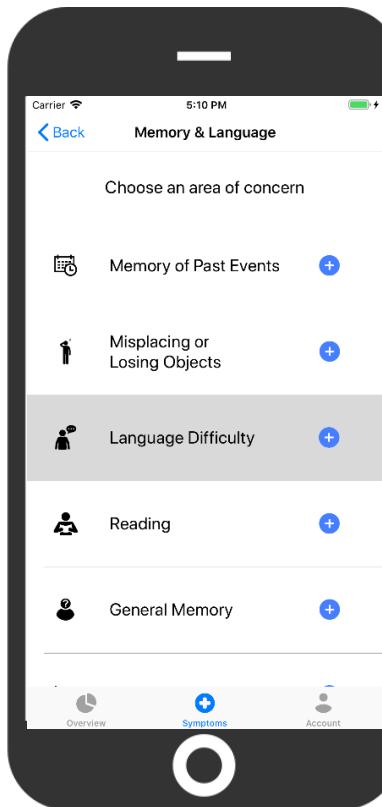
# HOW WE COLLECTED DATA ON 3909 USERS

2006-2018

The screenshot shows the 'Creating 's Symptom Profile' section of the DementiaGuide website. At the top, there's a navigation bar with links like HOME, SYMPTOMGUIDE™, PROFILE, JOURNAL, SYMPTOM LIBRARY, COMMUNITY, SUPPORT, ACCOUNT, and LOGOUT. Below the navigation is the 'DementiaGuide' logo with the tagline 'HELPING PEOPLE AFFECTED BY DEMENTIA'. The main content area has a heading 'SymptomGuide™ Creating 's Symptom Profile'. It includes a sub-instruction: 'This section allows you to record and track the progress of symptoms. You will be prompted to categorize and rank the symptoms at each step. If you have any technical difficulties while completing this section, please contact us.' Below this, there are three numbered steps: 1. Describe Symptoms, 2. Rank Symptoms, and 3. Save Profile. Step 1 is currently active. A large callout box contains the following fields:

- Category:** Everyday Activities, Memory & Language, Thinking & Judgment, Behaviour, Leisure Activities, Personality Changes, Physical Changes.
- Symptoms:** Judgment, Comprehension/ Understanding, Attention/Concentration (lack of), Following Instructions, Decision Making (problems with), Insensitivity, Inappropriate Language and Behi, Unsafe Actions.
- Definition:** Inability to remain focused or alert.
- Action:** A blue button labeled 'Select & Continue'.

2018

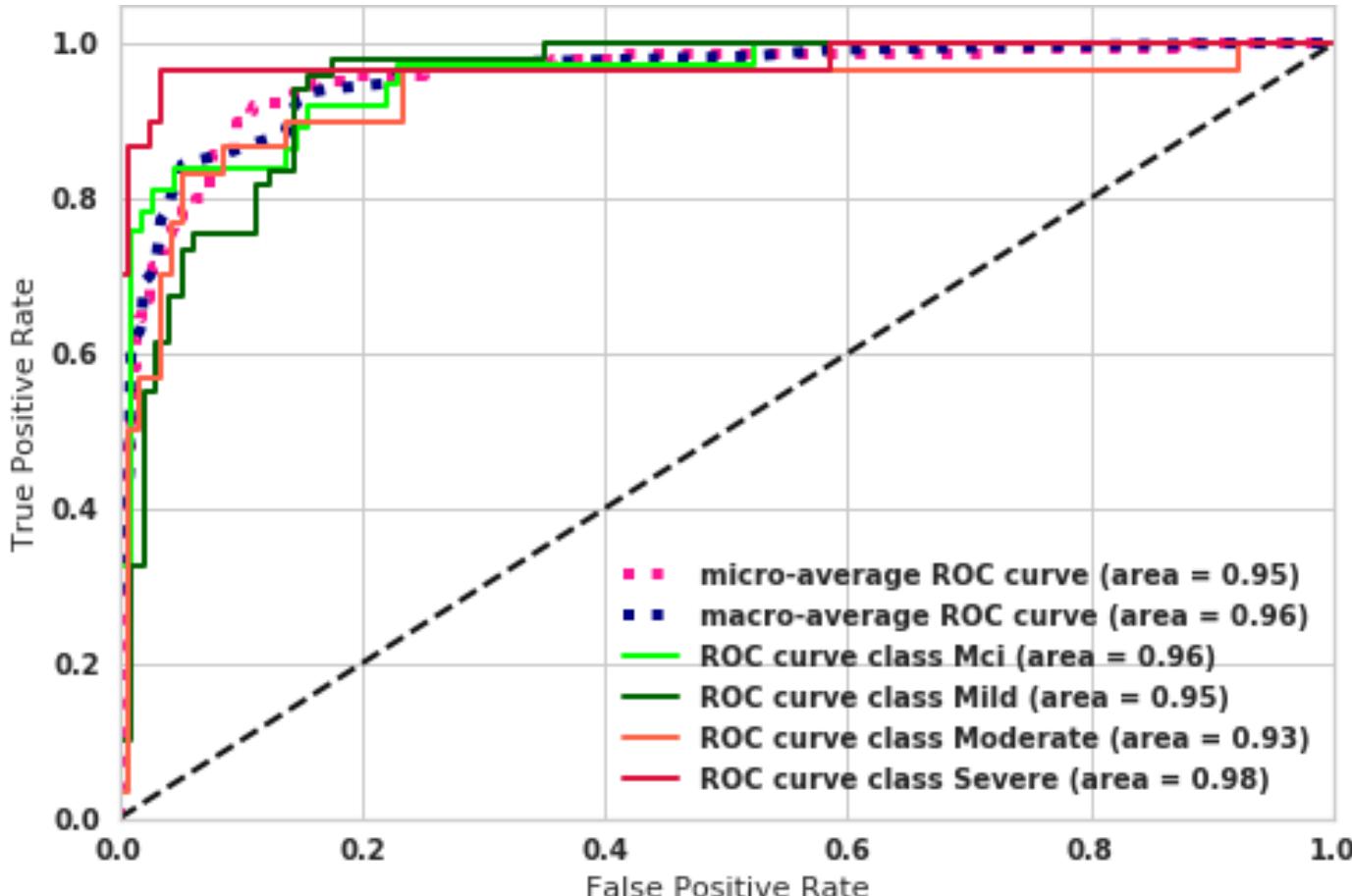




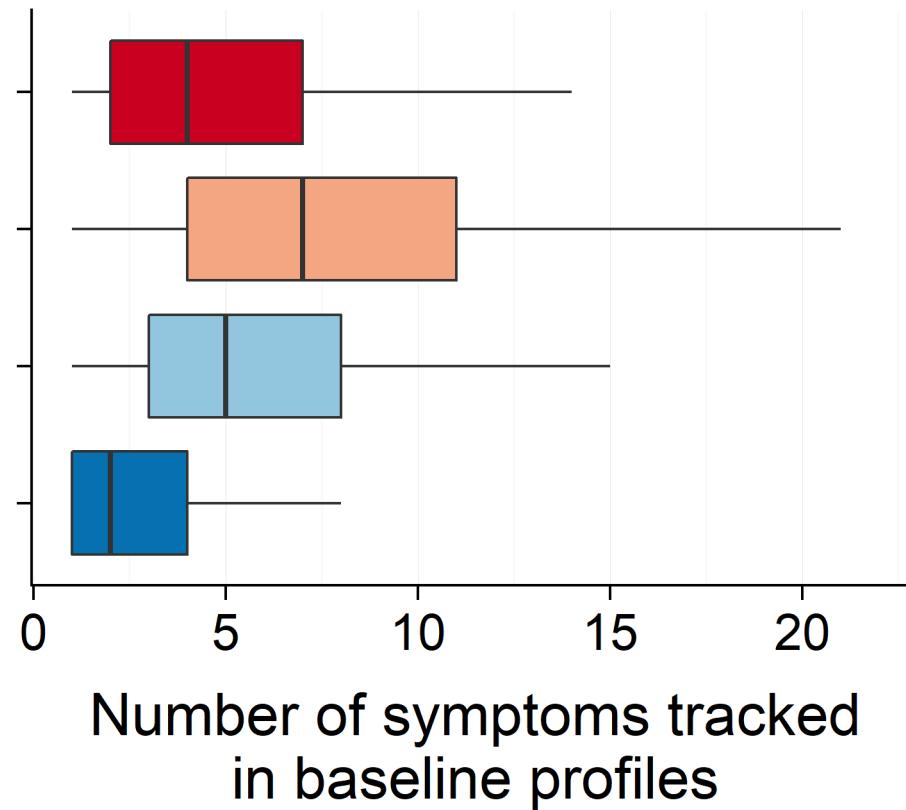
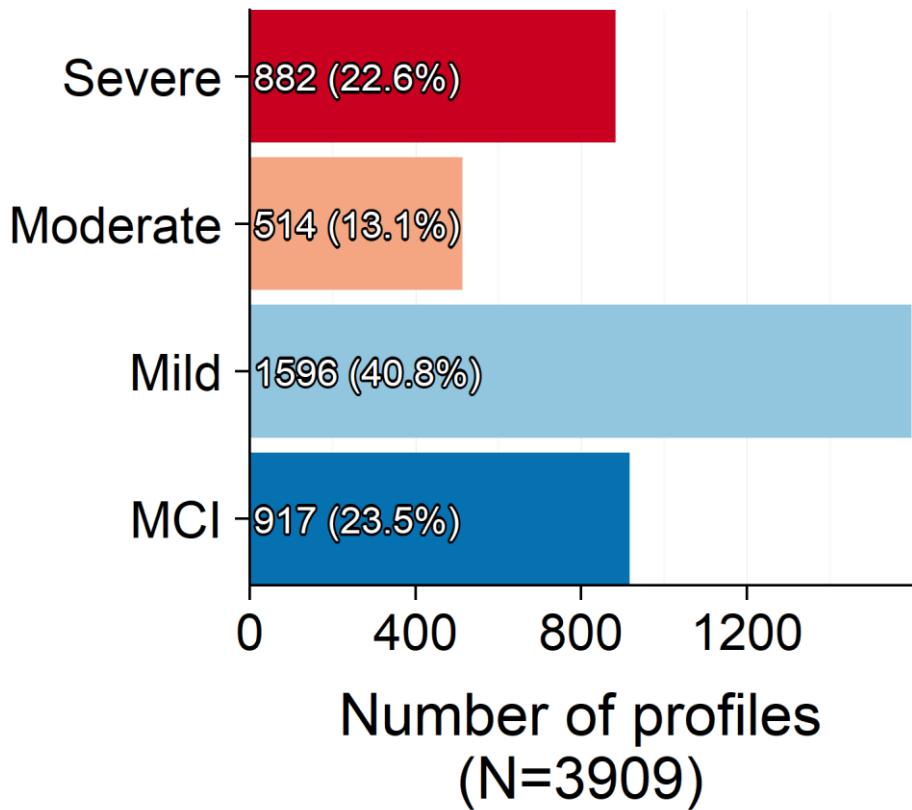
# THE STAGING ALGORITHM

- Trained on 688 symptoms profiles from a memory clinic and two dementia clinical trials.
  - 25% MCI, 34% Mild, 20% Moderate, 20% Severe
- Implemented in 3909 users; July-Nov '18 app users (n=156).
- Support-vector machine learning algorithm.
  - Inputs: 48 symptoms and patient age.

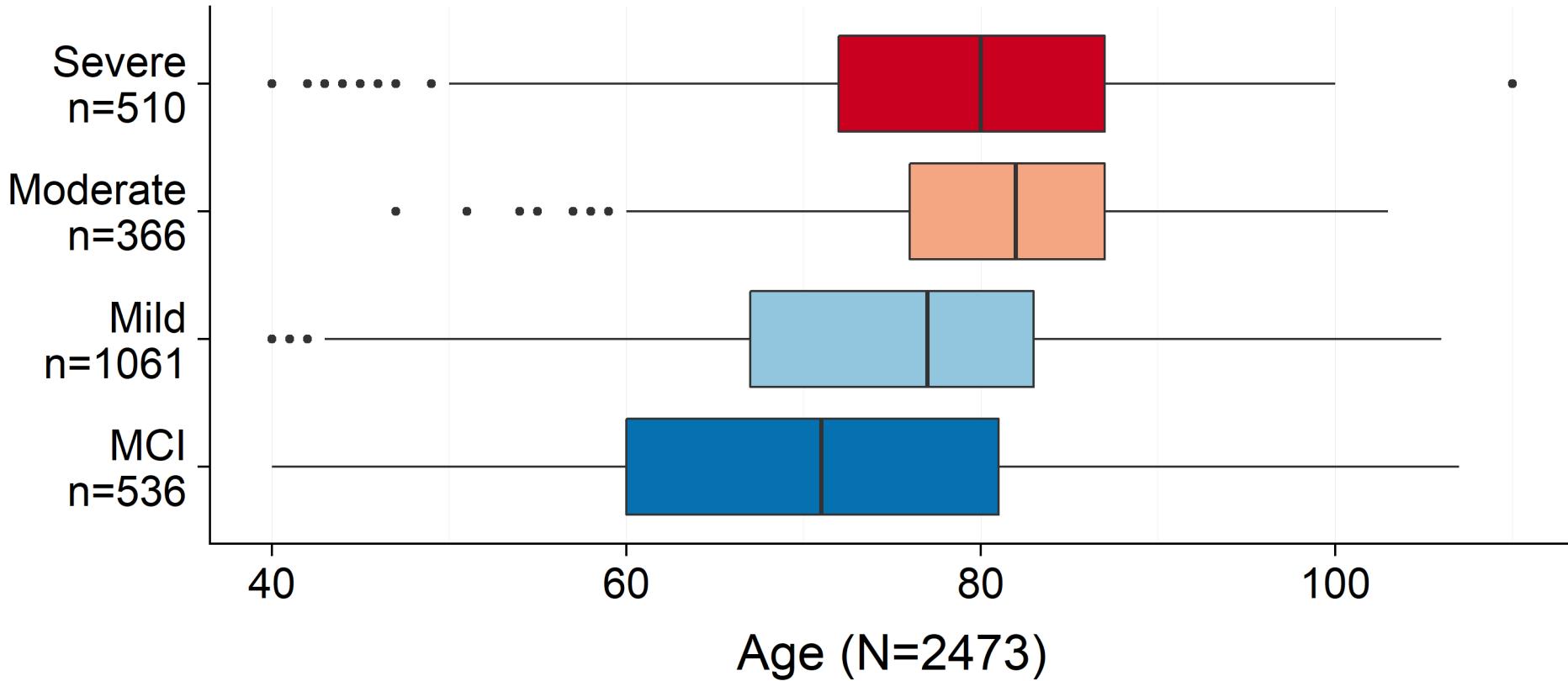
# STAGING ALGORITHM PERFORMANCE



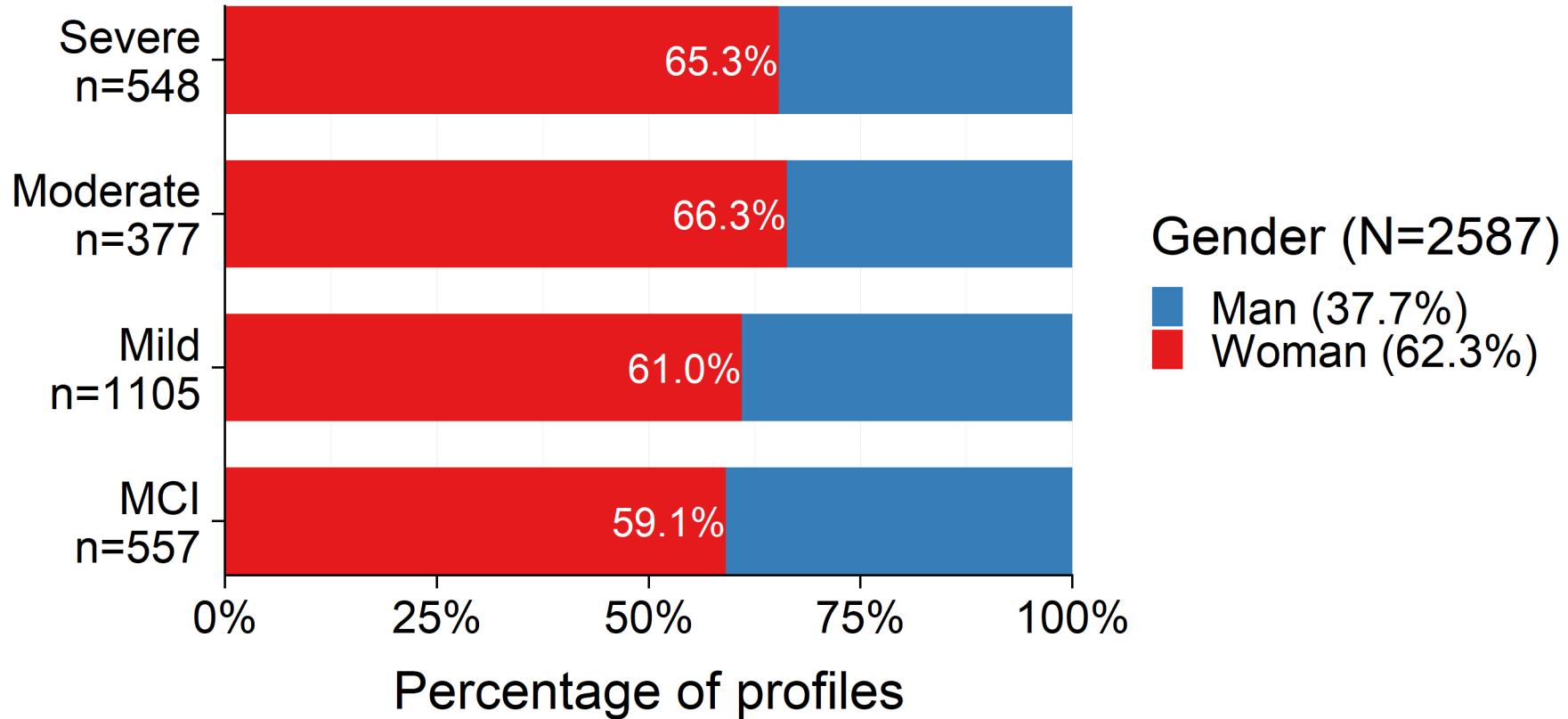
# SAMPLE SIZE BY STAGE



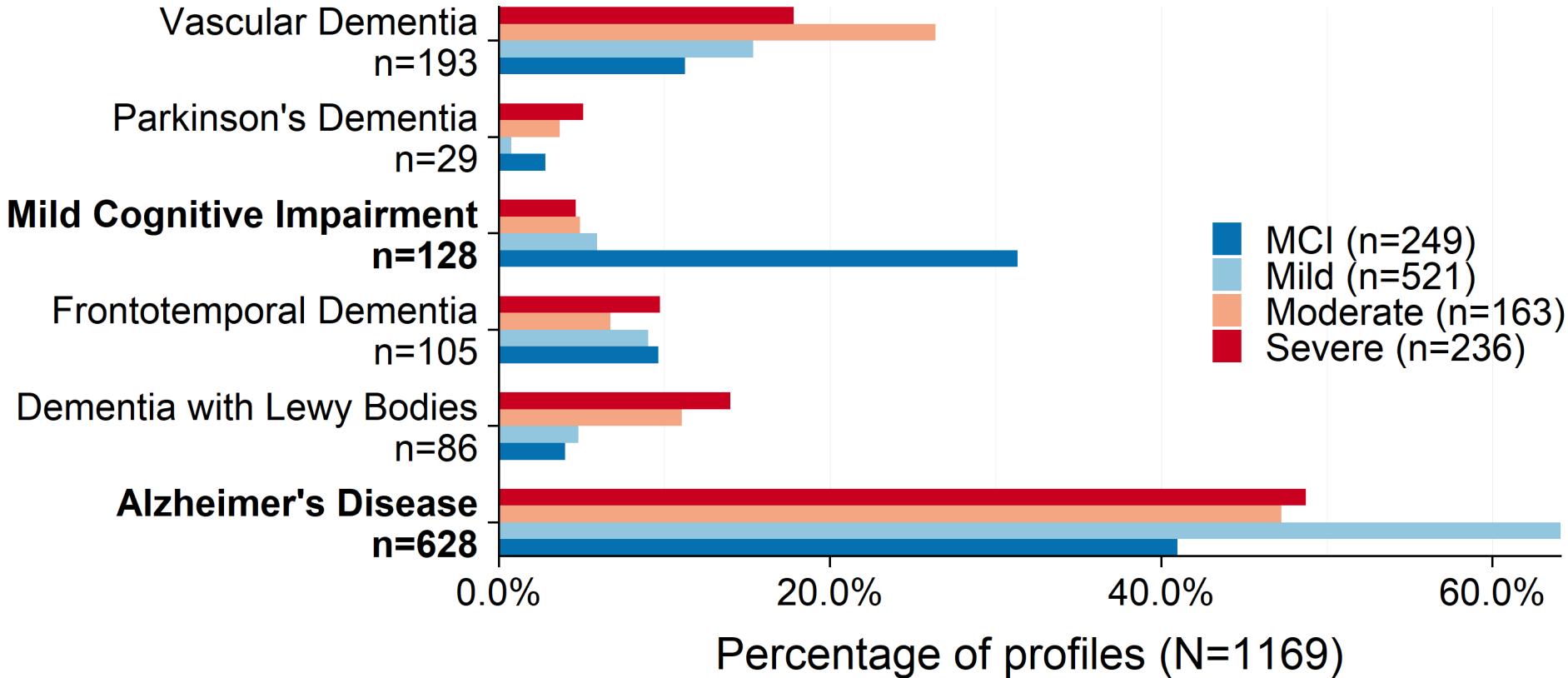
# AGE DISTRIBUTION BY STAGE



# GENDER DISTRIBUTION BY STAGE

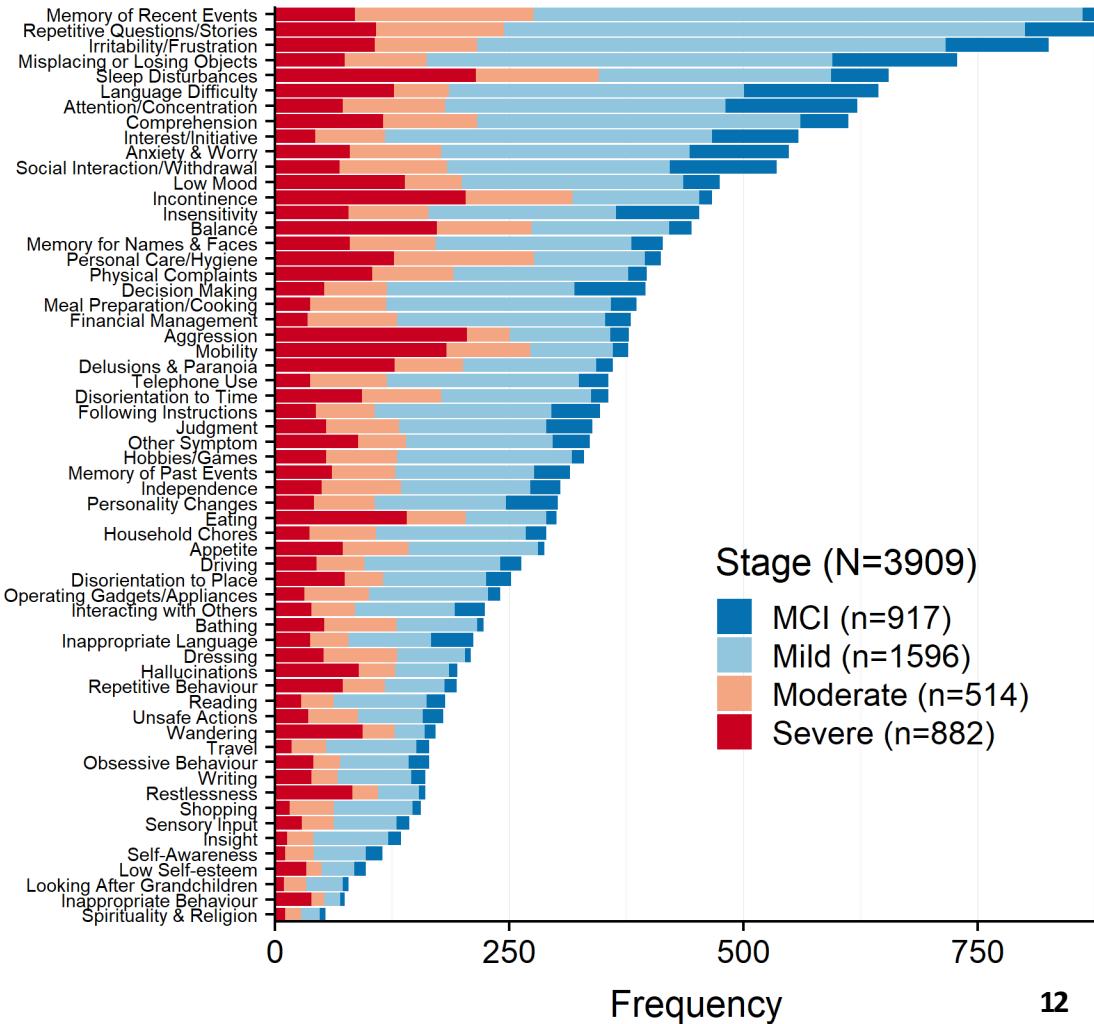


# COGNITIVE DIAGNOSIS BY STAGE

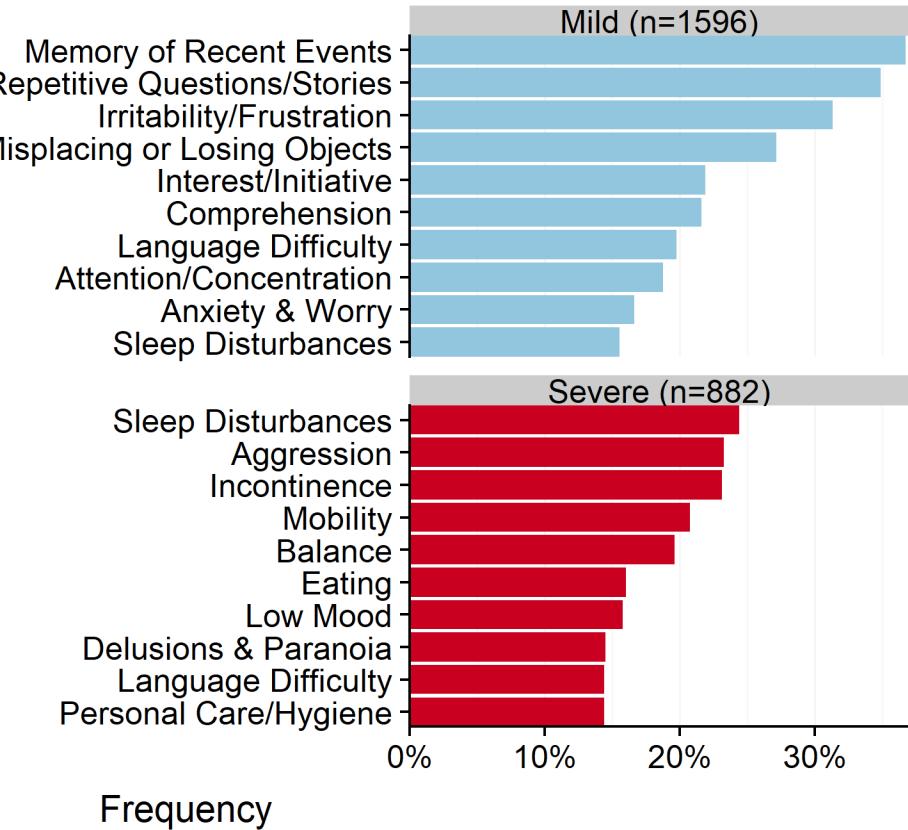
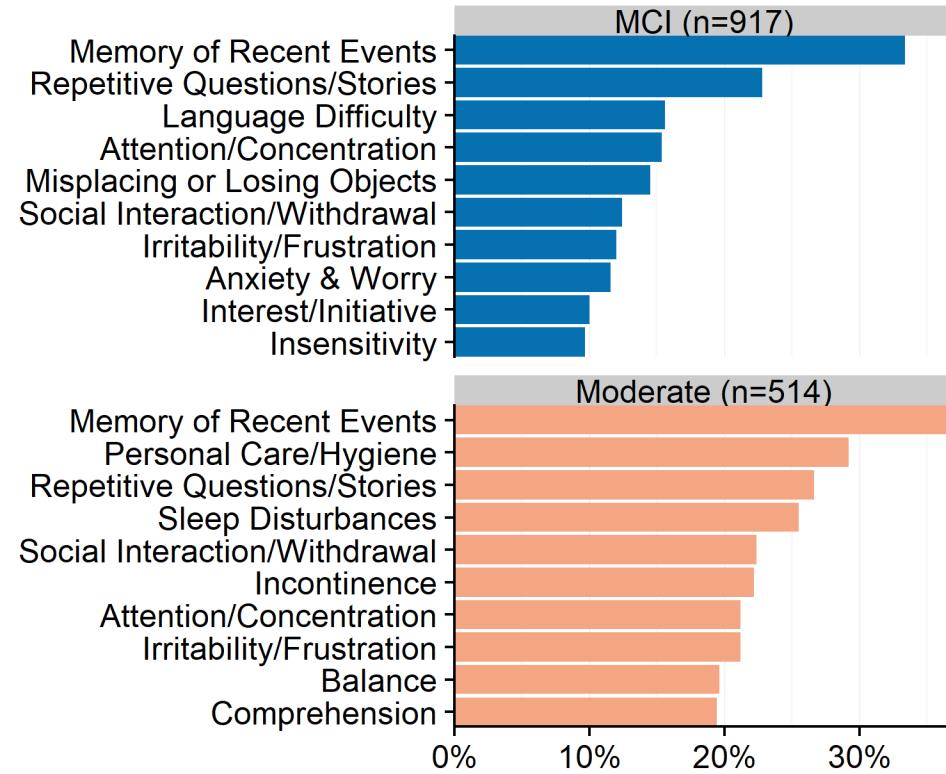


# SYMPTOM TRACKING FREQUENCY

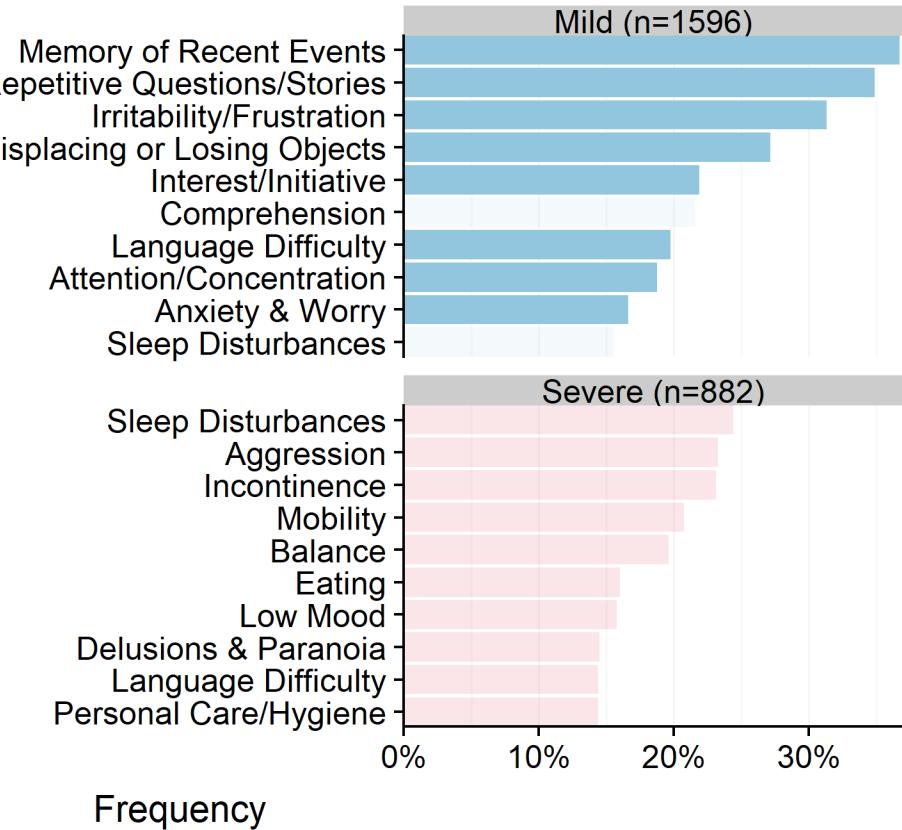
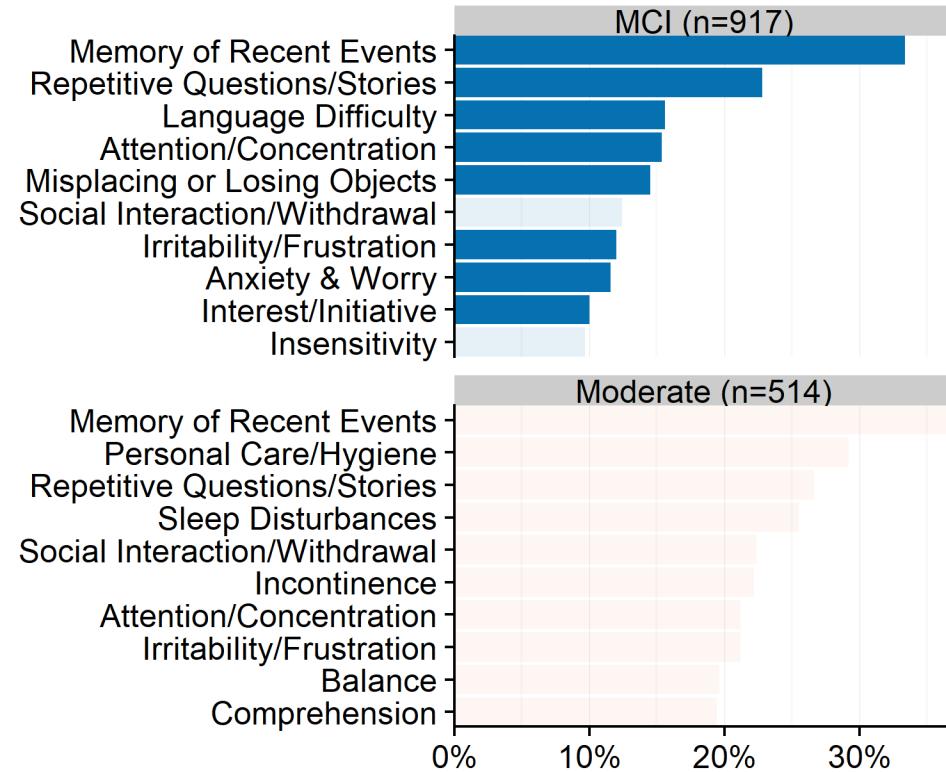
Frequency varies considerably by stage



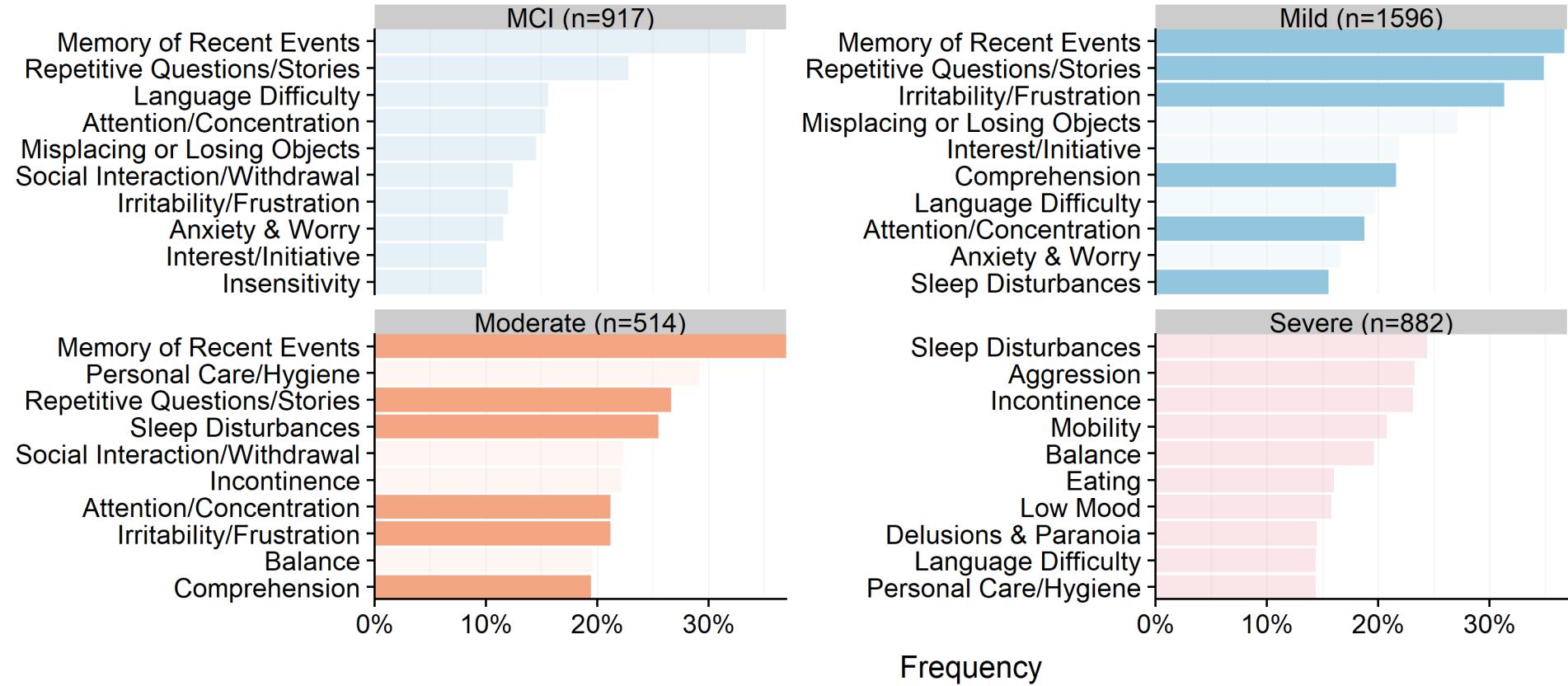
# TEN MOST FREQUENT SYMPTOMS, BY STAGE



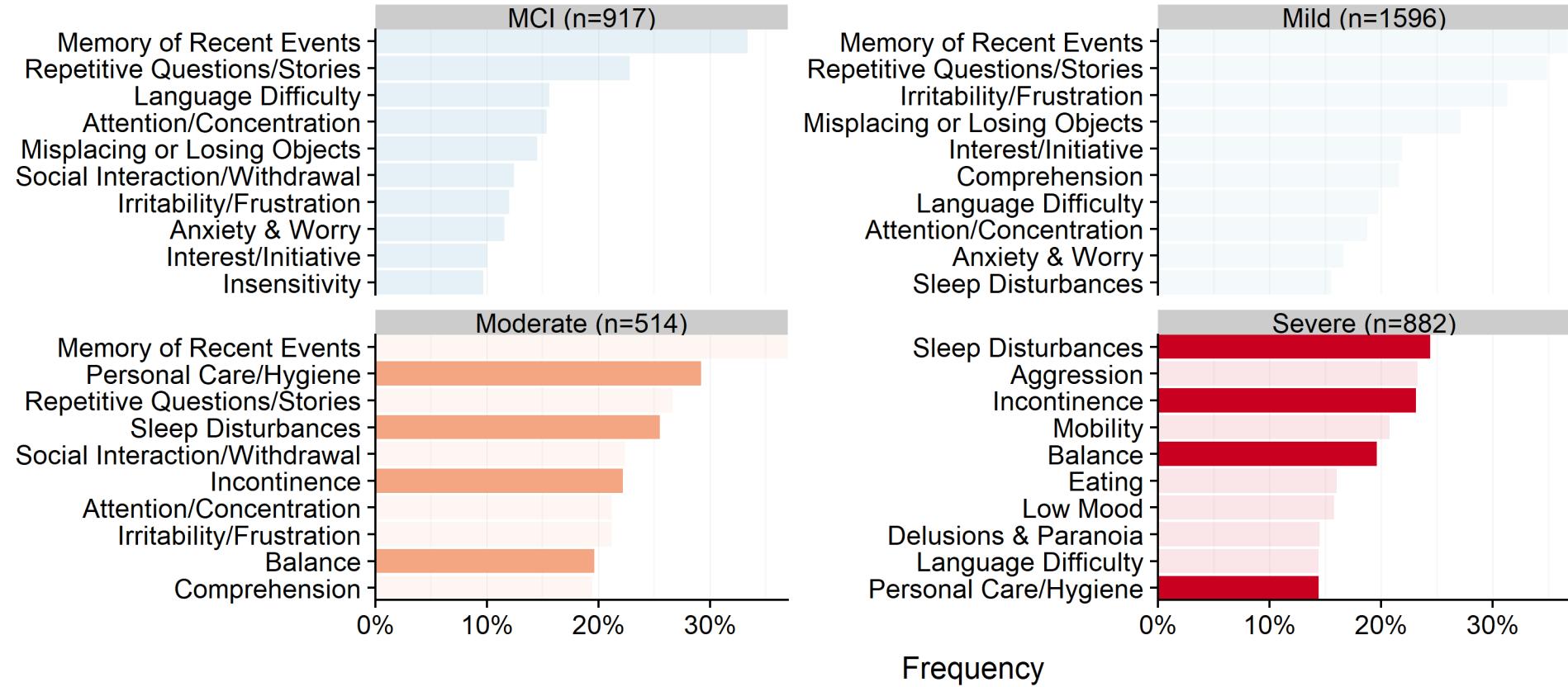
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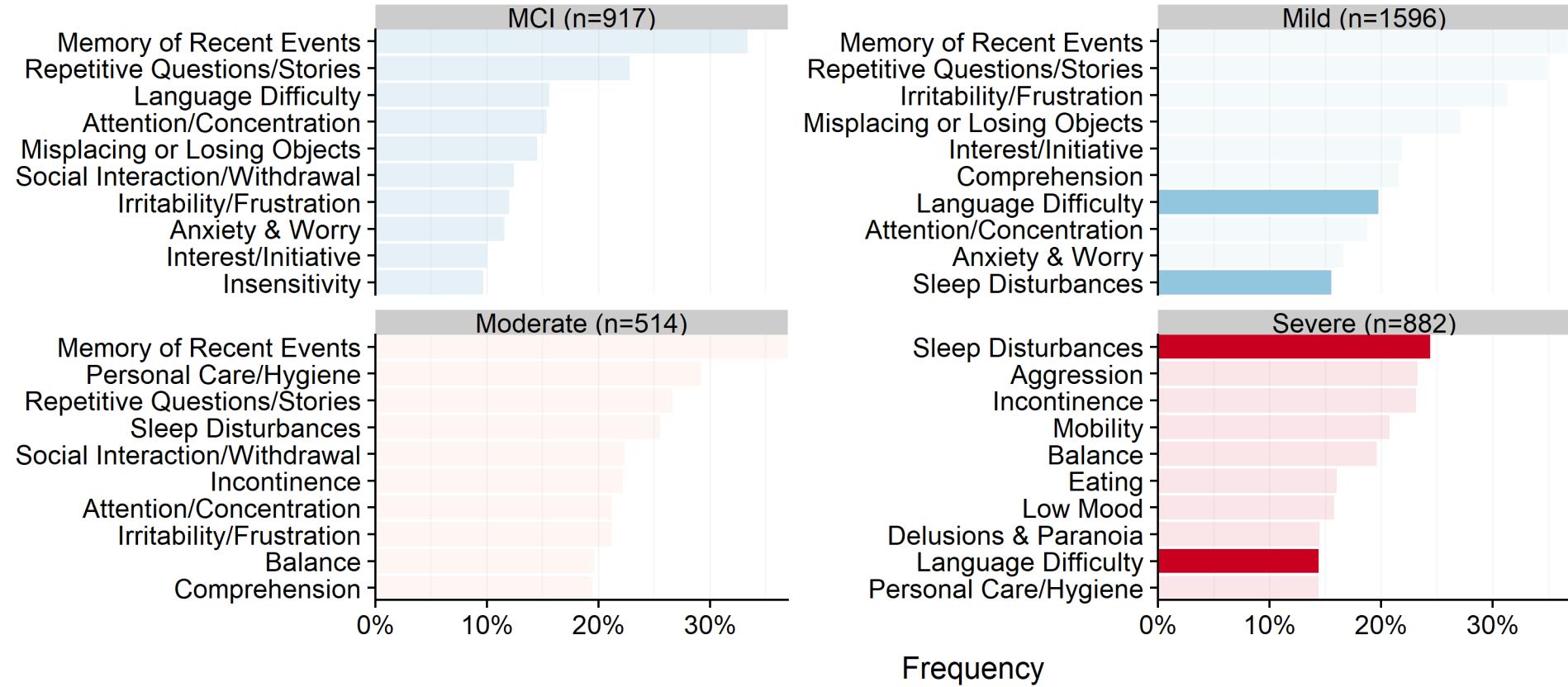
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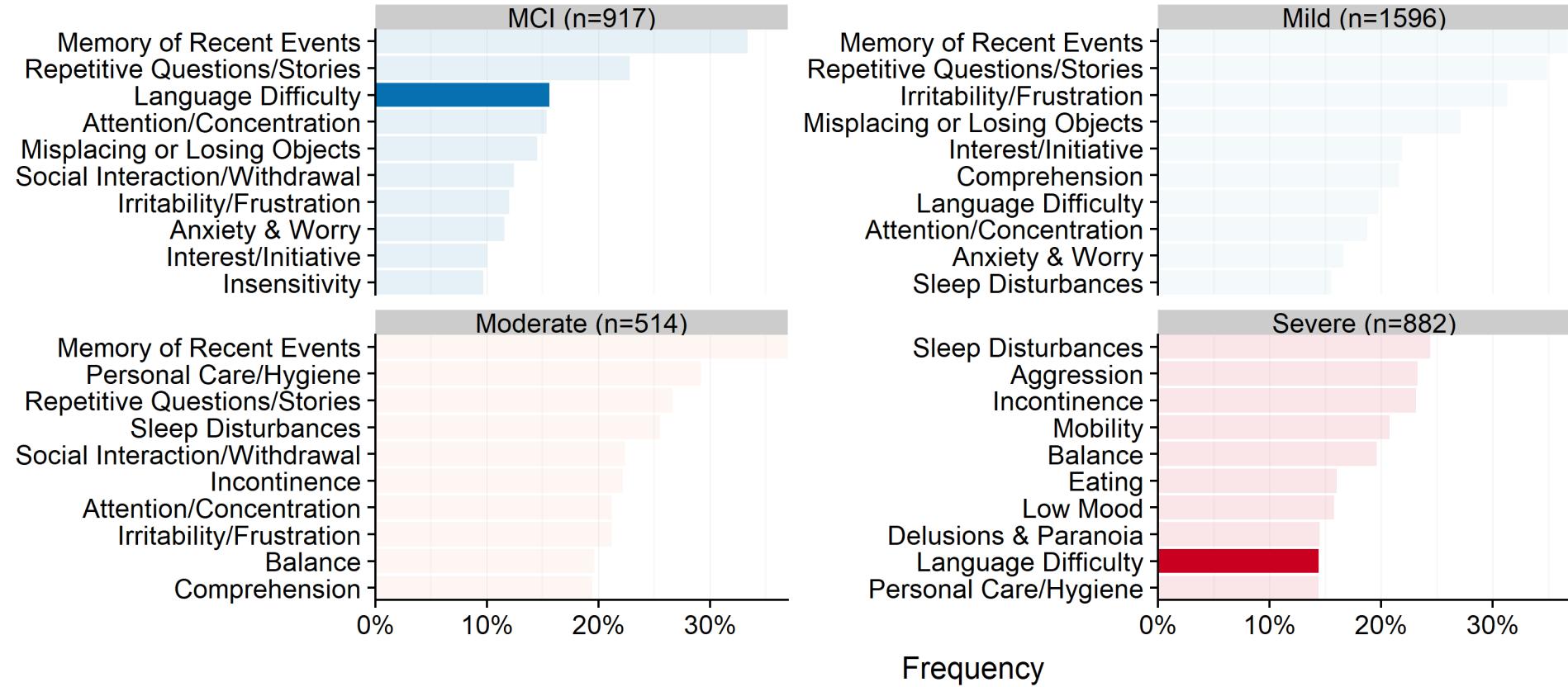
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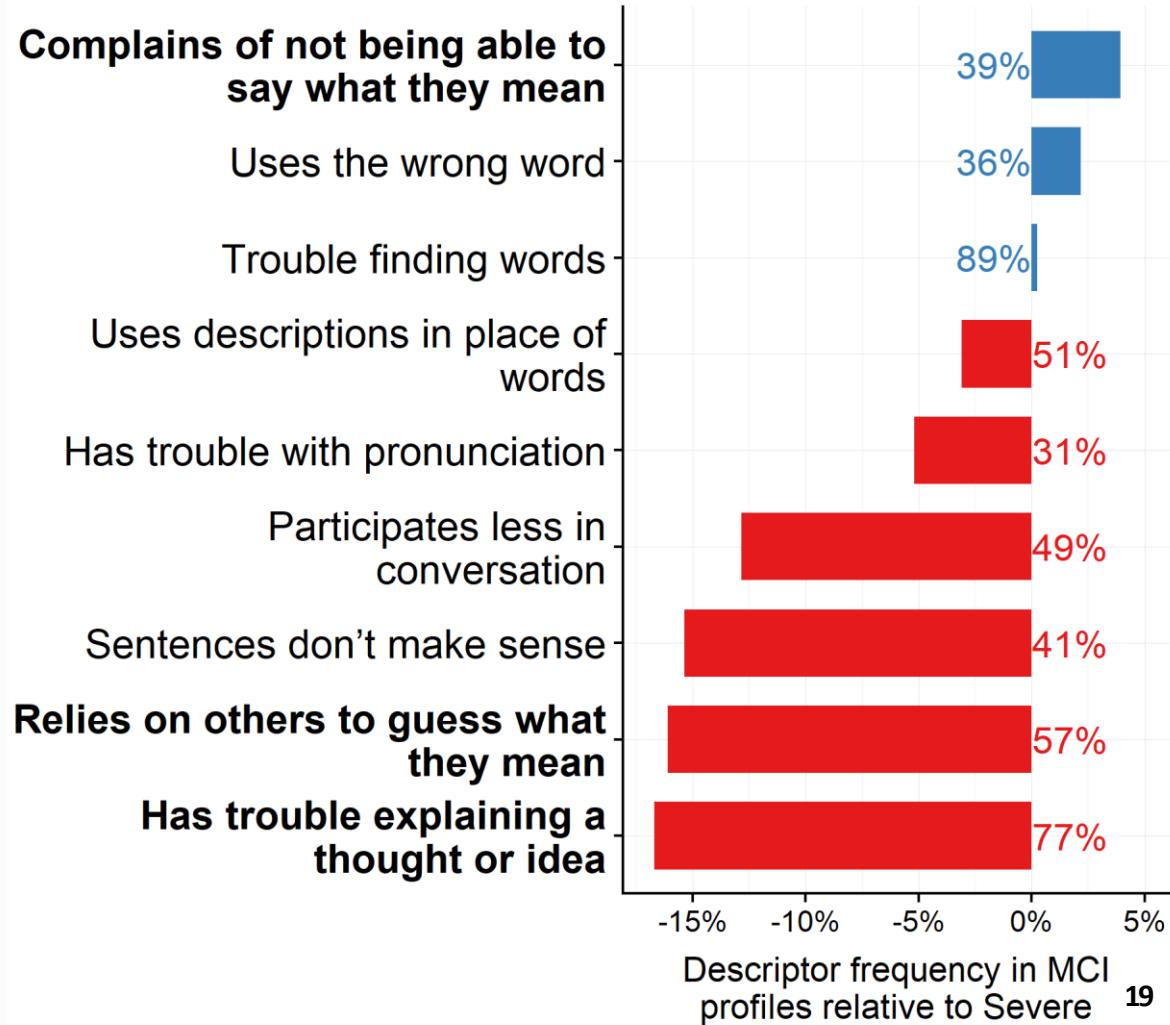


# TEN MOST FREQUENT SYMPTOMS, BY STAGE



# LANGUAGE DIFFICULTY DESCRIPTORS

Frequency in  
MCI vs Severe



# MOST IMPORTANT SYMPTOMS, BY STAGE

Rank	MCI (n=630)	Mild (n=1210)	Moderate (n=408)	Severe (n=626)
1	Inappropriate Language	Travel	Travel	Travel
2	Incontinence	Hobbies/Games	Looking After Grandchildren	Insight
3	Operating Gadgets/Appliances	Looking After Grandchildren	Writing	Hobbies/Games
4	Telephone Use	Inappropriate Behaviour	Hobbies/Games	Operating Gadgets/Appliances
5	Travel	Spirituality & Religion	Operating Gadgets/Appliances	Reading
6	Writing	Interest/Initiative	Household Chores	Financial Management
7	Looking After Grandchildren	Social Interaction/Withdrawal	Shopping	Household Chores
8	Eating	Operating Gadgets/Appliances	Interacting with Others	Looking After Grandchildren
9	Hobbies/Games	Shopping	Other Symptom	Memory for Names & Faces
10	Reading	Other Symptom	Interest/Initiative	Sensory Input

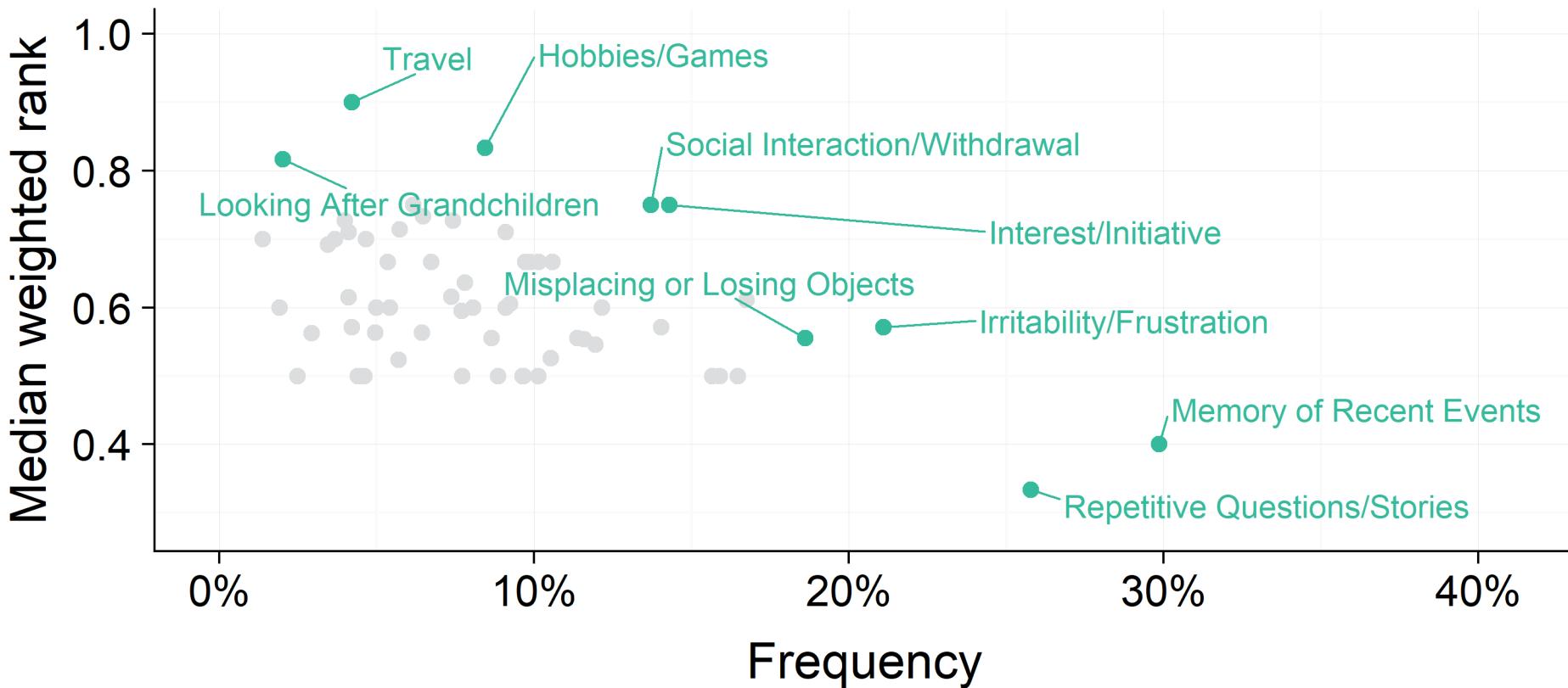
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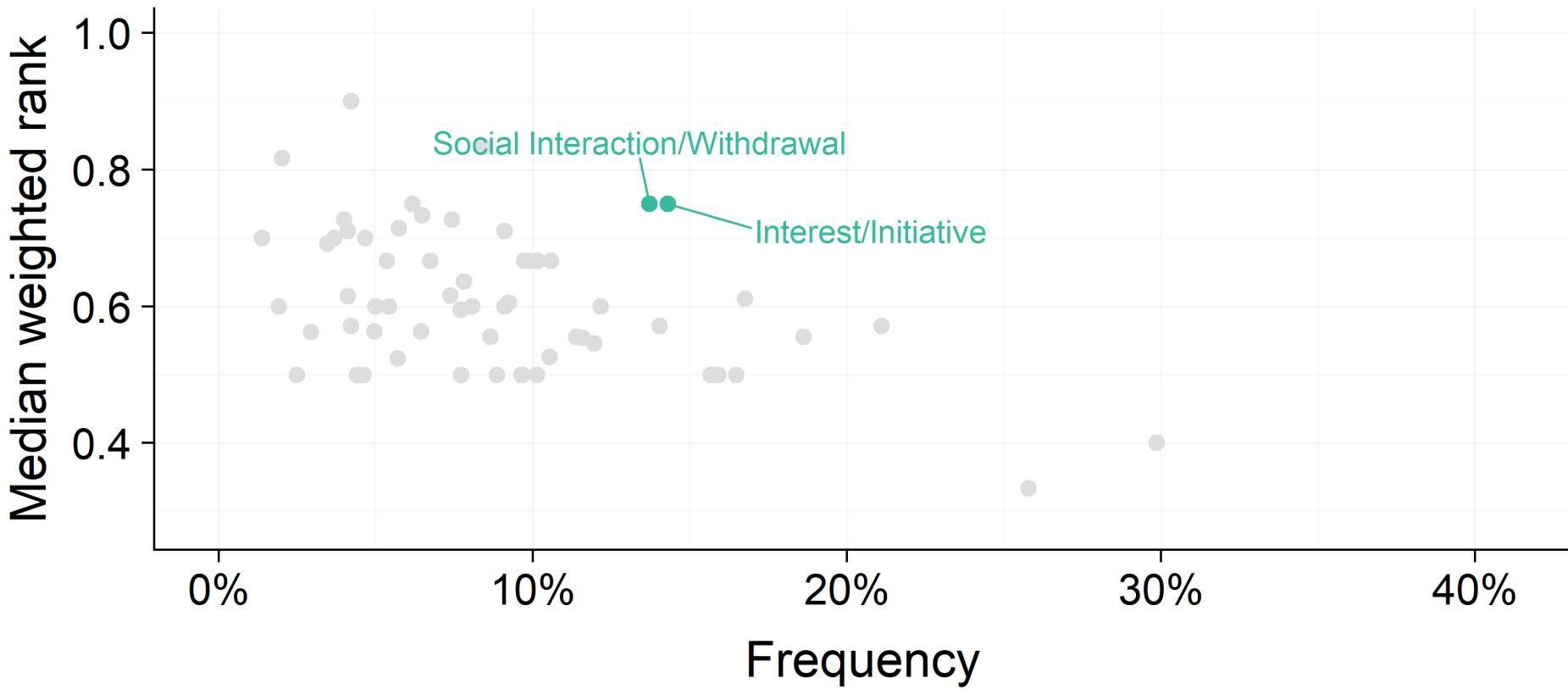
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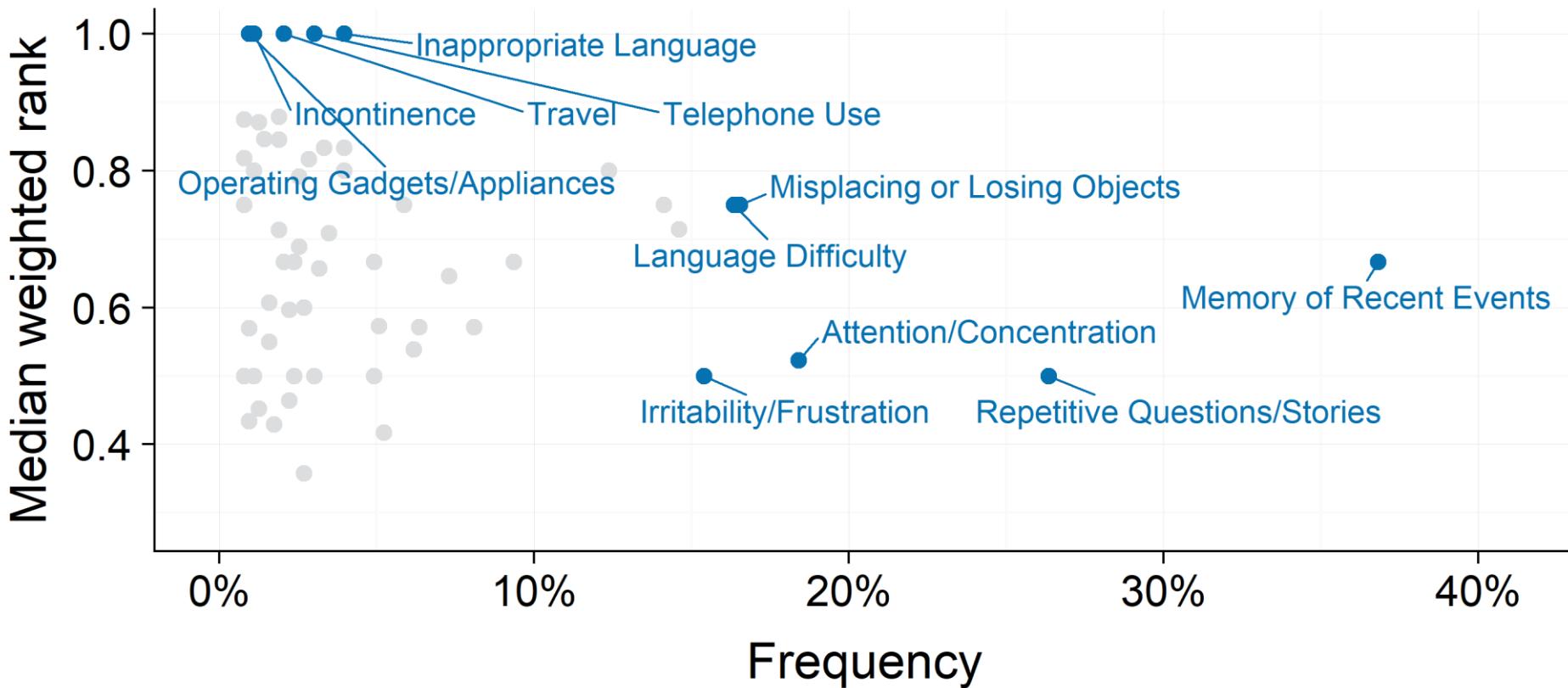
# FREQUENCY VS POTENCY, ALL STAGES



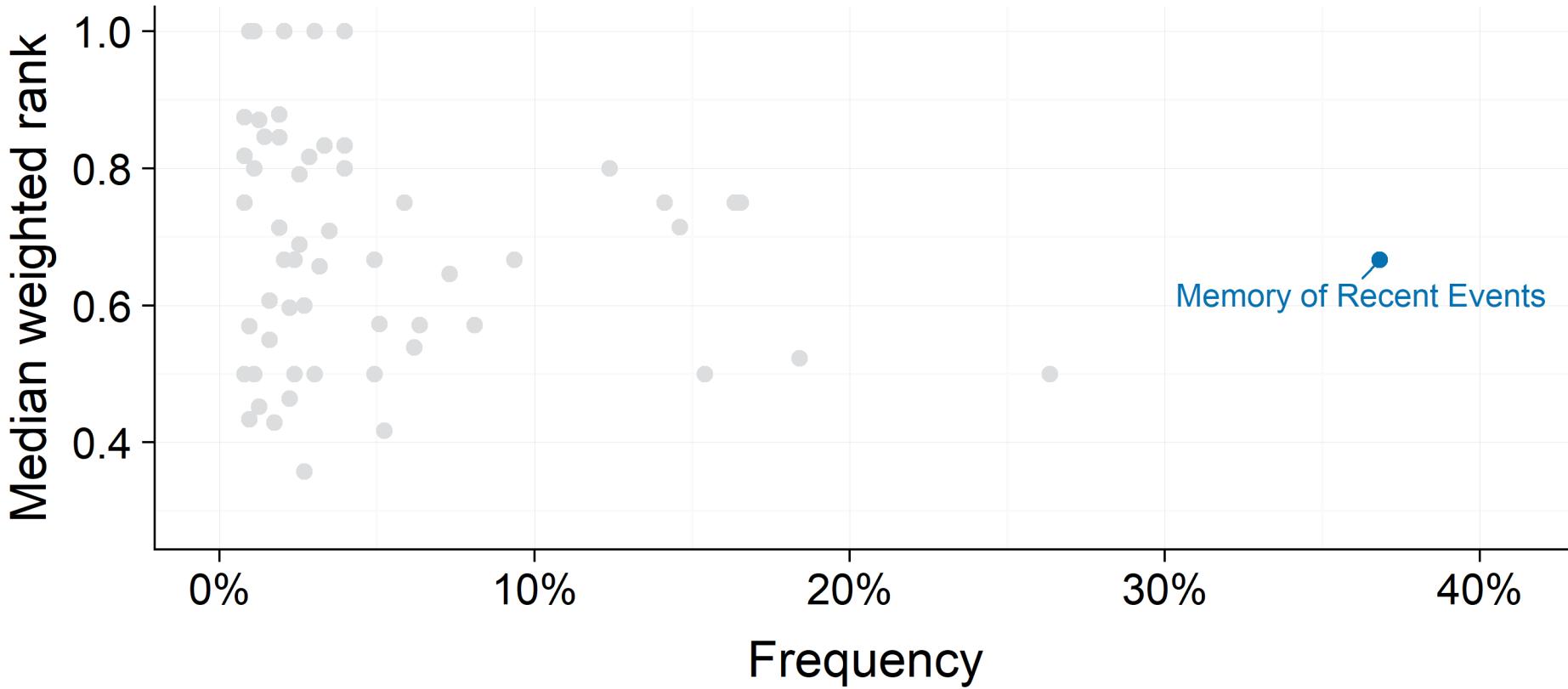
# FREQUENCY VS POTENCY, ALL STAGES



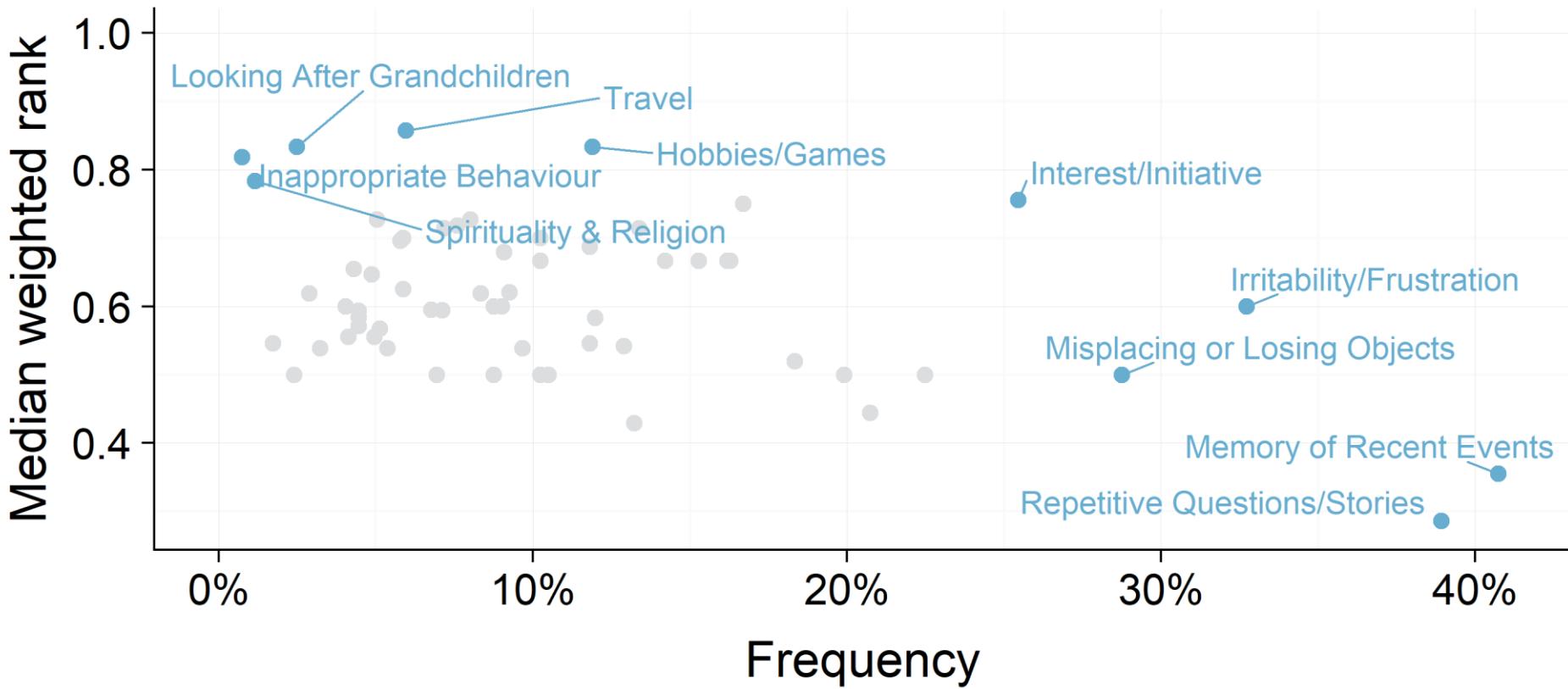
# FREQUENCY VS POTENCY, MCI



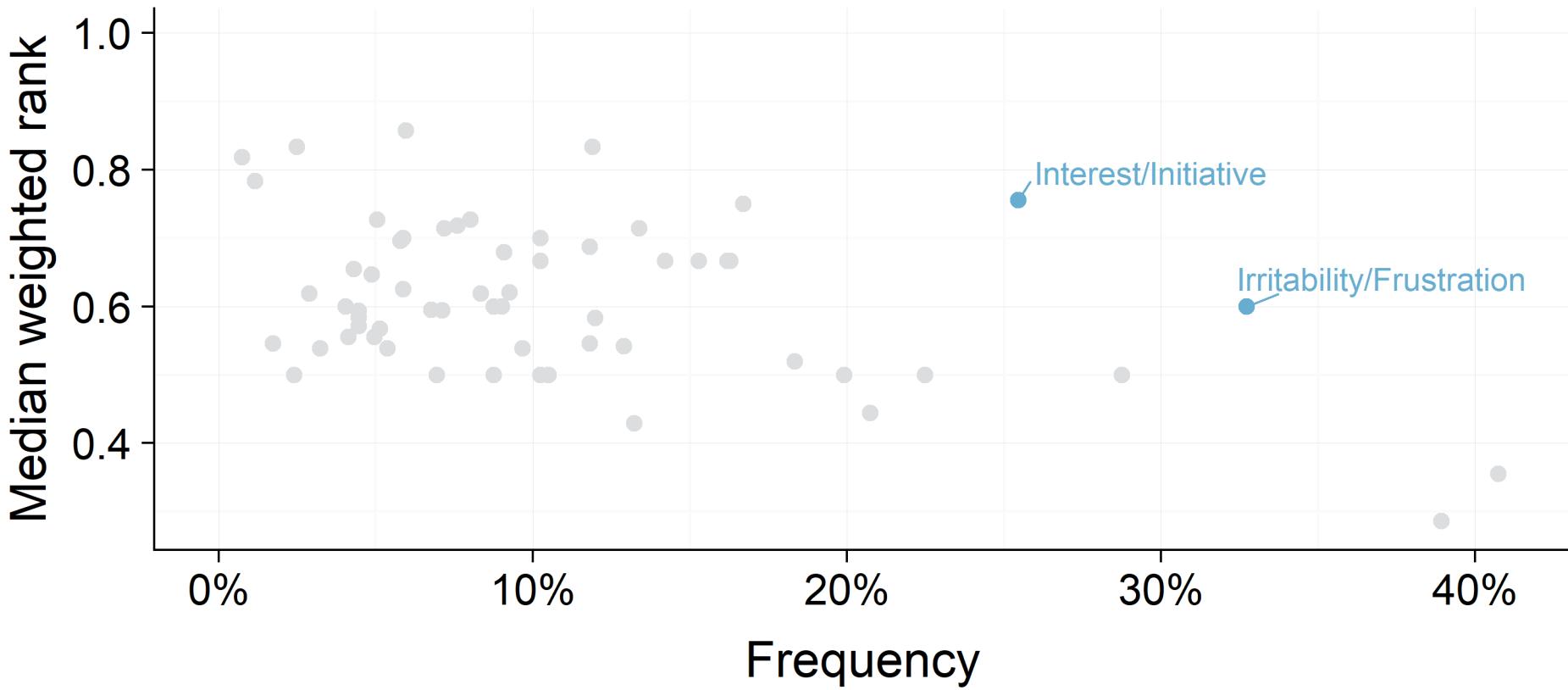
# FREQUENCY VS POTENCY, MCI



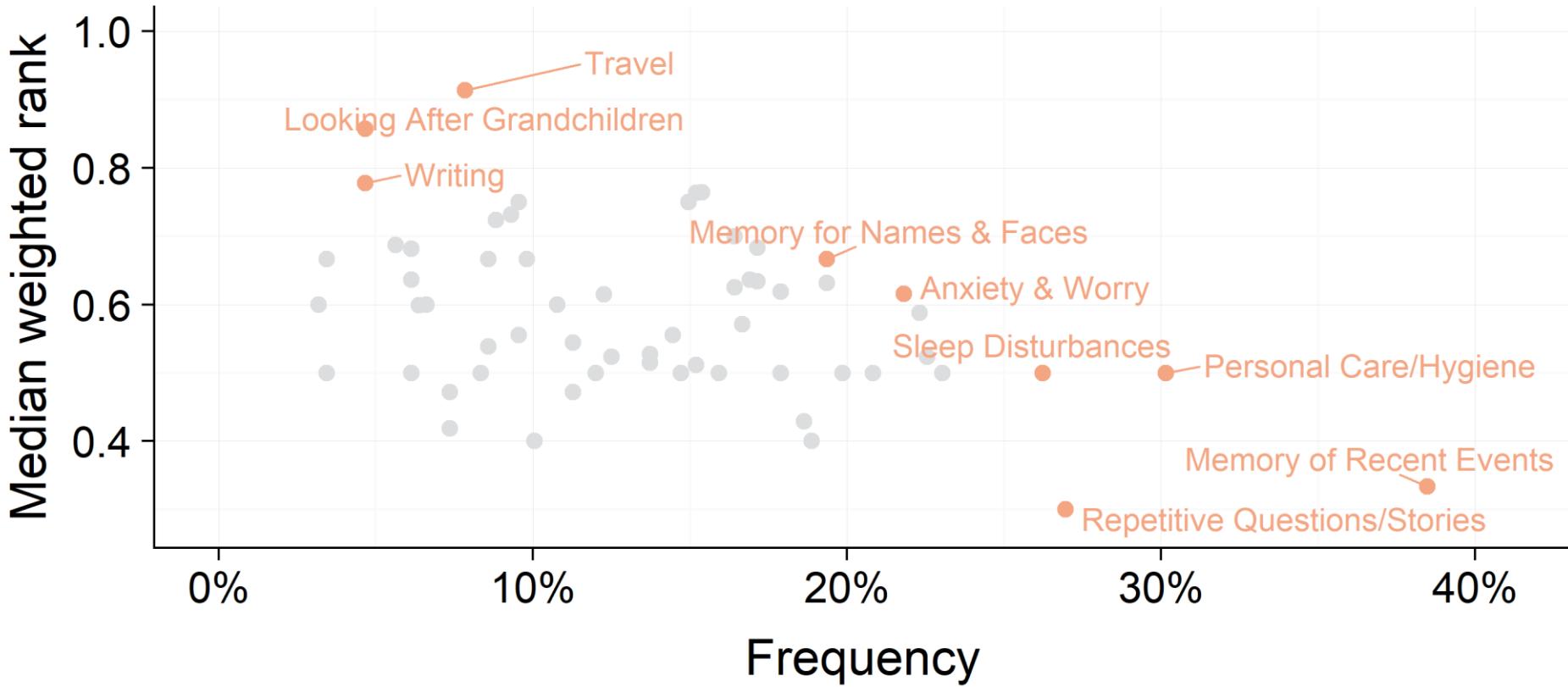
# FREQUENCY VS POTENCY, MILD



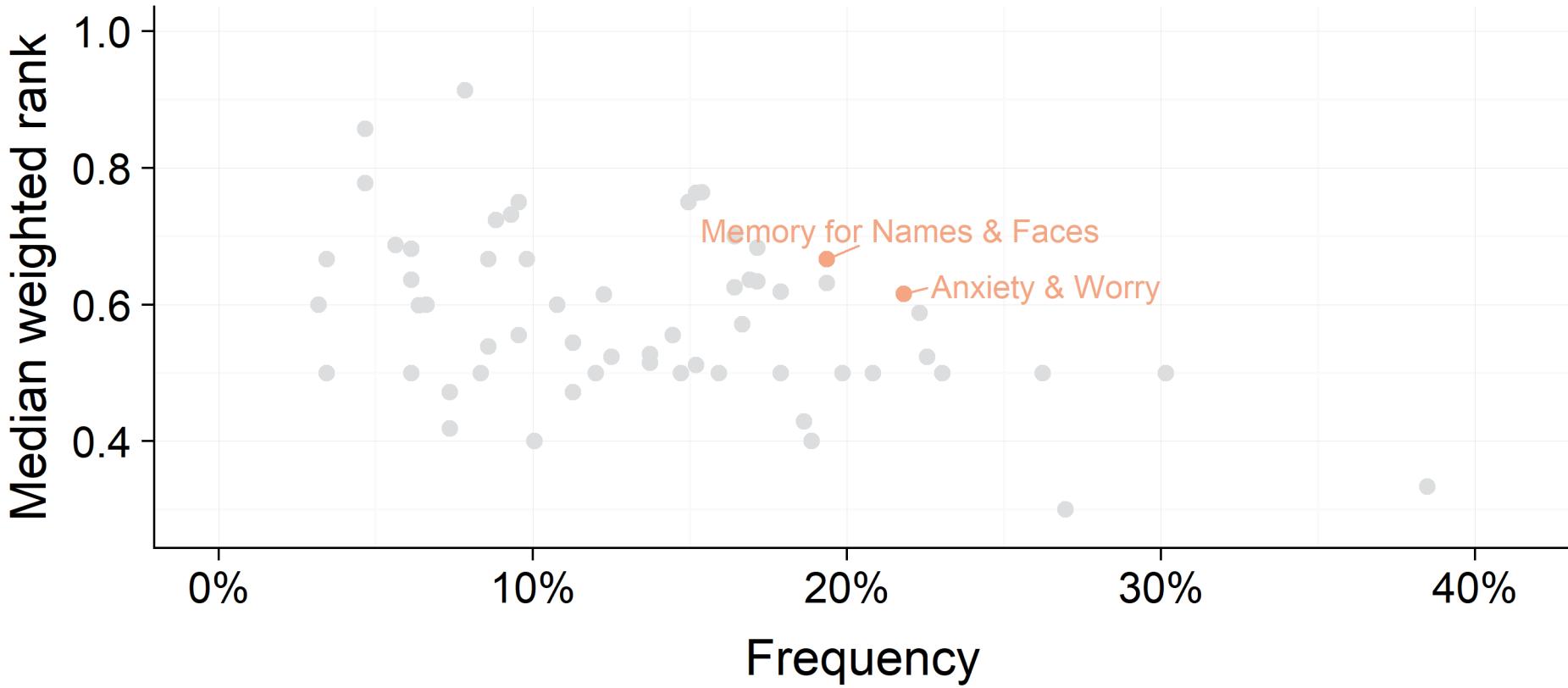
# FREQUENCY VS POTENCY, MILD



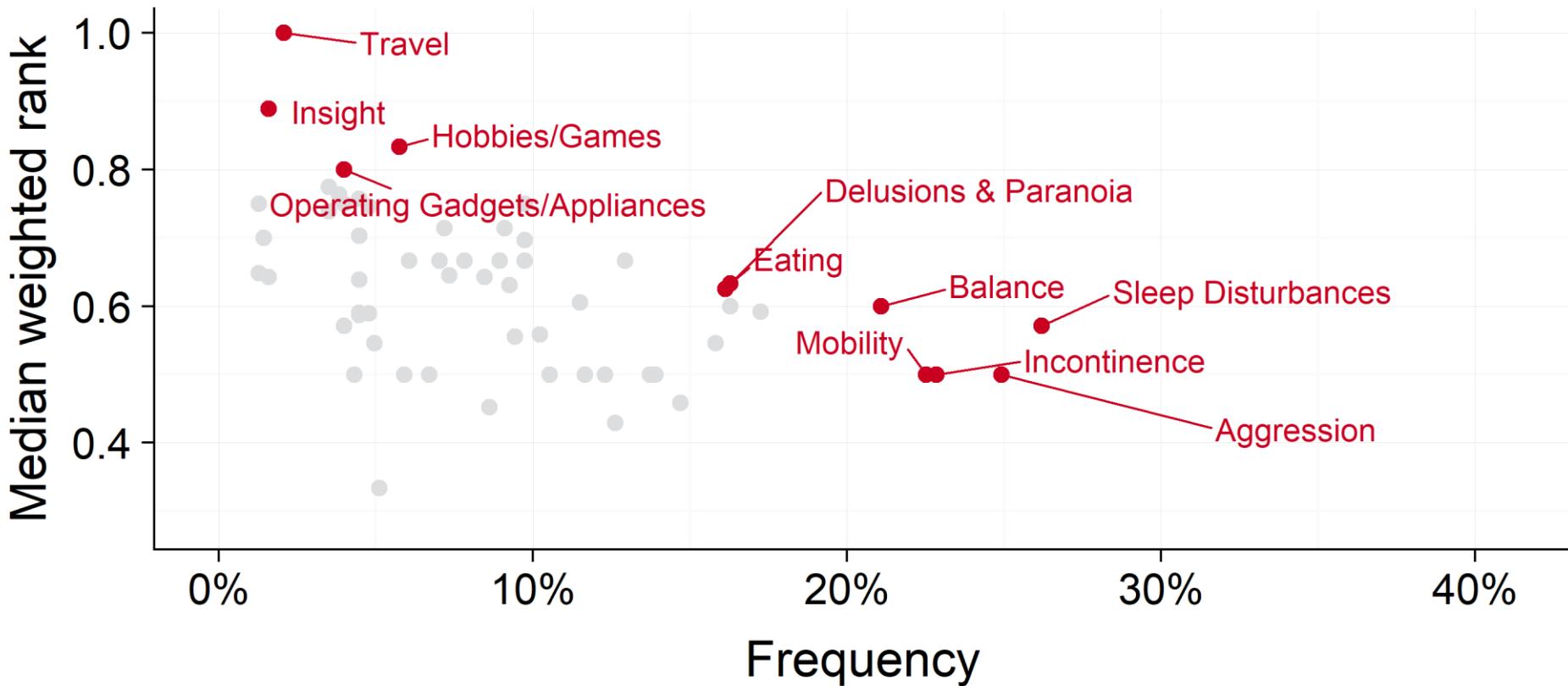
# FREQUENCY VS POTENCY, MODERATE



# FREQUENCY VS POTENCY, MODERATE

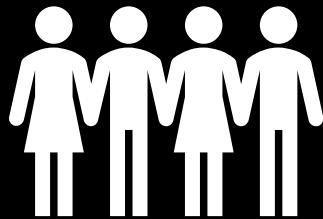
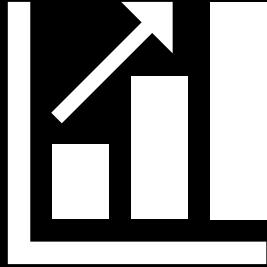


# FREQUENCY VS POTENCY, SEVERE



# FREQUENCY VS POTENCY, SEVERE





## CONCLUSIONS

- An **online symptom tracking tool** allowed us to understand what is most important to people with cognitive impairment and their caregivers.
- The **most frequent** MCI and Mild dementia symptoms had considerable overlap, but there was little overlap between MCI and later stage dementia.
- At all stages, symptom **potency** was inversely related to symptom **frequency**.
- **Individualized** online tracking provides a personalized approach to patient management, even if their symptoms are uncommon.



# IMPLEMENTATION (IN CLINICAL PRACTICE)

- Broad scale implementation of **SymptomGuide®** tracking in clinical practice is likely to add new insights.
- Research on symptomatic management should be seen as important as on disease-modifying drugs when/if they become available, as the main goal is (and will always be) to improve daily functioning in people with cognitive impairment.
- Some real-world studies have looked into symptoms, as well as ADL management with **Souvenaid**, and this could be elaborated further using an online symptom tracking tool.

# ACKNOWLEDGMENTS

- Presented on behalf of authors: Taylor Dunn, Jovita Balcaitiene, and Susan Howlett.
- KR receives support from the Canadian Institutes of Health Research, Alzheimer Society of Canada, the Fountain Family Innovation Fund, and the Dalhousie Medical Research Foundation.



# IMPLEMENTATION (IN CLINICAL PRACTICE)

- Few attempts to dig into treatments' effectiveness on **symptoms** as well as **activities of daily living** were done with medical food Souvenaid and could be elaborated further using the tool:
  - MEMENTO study: Effectiveness of a specific nutritional supplement on cognitive, behavioral and functional symptoms in MCI and AD (Biancetti et al.): suggested effectiveness on behavioral and functional deficits.
  - AWARE study: Effect of the medical food Souvenaid on **instrumental activities of daily living** in people with mild AD (Ziere et al., poster at CTAD 2019): suggested beneficial effects on instrumental activities of daily living in mild AD in a real-world clinical setting.

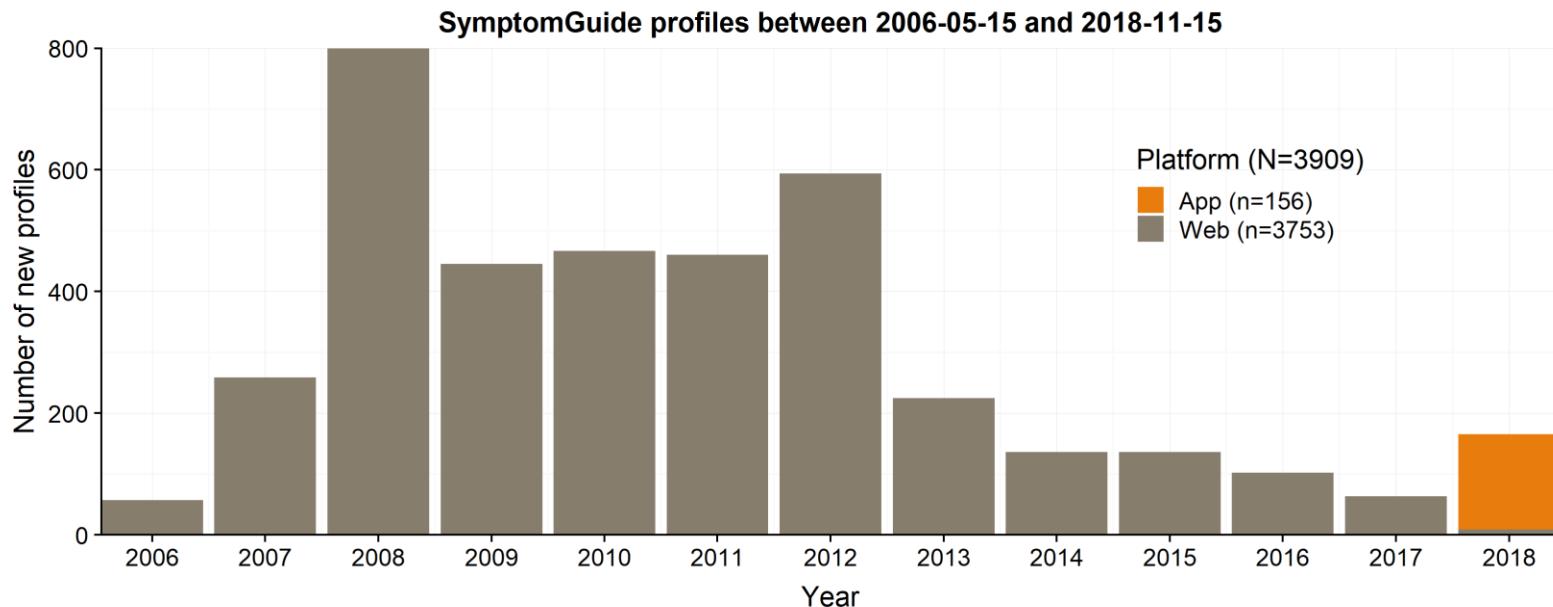
# OTHER SYMPTOMS, MCI

Symptom (verbatim text)	Weighted rank (rank / number of symptoms)
seems more tired than usual	0.75 (9/12)
Multi-Tasking	0.83 (5/6)
E-mails (problems)	1.00 (6/6)
shadowing	0.64 (9/14)
Initiative	1.00 (4/4)
Misplacing or Losing Objects	1.00 (2/2)
going out and leaving the house door open	0.20 (1/5)

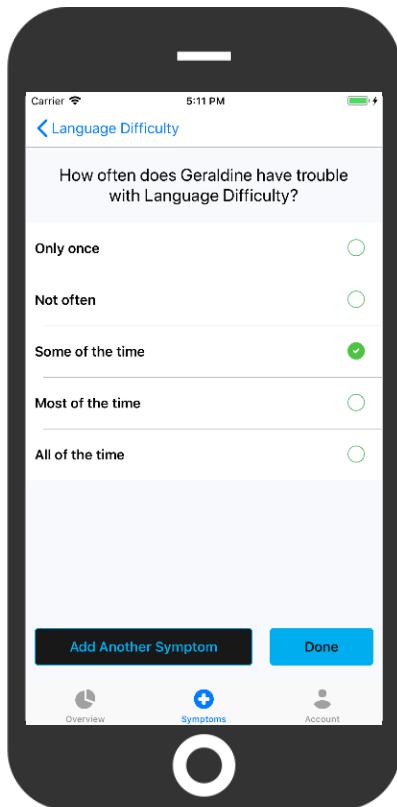
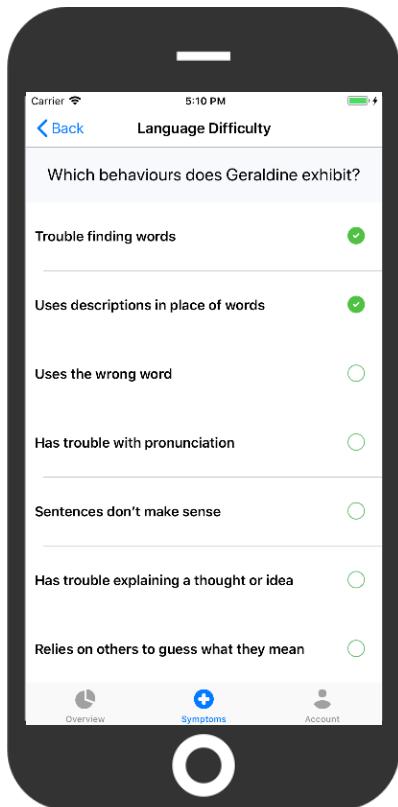
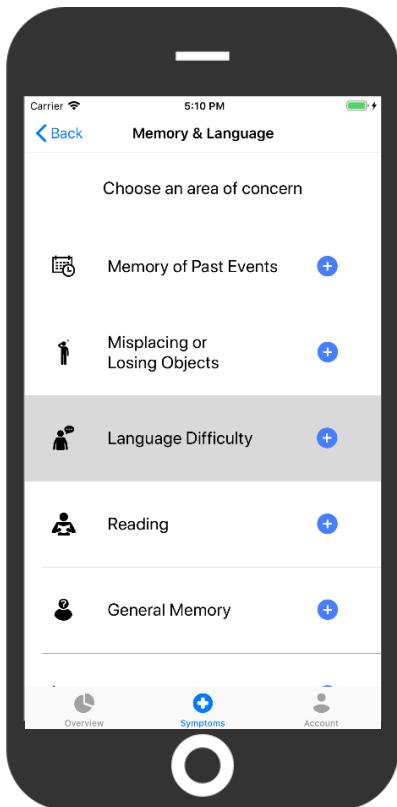
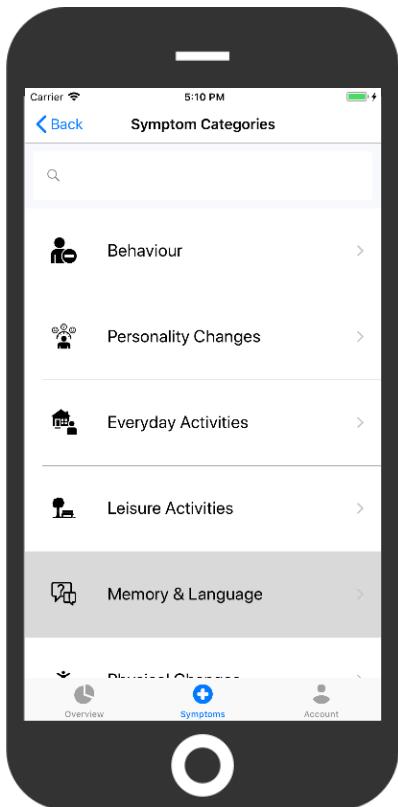
# OTHER SYMPTOMS, MILD

Symptom (verbatim text)	Weighted rank (rank / number of symptoms)
Isn't interested in what any one else wants to do - it's not my thing is the phrase he uses	0.56 (10/18)
Sundowning	1.00 (10/10)
Childlike	1.00 (8/8)
Sarcastic	1.00 (5/5)
no balance between personal hygiene, one day she cares and is frustrated with her appearance and other days she is bothered to have to comb her hair or bathe	0.83 (5/6)
Talks to herself	0.33 (1/3)
Shadowing/Being Left Alone	0.86 (6/7)
Confidence	0.80 (8/10)
Hesitant and uncertain	0.92 (11/12)

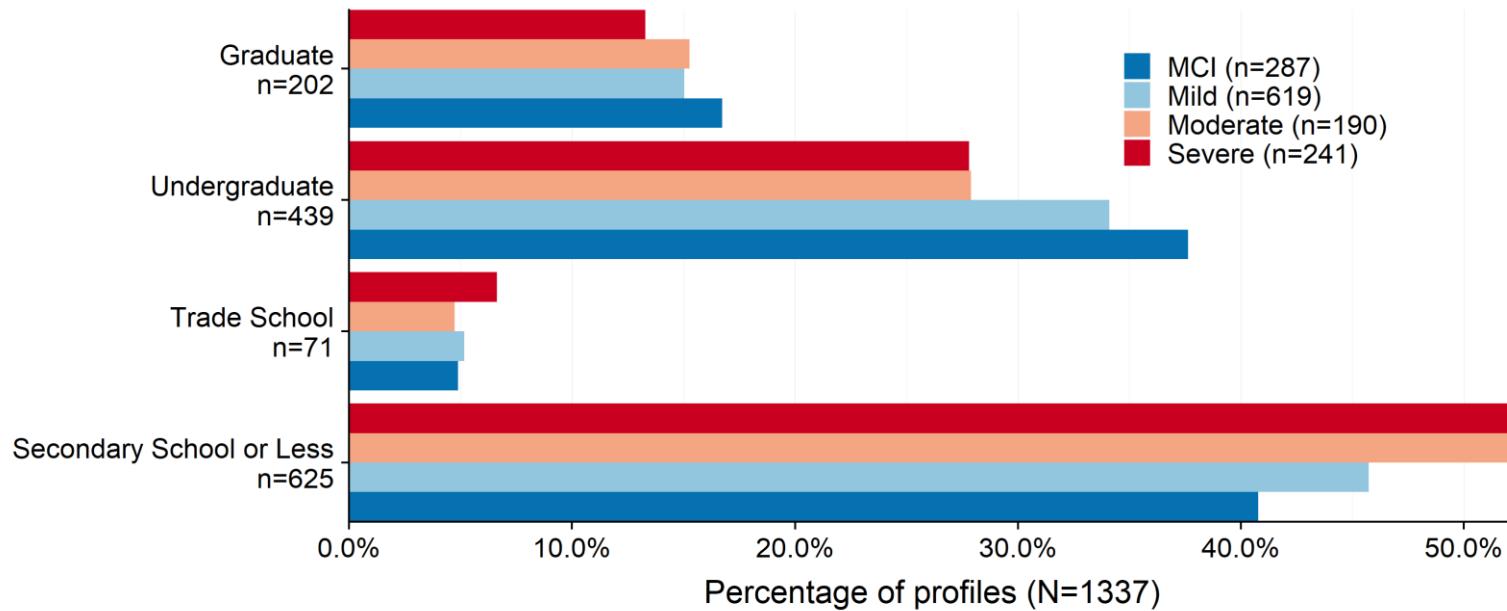
# SAMPLE SIZE BY YEAR



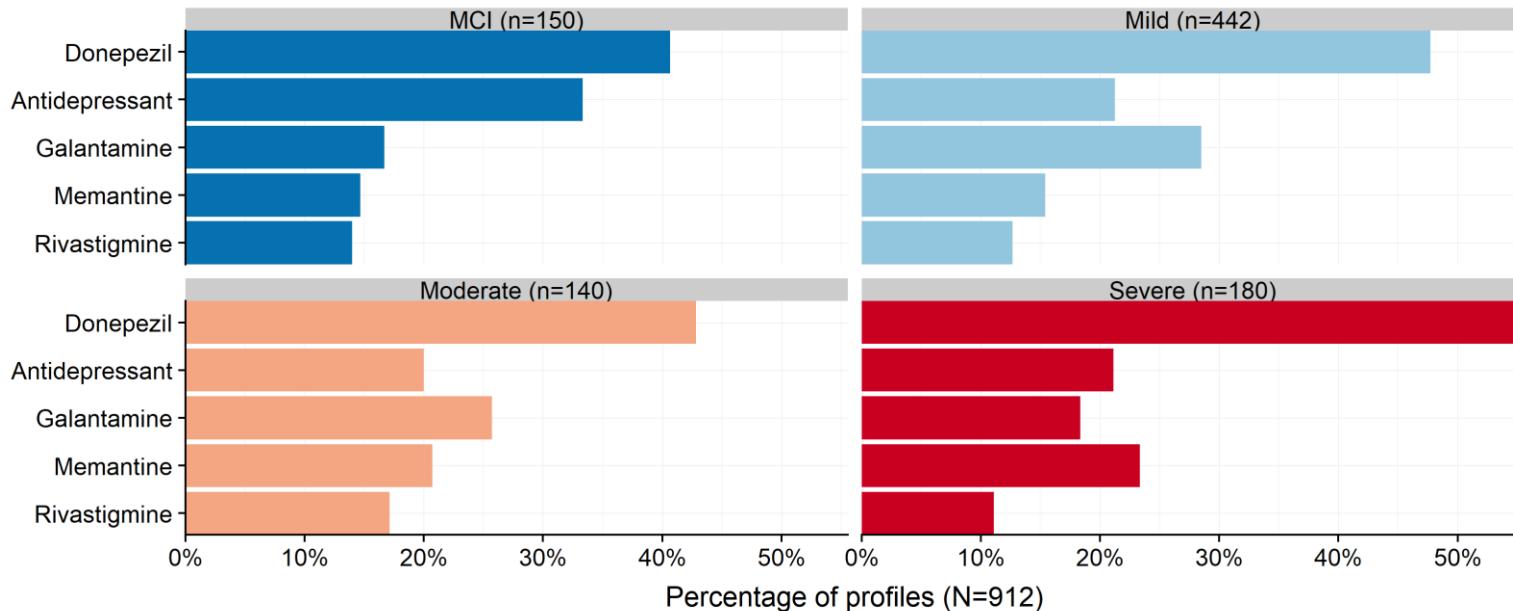
# SYMPTOMGUIDE SCREENSHOTS



# HIGHEST EDUCATION BY STAGE

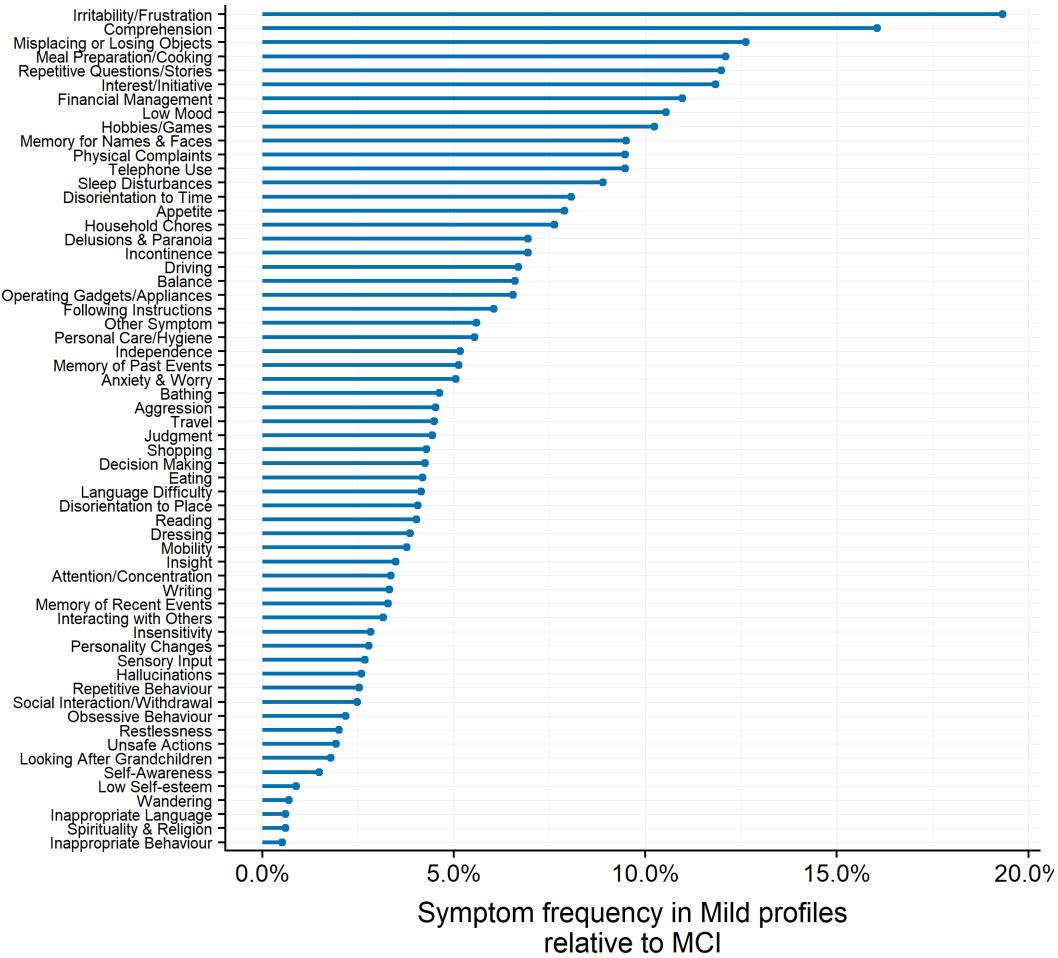


# REPORTED MEDICATION USE BY STAGE



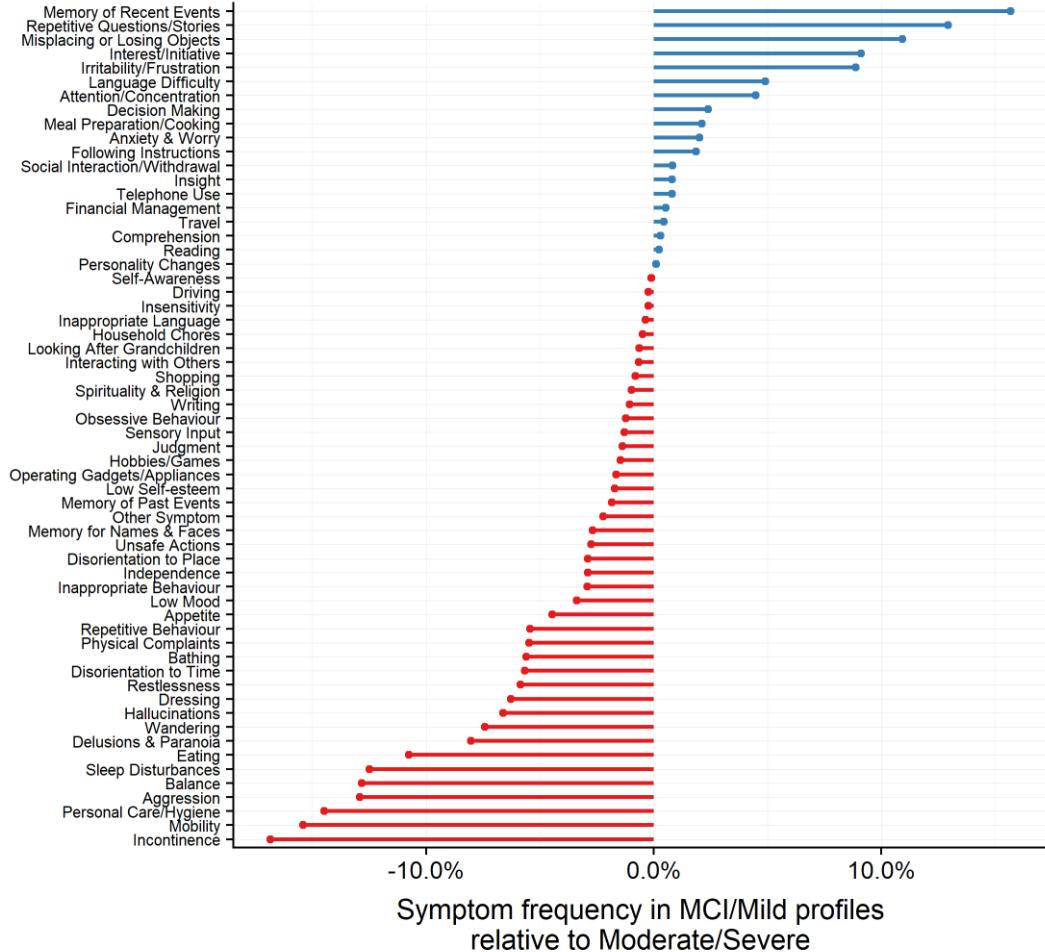
# RELATIVE SYMPTOM FREQUENCY

Difference between  
MCI and Mild



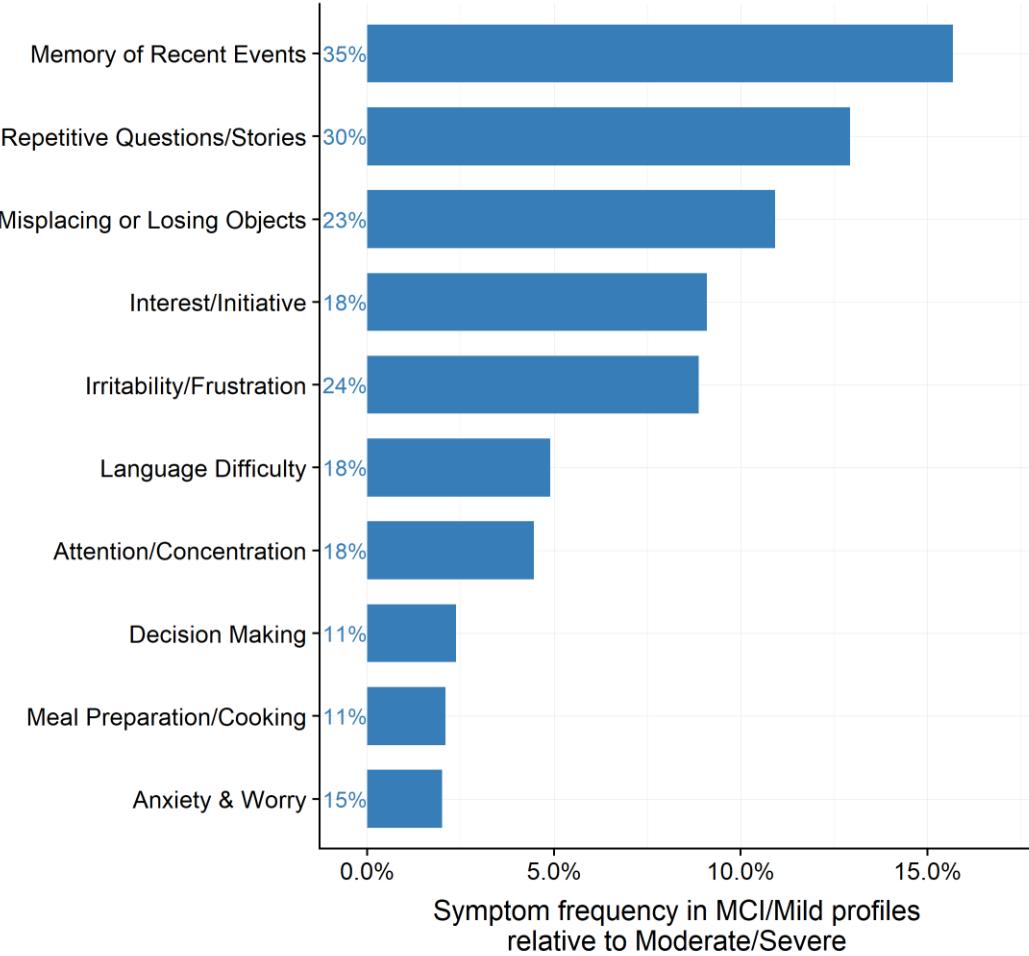
# RELATIVE SYMPTOM FREQUENCY

Difference between  
MCI/Mild and Moderate/Severe



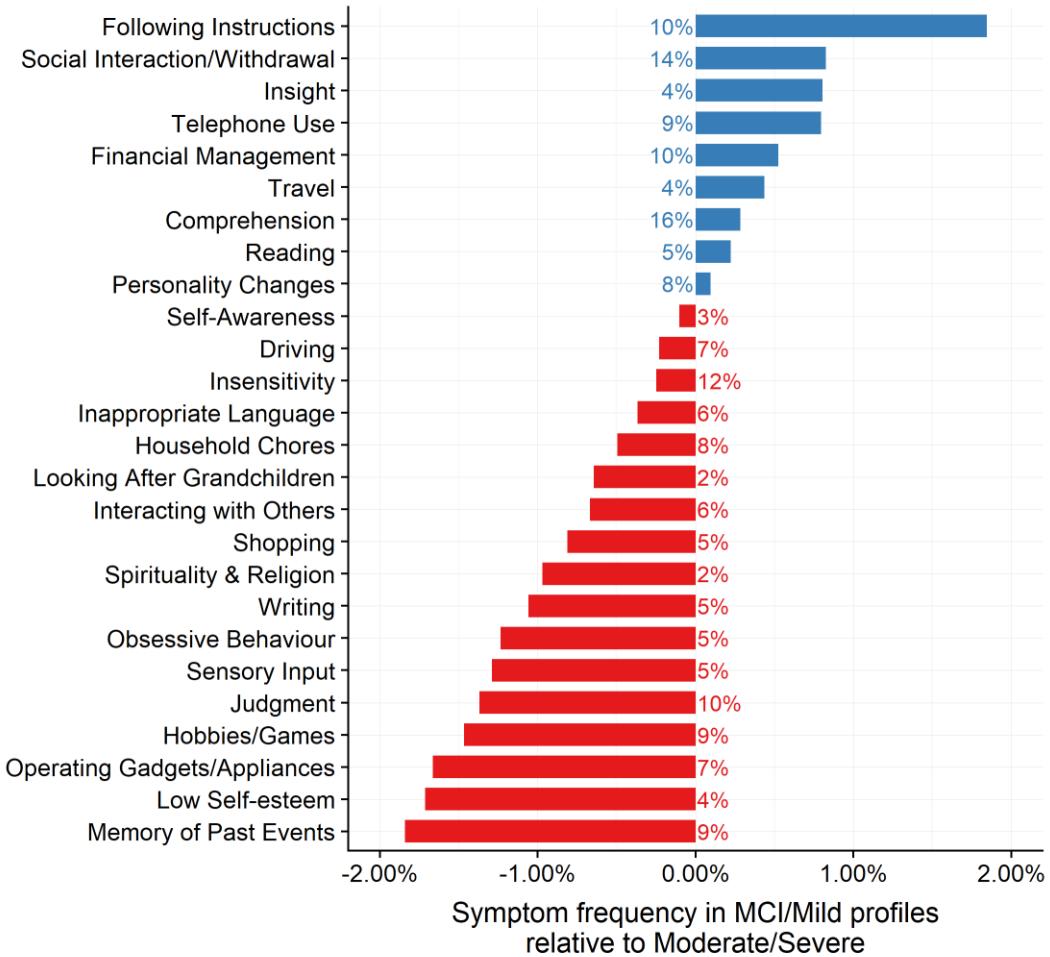
# RELATIVE SYMPTOM FREQUENCY

Symptoms more common in MCI/Mild



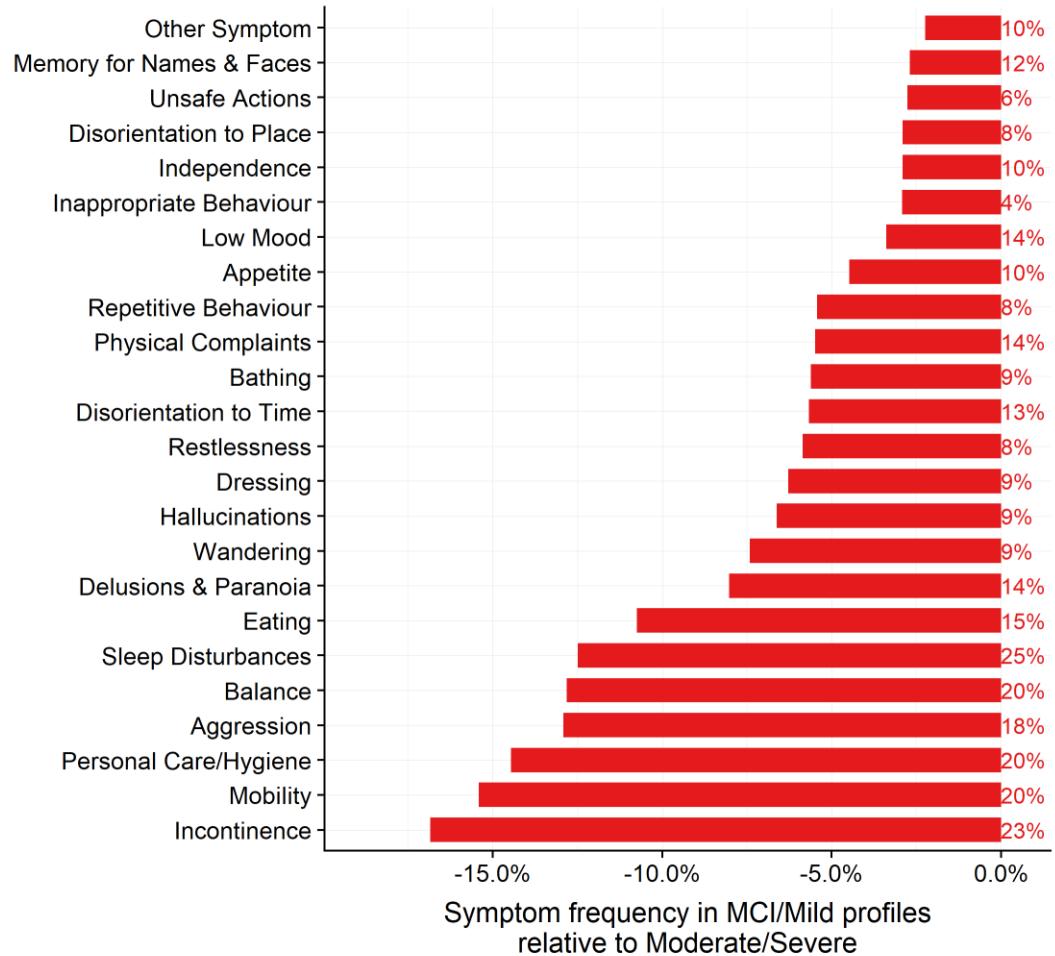
# RELATIVE SYMPTOM FREQUENCY

Symptoms with similar frequencies

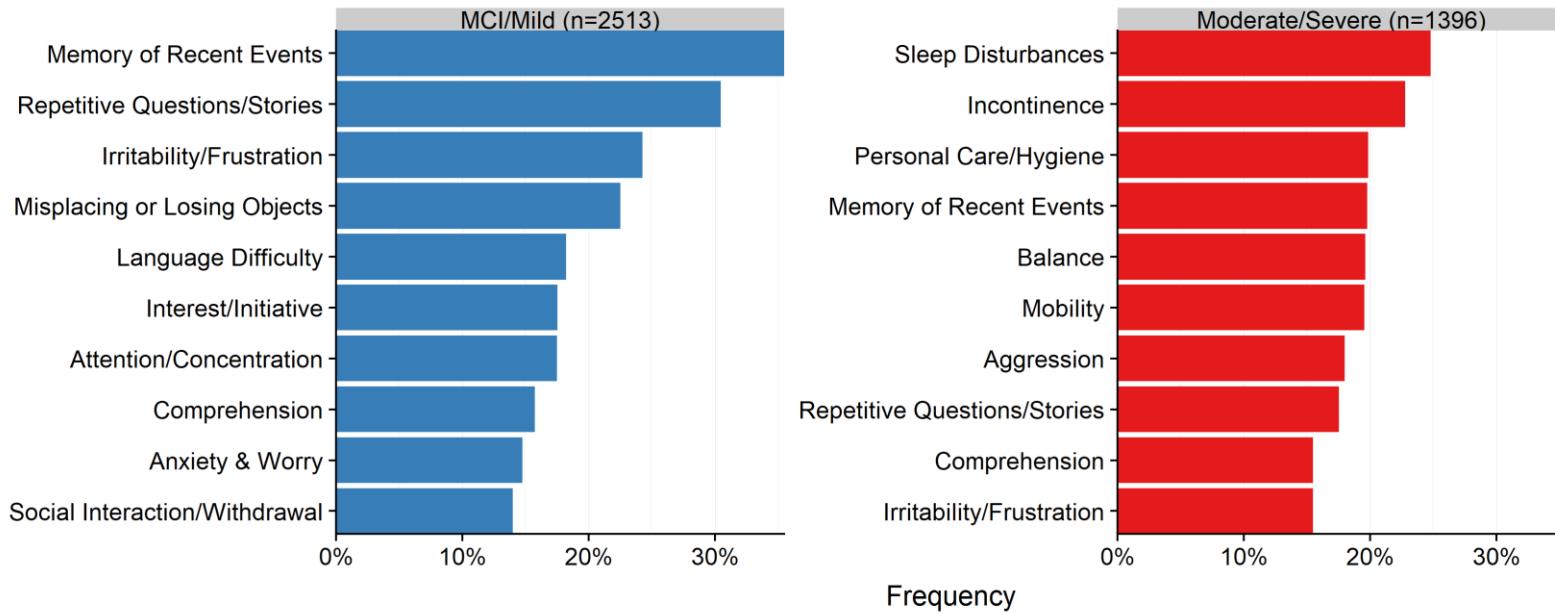


# RELATIVE SYMPTOM FREQUENCY

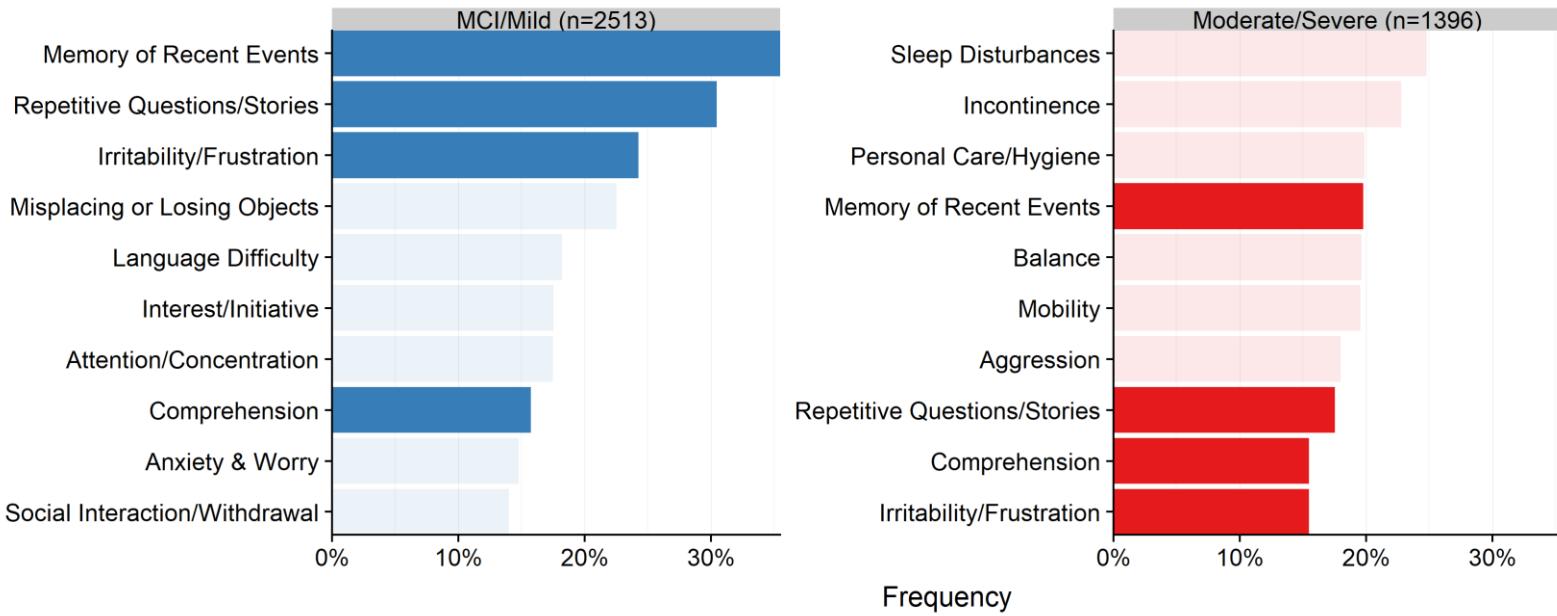
Symptoms more common in Moderate/Severe



# TOP 10 SYMPTOMS BY STAGE GROUP



# TOP 10 SYMPTOMS BY STAGE GROUP



# TOP 10 MOST FREQUENT AND IMPORTANT SYMPTOMS

Most frequent symptoms	Median weighted rank	Frequency
Memory of Recent Events	0.40	29.9%
Repetitive Questions/Stories	0.33	25.8%
Irritability/Frustration	0.57	21.1%
Misplacing or Losing Objects	0.56	18.6%
Sleep Disturbances	0.61	16.8%
Language Difficulty	0.50	16.5%
Attention/Concentration	0.50	15.9%
Comprehension	0.50	15.7%
Interest/Initiative	0.75	14.3%
Anxiety & Worry	0.57	14.0%

Most important symptoms	Median weighted rank	Frequency
Travel	0.90	4.2%
Hobbies/Games	0.83	8.4%
Looking After Grandchildren	0.82	2.0%
Interest/Initiative	0.75	14.3%
Operating Gadgets/Appliances	0.75	6.2%
Social Interaction/Withdrawal	0.75	13.7%
Other Symptom	0.73	6.5%
Household Chores	0.73	7.4%
Shopping	0.73	4.0%
Interacting with Others	0.71	5.7%