

# Identifying Patterns in Patient-Reported Dysphagia Across Dementia Progression

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## Background

- Oropharyngeal dysphagia (swallowing dysfunction) is commonly seen in persons living with dementia and can lead to serious consequences including social isolation, malnutrition, and aspiration pneumonia<sup>1</sup>.
- Despite its significance, there is no universal screening method to identify dysphagia, leading to large discrepancies in estimates of prevalence across various screening practices, especially in older adults<sup>2</sup>.
- Care partners are a crucial component of care for persons with dementia and dysphagia but often experience challenges including care partner burden<sup>3</sup>.

## Project Aims

- To examine whether under-reporting of dysphagia occurs in persons living with dementia
- To compare relationships among patient-reported dysphagia symptoms, care partner burden, and health literacy

## The Care Research Core Registry

The UW-Madison Alzheimer's Disease Research Center (ADRC) Care Research Core maintains a registry of patient-reported outcome measures and survey data from 85 persons living with dementia and their care partners. This study consisted of 59 participants who completed the Care Research Core swallowing inventory and their care partners. Care Research Core questionnaires included in this analysis include:

### Patient:

- Swallowing Inventory
- Clinical Dementia Rating (CDR)
- Demographic information

### Care Partner

- Zarit Burden Interview (ZBI)
- Health Literacy Questionnaire (HLQ)
- Demographic information

## Methods

### Defining "Under-Reporting"

Participants who denied swallowing difficulties on the general "Do you have difficulty swallowing?" question (Q1) but endorsed symptoms of dysphagia on symptom-specific items (Q2-10) were defined as under-reporting dysphagia symptoms

Criteria for Under-Reporting Status			
General Question (Q1)	Symptom-Specific Questions (Q2-10)		
	Yes	Yes	No
Yes	Positive	N/A	
No	Under-Report	Negative	

## Methods Continued

The number of swallow symptoms a participant experienced was defined as the number of swallow inventory questions (Q2-10) endorsed. Severity of symptoms was determined based on the 4-item ordinal frequency scale and yes/no responses, with a "severe" response defined as at least one response rated "Sometimes" or "All the time" on Q1-7 or "Yes" on Q8-10.

### Statistical Methodology

ANOVA tests assessed difference across dementia severity groups for continuous variables. Post-hoc tests determined specific group differences following a significant ANOVA result. For categorical variables, chi-square or Fisher's exact tests examined associations between variables and dementia severity categories. Linear regression models determined relationships between variables. All statistical analyses were conducted using STATA version 18

### Care Research Core Swallowing Inventory

- Do you have difficulty swallowing?
- Do you have to use extra effort when you swallow foods or liquids?
- Do you ever cough when eating or drinking?
- Do you ever clear your throat during or after eating or drinking?
- Do you ever choke when eating or drinking?
- Does food stick in your mouth or throat after you swallow?
- Do you have trouble swallowing your pills?
- Does the sound of your voice change after eating or drinking (e.g., wet or gurgly sound)?
- Have you modified your diet due to difficulties with swallowing (e.g., choose softer foods/add moisture to your foods or eliminated specific foods)?
- Have you had unintentional weight loss in the last year?

\*Two questions were omitted from analysis due to minimal correlation with oropharyngeal dysphagia

## Discussion

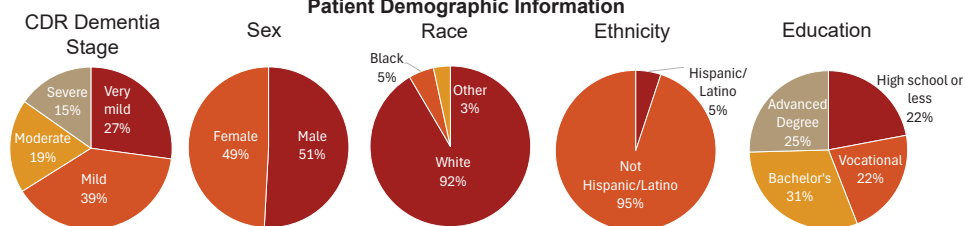
- Findings indicate that under-reporting of dysphagia symptoms is highly prevalent in persons with dementia
- There is a need for in-depth dysphagia screening using validated tools and symptom-specific questions to facilitate early identification and intervention
- As dementia progresses, patients may be more likely to experience a tendency to modify their diet due to swallowing difficulties and unintentional weight loss
- It is important to support care partners and address care partner burden when managing dementia

## Limitations

- The Care Research Core Swallowing Inventory is an internally-developed tool and has not been validated.
- Use of a validated tool for dysphagia screening such as the Eating Assessment Tool (EAT-10) could strengthen this investigation
- Five of the symptoms addressed in the Swallowing Inventory aligned with symptoms addressed on the EAT-10, including food sticking in throat and coughing when eating
- Interdisciplinary collaboration among professions, including speech-language pathology, can give access to more perspectives and expertise, leading to improved outcomes

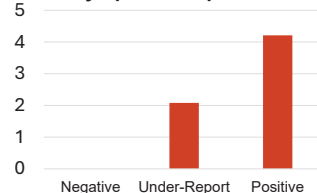
## Results

### Patient Demographic Information

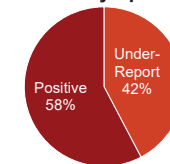


- A majority (76.3%) of participants endorsed the presence of at least one specific dysphagia symptom
- The general screening question had a sensitivity of 42.2% in this cohort

### Average Number of Swallow Symptoms Reported



### 26 participants reported 1+ severe symptoms



### Patient Report of Dysphagia Symptoms

Positive N (%)	Negative N (%)	Under-Report N (%)
19 (32.2)	14 (23.7)	26 (44.1)

### Significant Results by Dementia Severity

	Very Mild N (%)	Mild N (%)	Moderate/Severe N (%)
Diet Modification (Yes to Q9)	0 (0%)	3 (13.6%)	6 (30.0%)
Unintentional Weight Loss (Yes to Q10)	0 (0%)	2 (8.7%)	7 (35.0%)
Caregiver Age (mean)	70.56	62.48	60.80
Caregiver Burden Score (mean)	19.75	33.26	31.65

### Predictors of Under-Reporting

- Sex: More likely to be female (65.4%) vs male (34.6%) (p=0.037)
- Race: All patients who identified as Black or Other under-reported (p=0.013)

### The most common symptoms reported by under-reporters:

- Clearing throat when eating/drinking (65.4%)
- Coughing when eating/drinking (38.5%)
- Food sticking in mouth/throat when eating/drinking (23.1%)

## Acknowledgements

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## References

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