

Dysphagia Patient-Reported Outcomes in Multiple Sclerosis

Madeline Sheppard-Marvin, BS
Speech, Language, and Hearing Sciences
sheppmar@austin.utexas.edu

Corinne Jones, PhD, CCC-SLP
Speech, Language, and Hearing Sciences
Neurology
corinne.jones@austin.utexas.edu



Introduction

Dysphagia is relatively common in patients with multiple sclerosis (MS), with a prevalence of about 33-43%.¹ Dysphagia can lead to aspiration pneumonia, which is the leading cause of death among MS patients.¹ However, dysphagia in MS patients is poorly characterized.

Early detection of dysphagia is imperative to prevent serious dysphagia-related complications.¹ Patient-reported outcome measures can be used as screening tools to detect signs and symptoms of dysphagia and to determine which patients to refer for further instrumented testing.¹ The Dysphagia in Multiple Sclerosis (DYMUS) is a dysphagia questionnaire developed specifically for MS, but it lacks validation. Recent research has investigated its relationship to VFSS results and ENT diagnosis of dysphagia and results have questioned its accuracy as a screening tool.^{2,5} The Sydney Swallow Questionnaire (SSQ) is a validated visual analogue scale but has not been studied in persons with MS.^{3,8} The SSQ allows for a more descriptive report of symptoms due to the use of visual analogue scales, while the DYMUS is limited in this regard as each question is answered as yes or no.

The relationship between dysphagia symptoms and fatigue in MS is unknown. However, dysphagia presence and severity in MS has been associated with disease severity according to the Expanded Disability Status Scale.^{4,6}

We aimed to capture patient reported swallowing measures using an online survey in a large group of persons with MS and compare dysphagia complaints with other MS symptoms.

Hypotheses

We hypothesized that:

- There would be a significant relationship between the SSQ and DYMUS
- Disease duration, MFIS, and MSIS-29 would predict abnormal scores on the SSQ and DYMUS

Methods

- Inclusion criteria:
 - At least 18 years old
 - Neurologist confirmed diagnosis of any subtype of MS
 - Without diagnosis of any other neurological disease
 - Able to read and understand English
 - Have access to a computer and the internet
- n = 513 adults (411 female) with diagnosis of MS
 - 24 - 85 years (mean = 51.92 +/- 12.5)
- Online survey consisting of electronic versions of:
 - Dysphagia in Multiple Sclerosis (DYMUS)
 - Sydney Swallow Questionnaire (SSQ)
 - Modified Fatigue Impact Scale (MFIS)
 - Multiple Sclerosis Impact Scale (MSIS-29)
- Spearman's rank correlations to determine relationship between DYMUS and SSQ scores
- Logistic regression to describe abnormal DYMUS and SSQ scores in the context of MFIS and MSIS-29 scores

Results

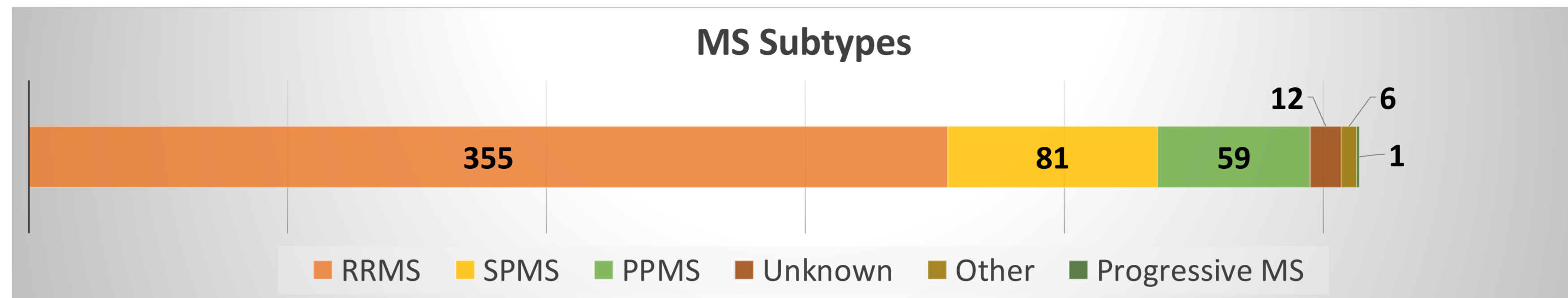


Figure 1: Number of participants in each reported MS subtype. RRMS=Relapsing-remitting MS, SPMS=Secondary progressive MS, PPMS=Primary progressive MS.

- Reported MS subtypes (Figure 1): 69% relapsing remitting MS, 16% secondary progressive MS, 12% primary progressive MS, 2% unknown, 1% progressive MS, 1% other
- Average total scores:
 - DYMUS: 3.12/10 (SD = 2.98, range = 0-10)
 - SSQ: 280.13/1700 (SD = 285.49, range = 0-1366)
 - MFIS: 42/84 (SD = 19.92, range = 0-84)
 - MSIS: 75.06/145 (SD = 24.94, range = 29-137)
- 49.7% of respondents had an abnormal DYMUS (≥ 3)¹ (Figure 2)
- 38.4% of respondents had an abnormal SSQ (>234)⁷ (Figure 2)

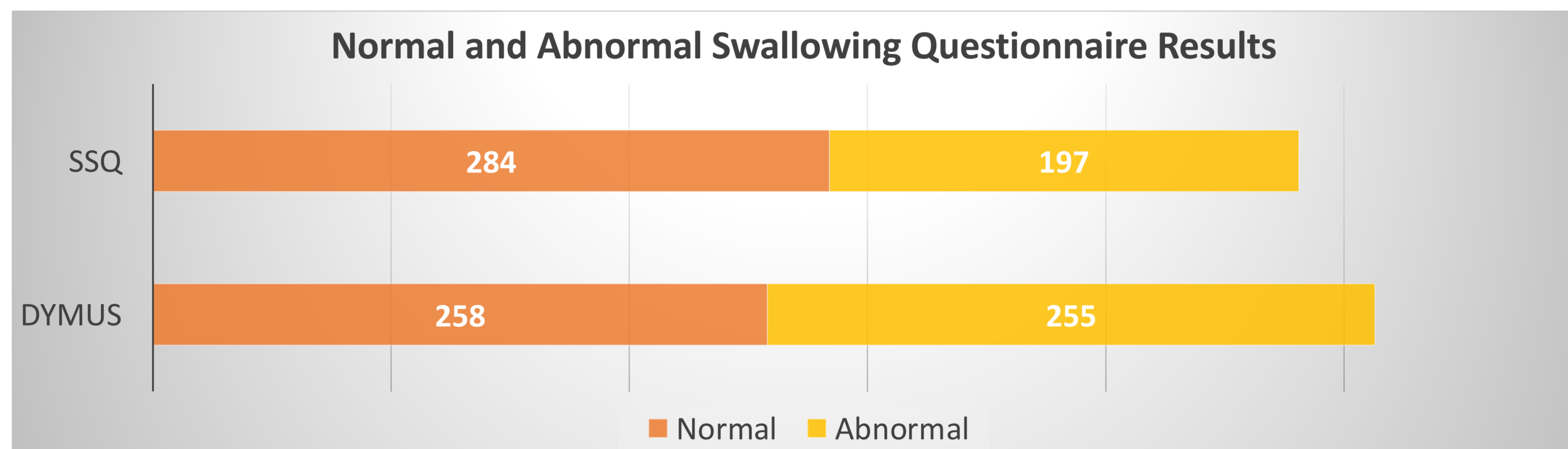


Figure 2: Number of participants with normal and abnormal scores on the DYMUS and SSQ.

- 76.9% of respondents with abnormal DYMUS scores and 64.2% of respondents with abnormal SSQ scores reported never having received an instrumented swallowing evaluation (Figure 3)

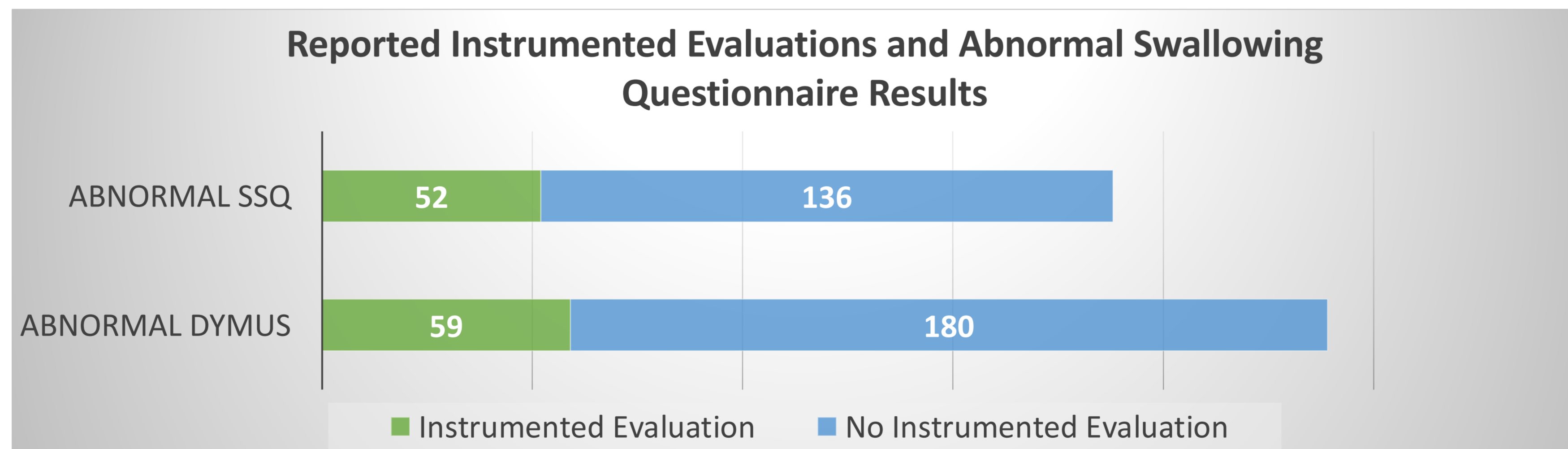


Figure 3: Number of participants with abnormal DYMUS and SSQ scores who reported receiving versus not receiving instrumented swallowing evaluation.

- DYMUS and SSQ scores had a very strong, positive correlation ($r=0.83$, $p<0.001$)
- Abnormal DYMUS scores were best described by total MFIS (OR=1.0546, $p<0.001$)
- Abnormal SSQ scores were best described by total MFIS (OR=1.033, $p<0.001$), total MSIS (OR=1.02, $p<0.01$), and sex (OR(male)=0.44, $p<0.01$)

Conclusion

- A high proportion of respondents reported complaints of dysphagia
- Most respondents with complaints of dysphagia reported never receiving an instrumented swallow study
 - Swallowing concerns are not being evaluated and treated
- DYMUS showed strong convergent validity to the SSQ
 - DYMUS may be suited as a screener, but further validation with swallowing physiology is warranted
- Abnormal DYMUS and SSQ scores were best described using a combination of general MS questionnaires including the MFIS
 - Fatigue should be evaluated and considered in assessment and management of dysphagia
- More widespread use of dysphagia PROs, including the introduction of electronic versions, is recommended to identify those with swallowing complaints prior to experiencing negative health outcomes associated with dysphagia

Acknowledgments

We thank Leorah Freeman, MD, PhD; Odelin Charron, MSc; Ethan Meltzer, MD; Ashlea Lucas, PA-C for assistance with PRO selection.

We thank the National MS Society and local support groups including Smyelin Myelin, Self-Help Group Austin: Be All You Can Be, MS Matters – Living Beyond Self-Help Support Group, and Brazos Valley, The Woodlands, El Paso, Rockport, Sugar Land, Houston, Bandera, Lakehills, McKinney, Heart of Texas, Beaumont, West Texas, and Clear Lake MS support groups for assistance with distributing the survey to members.

References

1. Bergamaschi, R., Crivelli, P., Rezzani, C., Patti, F., Solaro, C., Rossi, P., Restivo, D., Maimone, D., Romani, A., Bastianello, S., Tavazzi, E., D'Amico, E., Montomoli, C., & Cosi, V. (2008). The DYMUS questionnaire for the assessment of dysphagia in multiple sclerosis. *Journal of the Neurological Sciences*, 269(1-2), 49-53.
2. Conte, W. (2019, February 28-March 2). *Validating the DYMUS dysphagia screening questionnaire with the video fluoroscopic swallow study* [Poster Session]. ACTRIMS Forum 2019, Dallas, TX, USA.
3. Dwivedi, R. C., Rose, S. S., Roe, J. W. G., Khan, A. S., Pepper, C., Nutting, C. M., Clarke, P. M., Kerawala, C. J., Rhys-Evans, P. H., Harrington, K. J., & Kazi, R. (2010). Validation of the Sydney Swallow Questionnaire (SSQ) in a cohort of head and neck cancer patients. *Oral Oncology*, 46(4), e10-e14.
4. Fernandes, A. M. F., de Campos Duprat, A., Eckley, C. A., da Silva, L., Ferreira, R. B., & Tilbery, C. P. (2013). Oropharyngeal dysphagia in patients with multiple sclerosis: Do the disease classification scales reflect dysphagia severity? *Brazilian Journal of Otorhinolaryngology*, 79(4), 460-465.
5. Mahmoud, R. (2016, June 1-4). *Prevalence of dysphagia in multiple sclerosis and correlation with disability* [Presentation]. CMSC Annual Meeting, National Harbor, MD, USA.
6. Poorjavad, M., Derakhshandeh, F., Etemadifar, M., Soleymani, B., Minagar, A., & Maghzi, A.-H. (2010). *Oropharyngeal dysphagia in multiple sclerosis*. *Multiple Sclerosis Journal*, 16(3), 362-365.
7. Szczesniak, M. M., Maclean, J., Zhang, T., Liu, R., & Cook, I. J. (2014). The normative range for and age and gender effects on the Sydney Swallow Questionnaire (SSQ). *Dysphagia*, 29(5), 535-538.
8. Wallace, K. L., Middleton, S., & Cook, I. J. (2000). Development and validation of a self-report symptom inventory to assess the severity of oral-pharyngeal dysphagia. *Gastroenterology*, 118(4), 678-687.