

Variability of Spasticity in Multiple Sclerosis – Results From SEEN-MSS, a Large-Scale, Self-Reported Survey

Barry Hendin¹ | Ben Thrower² | Scott D. Newsome³ | Robert Chinnapongse⁴ | Sherry Danese⁵ | Jenifer Patterson⁴



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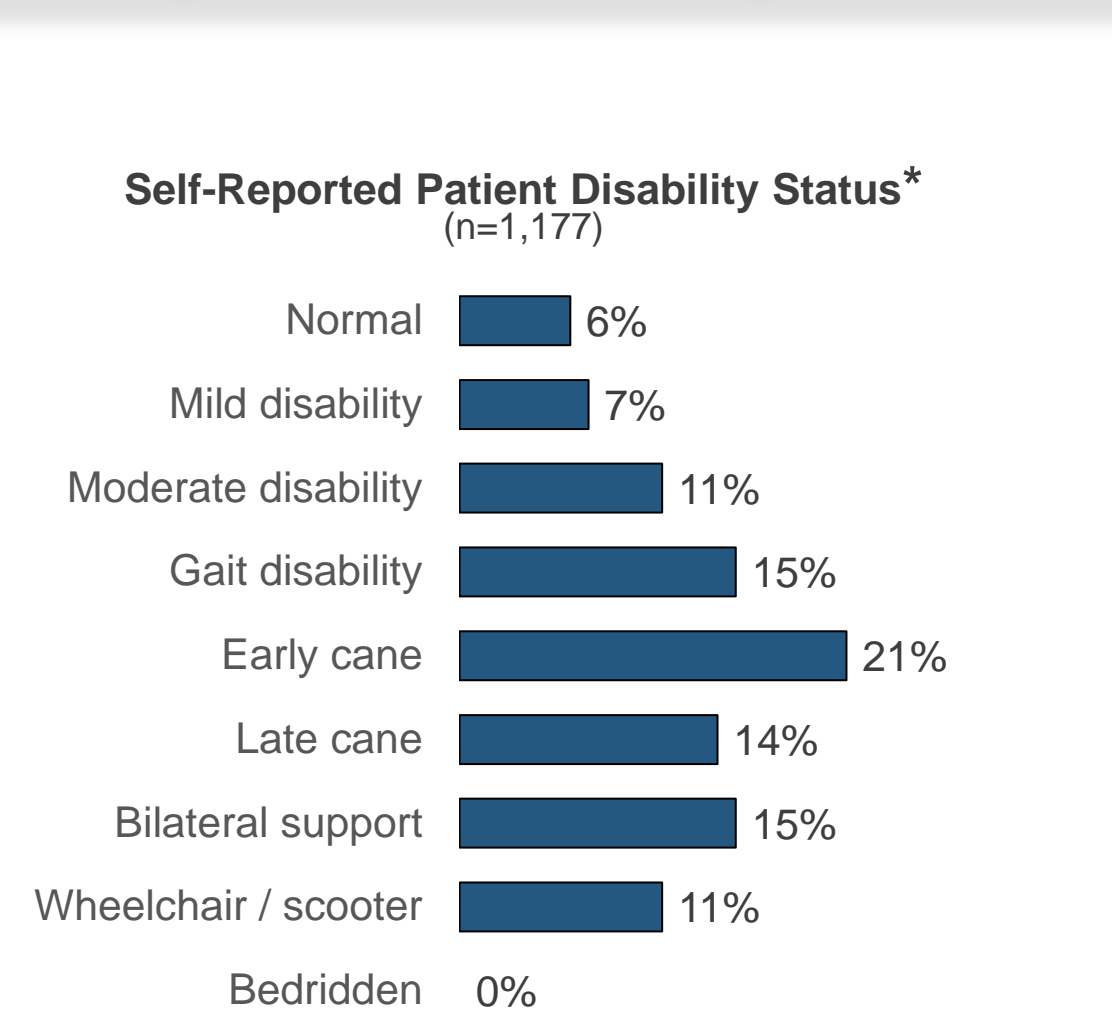
¹Department of Neurology, University of Arizona Medical School, Tucson, AZ, USA; ²Andrew C. Carlos Multiple Sclerosis Institute, Shepherd Center, Atlanta, GA, USA; ³Johns Hopkins University School of Medicine, Baltimore, MD, USA; ⁴Jazz Pharmaceuticals, Carlsbad, CA, USA; ⁵Outcomes Insights, Agoura Hills, CA, USA

- ### KEY POINTS
- SEEN-MSS (Symptoms and Emotions Exploration Needed in Multiple Sclerosis Spasticity), a cross-sectional, online survey, was developed in collaboration with three US-based MS advocacy organizations.
 - Survey respondents included 1,177 people with multiple sclerosis and spasticity (PwMSS), 78% female, mean age 57.
 - Variable triggers of MSS
 - Spasticity is triggered by a variety of factors, most commonly fatigue, physical activity, heat, and stress.
 - Variable frequency and time of day of MSS
 - Spasticity varies throughout the day and day-to-day.
 - Implications of the variable nature of spasticity
 - Variability of MSS prevents PwMSS from doing things they would like to do.
 - Half of PwMSS change their treatment dosing according to their spasticity that day.
 - Results emphasize that the variable nature of MS spasticity and lack of predictability necessitate customizable treatments, based on the severity, timing, and duration of spasticity symptoms.

INTRODUCTION

- Spasticity, a complex and multidimensional symptom of multiple sclerosis (MS), occurs in up to 80% of people with MS² and can have a discernible negative impact on overall well-being and multiple aspects of daily functioning.
- The experience of spasticity varies among people with MS and spasticity (PwMSS), and the variable and unpredictable nature of spasticity has not been well characterized.
- We developed a cross-sectional survey to understand how PwMSS experience and describe the variability of symptoms associated with spasticity, identify specific spasticity triggers, and describe how PwMSS manage the variability of spasticity and its impact on their daily lives.

Survey Recruitment and Respondent Characteristics



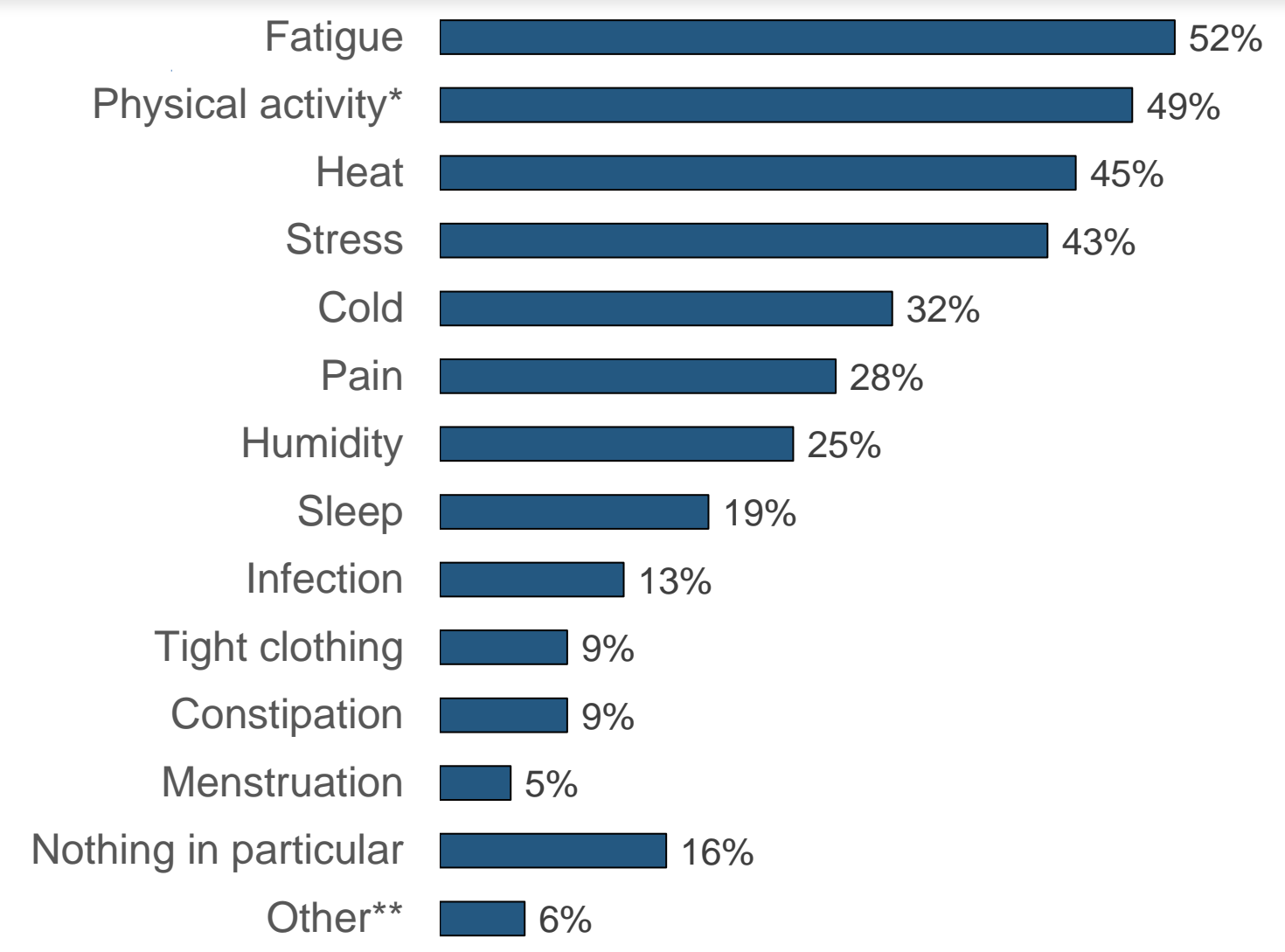
	All Respondents N=1,177
Mean age, y (SD)	56.8 (10.7)
Female, n (%)	913 (78)
Mean time from MS diagnosis, y (SD)	16.8 (10.0)
Mean duration of spasticity, y (SD)	11.5 (9.7)
Ethnicity, n (%)	
White	1004 (85)
Black	98 (8)
Hispanic, Latino, or Spanish origin	56 (5)
American Indian or Alaskan native	10 (1)
Asian	7 (1)
Other or Prefer not to respond	30 (3)
MS type, n (%)	
Relapsing-remitting MS (RRMS)	820 (70)
Secondary progressive MS (SPMS)	170 (14)
Primary progressive MS (PPMS)	145 (12)
Don't know / unsure	42 (4)

SD: standard deviation

*Disability Status: Self-reported Patient Determined Disease Steps (PDDS).^{3,4} Respondents were asked to read the list of PDDS descriptions and select the one that best describes their situation.

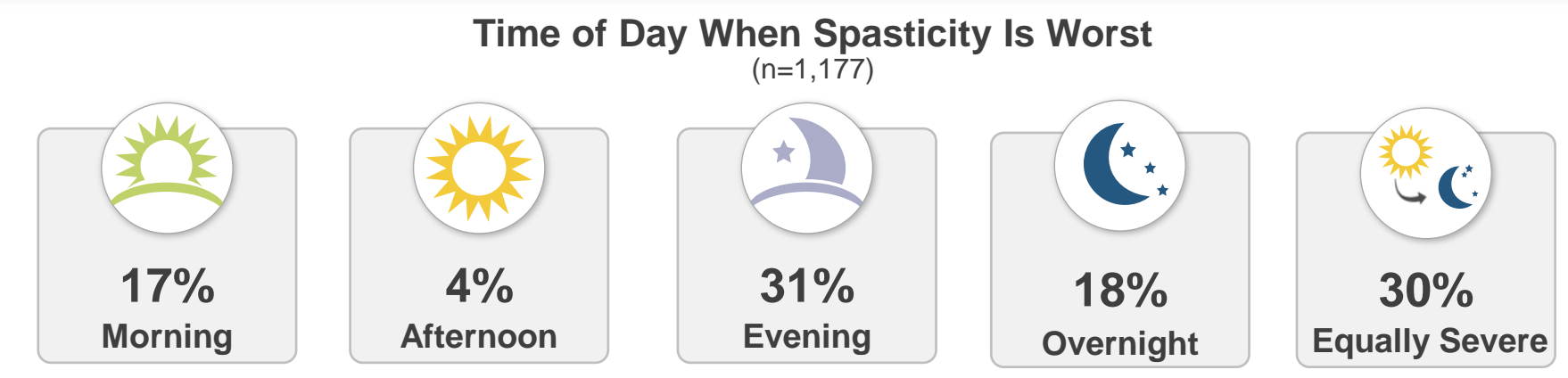
RESULTS

Variable Triggers of Spasticity



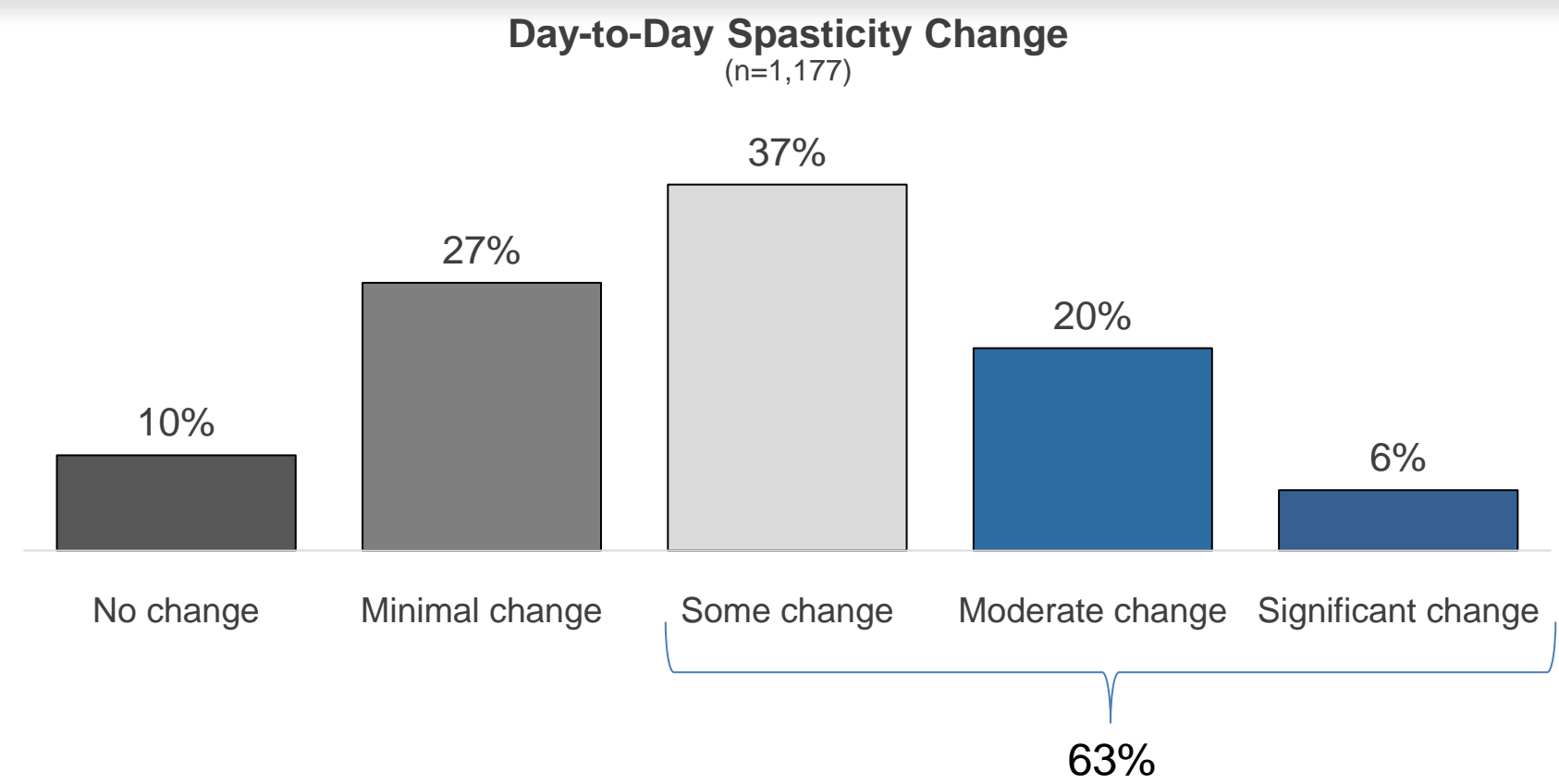
Respondents were asked "What triggers your spasticity or makes your spasticity worse? Select all that apply."
*Physical activity triggers included movement/daily activities; exertion; sitting/standing too long.
**Other triggers included skin lesions; full bladder; alcohol; stretching or changing position; weather or barometric change.

Variability of Spasticity Throughout the Day



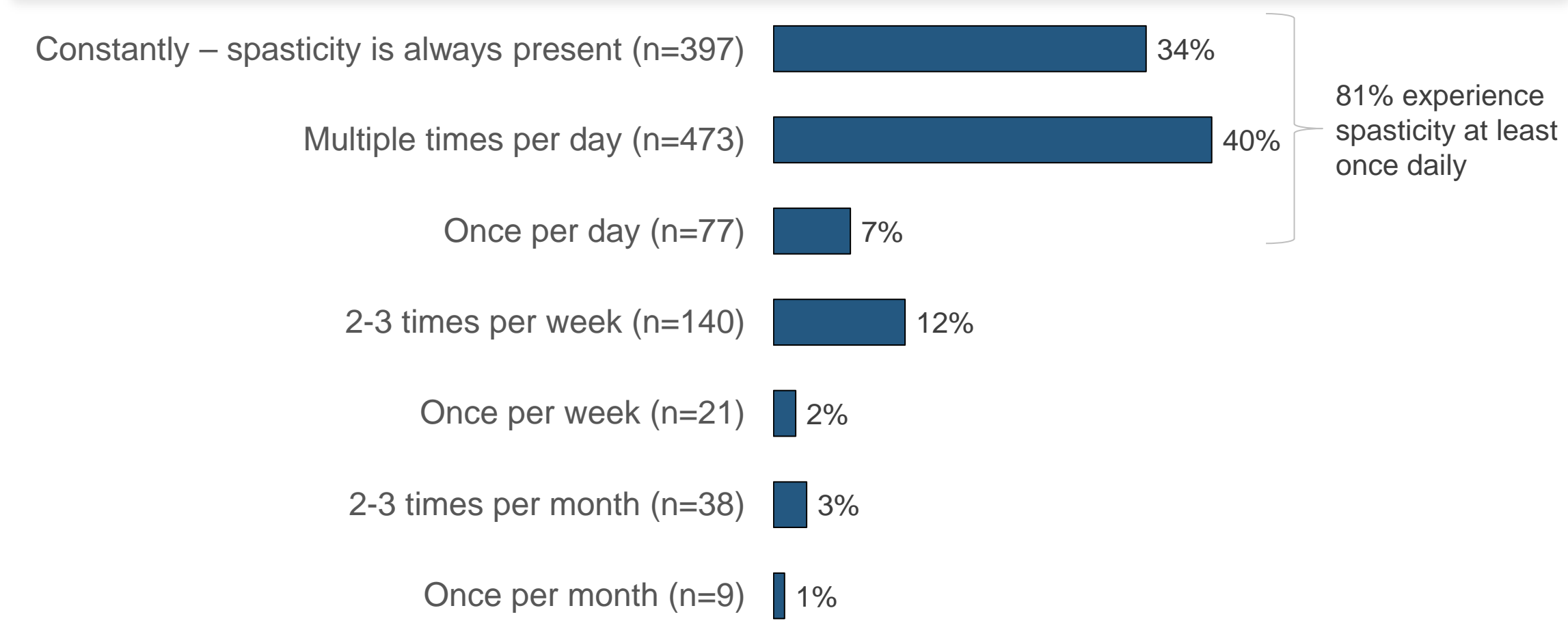
Respondents were asked, "What time of day is your spasticity typically worst?"

Variability of Spasticity Day to Day



Respondents were asked, "How much does your spasticity change from day-to-day (e.g., some days it is more severe than others)?"

Variable Frequency of Spasticity



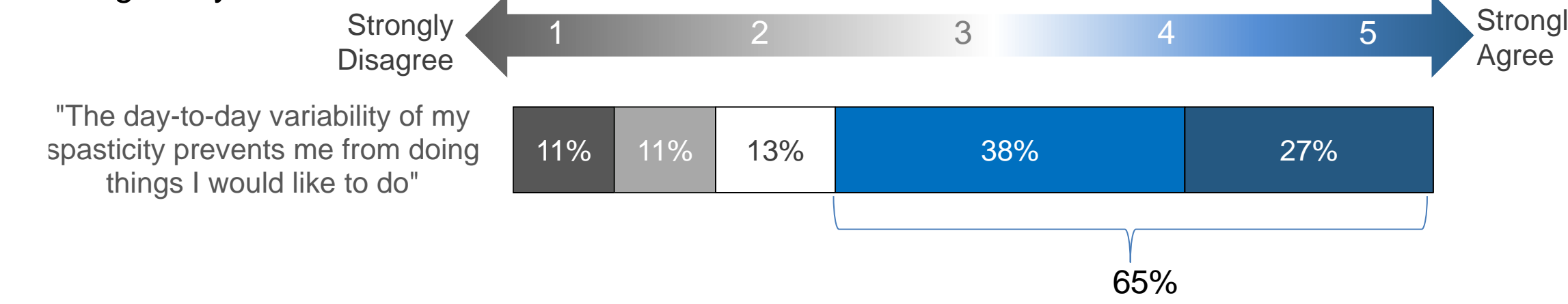
Respondents were asked, "How frequently do you typically experience spasticity related to your MS?"

Implications of the Variable Nature of Spasticity

- Half (49.7%) change the way they use their spasticity treatment depending on how troubling the spasticity symptoms are on a given day.

Respondents were asked, "Do you typically change the way you use your current spasticity treatment depending on how troubling your spasticity symptoms are?" and responded "Yes" or "No."

- Almost two-thirds (65%) agree that the variability of their MSS prevents them from doing things they would like to do.



Respondents were asked, "Please rate your agreement or disagreement with the following statements." Responses were provided on a 5-point scale: (1) Strongly Disagree; (2) Somewhat Disagree; (3) Neither Agree Nor Disagree; (4) Somewhat Agree; (5) Strongly Agree.

METHODS

- 20-minute online survey of US-based PwMSS developed by Greenwich Biosciences, Inc., and Scott Newsome in collaboration with three US-based MS patient advocacy organizations: Multiple Sclerosis Association of America, Multiple Sclerosis Foundation, and National Multiple Sclerosis Society.
- Respondents completed the survey between February and May 2021.
- Survey consisted of multiple-choice and rank-order questions, and scale-based responses.
- Analysis was performed using descriptive statistics.
- Further details of the SEEN-MSS survey can be found in the Supplemental Materials.

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References: 1. Farrar JT et al. Clin Ther. 2008;30(5):974-985. 2. Bethoux F et al. Patient. 2016;9(6):537-546. 3. Learmonth YC et al. BMC Neurol. 2013;13:37. 4. Hohol MJ et al. Neurology. 1995;45(2):251-255.
Contact Information: medinfo@greenwichbiosciences.com

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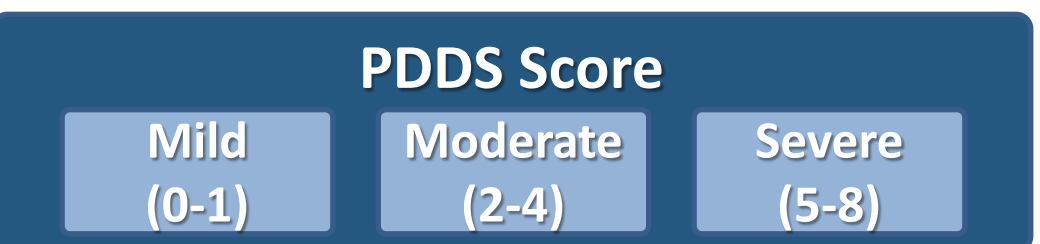
Supplemental Material

SUPPLEMENTAL METHODOLOGY

- SEEN-MSS (Symptoms and Emotions Exploration Needed in Multiple Sclerosis Spasticity)
 - Cross-sectional, observational, online survey.
 - Survey materials were reviewed, and a waiver was granted by an independent review board prior to study initiation.
- Survey was promoted by Multiple Sclerosis Association of America, Multiple Sclerosis Foundation, and National Multiple Sclerosis Society.
- No a priori parameters were used as quotas for recruitment.
 - Respondents provided consent prior to entering the survey using an online consent form.

SEEN-MSS Survey Questions

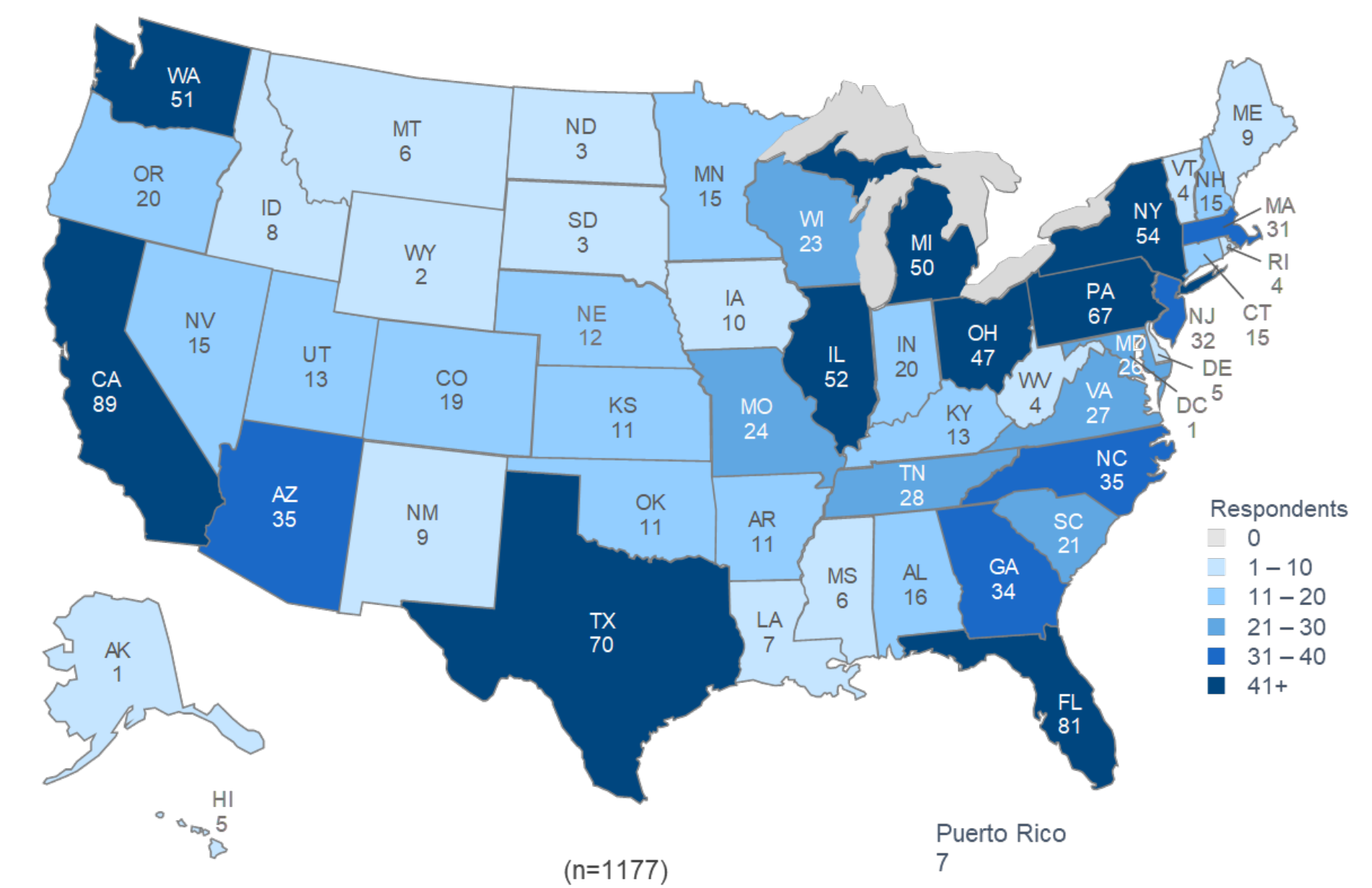
- Disease severity was captured via PDDS.^{1,2}



- Survey questions were original in nature, developed to elicit participant feedback regarding their overall experience with spasticity in MS.
 - The content for survey questions, including symptoms and treatment lists, was developed based on expert input and review of existing literature.
- Survey consisted of multiple-choice questions, rank-order questions (order of importance 1-5), and scale-based responses using a symmetrical 5-point Likert scale of agreement with presented statements (from “strongly disagree” to “strongly agree”).

SUPPLEMENTAL RESULTS

SEEN-MSS Respondent Location



SEEN-MSS Survey Question Examples:

PDDS: Patient-determined Disease Steps

Please read the choices listed below and choose the one that best describes your situation. This scale focuses mainly on how well you walk. You might not find a description that reflects your condition exactly but please mark the one category that describes your situation the closest.

0 – Normal	I may have some mild symptoms, mostly sensory, due to MS, but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.
1 – Mild disability	I have some noticeable symptoms from my MS, but they are minor and have only a small effect on my lifestyle.
2 – Moderate disability	I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.
3 – Gait disability	MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack.
4 – Early cane	I use a cane, a single crutch, or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks.
5 – Late cane	To be able to walk 25 feet, I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.
6 – Bilateral support	To be able to walk as far as 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.
7 – Wheelchair/scooter	My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet, even with crutches or a walker.
8 – Bedridden	Unable to sit in a wheelchair for more than one hour.

How much has spasticity caused you to limit your typical daily activities?

Not at all 1 2 3 4 5 Significantly

Which of your daily activities are most limited by spasticity?

Please select up to 5 activities starting with the activity that is most limited by spasticity.

<input checked="" type="radio"/> Walking	<input checked="" type="radio"/> Driving
<input checked="" type="radio"/> Stairs / stair climbing	<input type="radio"/> Writing or typing
<input checked="" type="radio"/> Household activities	<input type="radio"/> Sexual activity
<input type="radio"/> Standing	<input type="radio"/> Hygiene / bathing
<input checked="" type="radio"/> Sleep	<input type="radio"/> Dressing
<input type="radio"/> Moving from one position to another	<input type="radio"/> Using the toilet
<input type="radio"/> Sitting	<input type="radio"/> Eating

References: 1. Learmonth YC et al. BMC Neurol. 2013;13:37. 2. Hohol MJ et al. Neurology. 1995;45(2):251-255.
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