Recognition, Description, and Variability of Spasticity in Individuals With Multiple Sclerosis and Potential Barriers to Clinician-Patient Dialogue: Results From SEEN-MSS, a Large-Scale, Self-Reported Survey

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ABSTRACT

BACKGROUND: The experience with spasticity varies among individuals with multiple sclerosis and spasticity (MSS), as they may not recognize it as spasticity or have the language to describe their symptoms. This can lead to potential delays in diagnosis and treatment.

METHODS: Symptoms and Emotions Exploration Needed in Multiple Sclerosis Spasticity was an online survey completed by 1177 individuals with MSS in 2021. It sought to capture symptoms of spasticity, variability of symptoms, specific spasticity triggers, and how conversations with physicians were initiated.

RESULTS: The mean age of the cohort was 56.8 years and it was 78% women. Prior to spasticity onset, 65% of respondents felt minimally prepared or unprepared for possibly developing spasticity and were unaware that spasticity manifests as part of MS. Eighty percent experienced spasticity daily, which was variable in severity and duration. Spasticity was triggered by a range of factors and 90% of those surveyed were unable to predict when it would occur or its severity. Day-to-day variability of spasticity prevented 65% of respondents from doing things they wished to do. Sixty percent were confused by their symptoms, not recognizing them as spasticity. Although 91% reported experiencing muscle spasms, only 69% used "muscle spasms" to describe their symptoms. Other descriptors included "muscle tightness," "stiffness," "cramping," and "pain." After recognizing spasticity, 78% proactively initiated discussions with their physicians, 52% wished they had done so sooner, and 42% delayed the conversation by up to or more than a year.

CONCLUSIONS: Results emphasize the variable nature of spasticity and the lack of a common language to describe symptoms, underscoring the importance of education, earlier recognition, and customized treatments tailored to the severity and duration of spasticity symptoms.

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Multiple sclerosis (MS) is an autoimmune demyelinating disease of the central nervous system that can have a highly variable and unpredictable clinical course. It is estimated that 2.8 million people are living with MS globally.[1] The overall burden and neurological symptoms of MS can be experienced differently, based on location, size, and number of central nervous system lesions. For those with MS, symptoms can occur concurrently, in various combinations, potentially exacerbating each other, further compounding its unpredictability and management complexity.[2]

Spasticity involves the involuntary stimulus of muscles to contract or shorten and is a complicated, multidimensional symptom, contributing to disability in up to 84% of individuals with MS.[3,4] The muscle contractions that characterize spasticity can occur spontaneously or continuously.[5,6] Generally, spasticity may result in potentially debilitating musculoskeletal issues, including focal or diffuse pain, involuntary shaking, joint stiffness, muscle contractures, and limited range of movement, leading to multiple concurrent symptoms that negatively impact daily functioning and quality of life.[5,6] For those with MS, it has been well documented that spasticity can result in physical disability and mobility issues, profoundly impacting quality of life, functioning, and performing activities of daily living, more so as the disease progresses.[3,7,8]

As the experience of spasticity varies among individuals with MSS, the spectrum of its signs and symptoms has made quantifiable assessment challenging. Although clinician-assessed scales do exist, including the pendulum test, Ashworth Scale, modified Ashworth Scale, and the Tardieu and Modified Tardieu Scales, they are not widely used in the clinical setting. Patient-reported measures or scales

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TABLE 1. Respondent Characteristics (N = 1177)

Mean age, y (SD)	56.8 (10.7)
Female, n (%)	913 (78%)
Mean time from MS diagnosis, years (SD)	16.8 (10.0)
Mean duration of spasticity symptoms, years (SD)	11.5 (9.7)
MS type, n (%)	
Relapsing-remitting MS	820 (70%)
Secondary progressive MS	170 (14%)
Primary progressive MS	145 (12%)
Don't know/unsure	42 (4%)
Spasticity treatment	
Currently receiving any treatment for spasticity, n (%)	1018 (87%)
Oral medication or injectable treatment, n (%)	796 (68%)
Oral only, n (%[a])	724 (91%)
Injectable only, n (%[a])	8 (1%)
Both oral and injectable, n (%[a])	64 (8%)
Oral medications, n (%)	
Baclofen (Lioresal, Gablofen)	530 (45%)
Gabapentin (Neurontin)	271 (23%)
Tizanidine (Zanaflex)	196 (17%)
Clonazepam (Klonopin)	67 (6%)
Diazepam (Valium)	45 (4%)
Lorazepam (Ativan)	33 (3%)
Levetiracetam (Keppra)	11 (1%)
Methocarbamol (Robaxin)	10 (1%)
Dantrolene (Dantrium)	4 (< 1%)
Dronabinol (Marinol)	3 (< 1%)
Metaxalone (Skelaxin, Metaxall)	4 (< 1%)
Nabilone (Cesamet)	0 (0%)
Injectable treatments, n (%)	
Botulinum toxin (eg, Botox, Dysport, Xeomin)	58 (5%)
Intrathecal baclofen	16 (1%)
Phenol injection	1 (< 1%)
Nonpharmacological interventions[b]	760 (65%)
Spasticity neurologic rating scale score, n (%)	
Mild	211 (18%)
Moderate	476 (40%)
Severe	468 (40%)
Frequency of spasticity, n (%)	
Constant—spasticity is always present	34%
Multiple times per day	40%
Once per day	7%
2-3 times per week	12%
Once per week	2%
2-3 times per month	3%
Once per month	1%
Other response/nonresponse	1%

MS, multiple sclerosis.
[a]Percentage of those receiving oral or injectable treatment, n = 796.
[b]Includes acupuncture, cold/hot therapy, home exercise, massage, occupational therapy, physical therapy, stretching, transcutaneous electrical nerve stimulation, or yoga.

have also been developed, including the 88-question MS Spasticity Scale and the Numeric Rating Scale for Spasticity. Despite the availability of assessment tools, most often, spasticity is included as a component of the standard MS neurological examination that is briefly documented in the patient's chart. In addition, individuals with MSS may not recognize the characteristics of spasticity, have the language to describe their symptoms, or feel they are worth speaking to their physician about. All these factors may lead to potential delays in the clinician-patient dialogue resulting in delayed spasticity diagnosis and treatment.

To address this need and better understand the clinician-patient dialogue surrounding spasticity in individuals with MS, we conducted the Symptoms and Emotions Exploration Needed in Multiple Sclerosis Spasticity (SEEN-MSS) survey.[9] The aim was to provide a more comprehensive understanding of how individuals with MSS experience and describe their symptoms associated with spasticity, the variability of those symptoms, specific spasticity triggers, and how they initiate conversations with physicians.

METHODS

Survey methodology, eligibility, and a subset of analses of SEEN-MSS have been previously published.[9] A cross-sectional, observational, online survey, SEEN-MSS was developed by Greenwich Biosciences, now a part of Jazz Pharmaceuticals, Inc, and Scott Newsome, DO, in collaboration with 3 United States–based advocacy organizations for individuals with MS: the Multiple Sclerosis Association of America, the Multiple Sclerosis Foundation, and the National Multiple Sclerosis Society. These organizations assisted with online recruitment of survey participants.

The SEEN-MSS survey was conducted from February 4, 2021, to May 3, 2021. Prior to survey initiation, all materials were reviewed, and a waiver was granted by Advarra, an independent review board. All participants completed an online consent form prior to participating in the survey and all screening and survey details were self-reported.

Continuous variables were summarized as means, medians, and ranges; categorical variables were summarized as frequency distributions and percentages.

RESULTS

During the study period, the SEEN-MSS survey was completed by 1177 adults with MSS. Most participants were White (85%) and female (78%) with a mean age of 56.8 years (SD ± 10.7) (TABLE 1). Of those who reported their specific MS diagnosis, 70% had been diagnosed with relapsing-remitting MS and 73% were receiving treatment with a disease-modifying therapy. A high proportion (80%) of participants reported that they experience spasticity at least daily, and applying the Numeric Rating Scale for Spasticity score, 18% reported their spasticity as mild, 40% as moderate, and 40% as severe. Eighty-seven percent were receiving treatment for their spasticity, most commonly an oral medication (Table 1). Additional characteristics of survey participants have been previously published.[9]

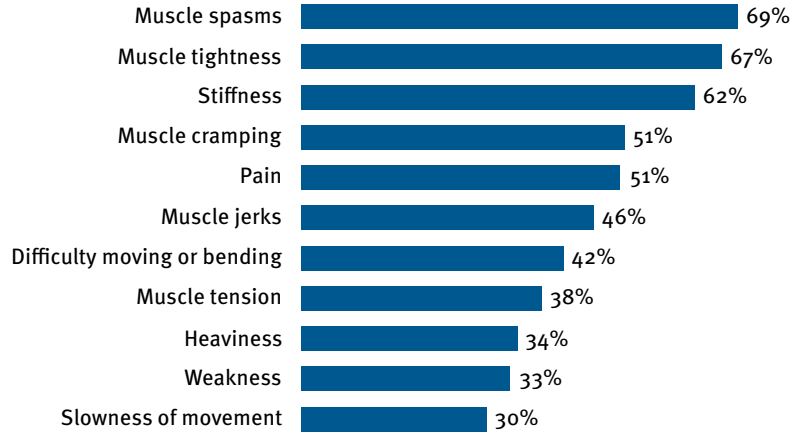
Describing and Diagnosing Spasticity

Survey respondents reported that there was a period of approximately 5 years between MS diagnosis, occurring 16.8 years (mean, SD ± 10.0) prior to taking the survey, and

FIGURE 1A. Patient-Reported Descriptors of the Multidimensional Nature of Spasticity (N = 1177)

(A)

Survey question:
Which of the following words or phrases do you typically use to describe your spasticity?
Select all that apply.



onset of spasticity symptoms, occurring 11.5 years (mean, SD ± 9.7) prior to taking the survey. While 91% reported that they experience muscle spasms, only 69% specifically used the phrase *muscle spasms* to describe their symptoms (**FIGURE 1A**). Other commonly used descriptors used by respondents included *muscle tightness* (67%), *stiffness* (62%), *muscle cramping* (51%), and *pain* (51%).

Spasticity does not appear to be a symptom that is immediately recognized by individuals with MS. When asked to look back, 60% reported that they were confused by the symptoms that they were experiencing and 70% recognized that they had been experiencing spasticity symptoms earlier than they had realized. Because specific symptoms may not have been recognized or acknowledged by the individual, this may have contributed to delays in clinician-patient dialogue.

Clinical Dialogue

Within the survey, 65% of respondents reported that they were either *not at all prepared* or *minimally prepared* for the possibility of developing spasticity, as their physician had not discussed this likelihood with them.

Following their MS diagnosis, physicians initiated a general discussion on possible MS symptoms with respondents within 3 months (30%), within 3 to 6 months (23%), within 7 to 11 months (4%), and after more than a year (30%). Of those who had had a discussion about spasticity specifically, it was started proactively by 78% of respondents while, for 22%, the physician was the one to initiate the discussion about spasticity. Interestingly, of the total cohort, 13% reported that they have never had a discussion with their physician about the symptoms of MS. Two-thirds (66%) of respondents stated that their physician used the word *spasticity* while discussing MS symptoms with them.

Although 87% of individuals with MSS had spoken with their physician about spasticity, 52% of those wished they had done so sooner. Among those wishing they had discussed spasticity sooner, 51% stated that it might have provided them with a better understanding of what was happening to their bodies, 48% might have sought treatment for their spasticity symptoms sooner, 34% shared that they may have had a name to explain what they were feeling, and 16% felt that earlier discussion might have given them more trust in their physician's overall management plan for their MS.

Looking back, the majority of respondents (70%) somewhat agreed or strongly agreed that they were experiencing spasticity symptoms earlier than they originally thought and 60% somewhat agreed or strongly agreed that they were confused by their symptoms because they did not recognize them for what they were.

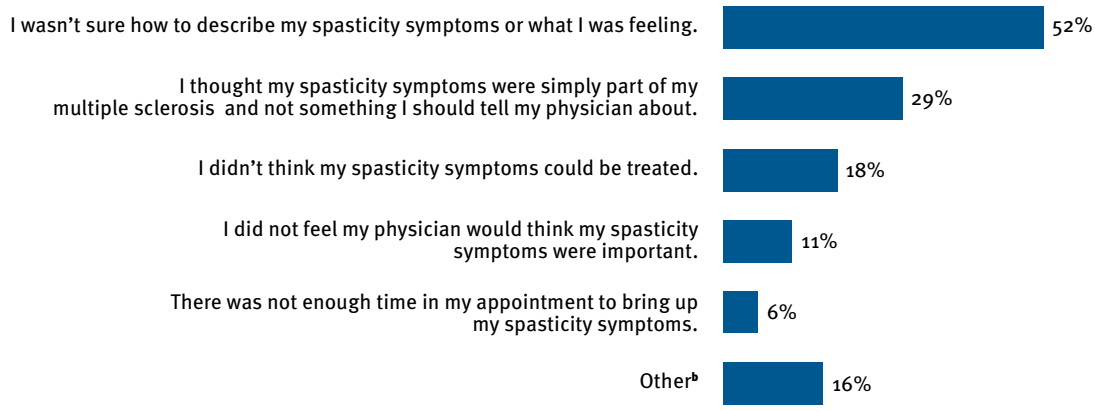
The survey identified 3 key barriers that prevented an earlier discussion about spasticity between participants and their physicians (**FIGURE 1B**). The most common barrier, noted by more than half (52%) of the individuals, was that they lacked the vocabulary to describe spasticity; they did not know how to describe their symptoms. They also assumed that spasticity was simply a part of their MS and not worthy of mentioning (29%) and, similarly, they made the presumption that their spasticity could not be treated (18%), so again, it was not worth mentioning.

Variable Nature of Spasticity

For 80%, spasticity is a once-daily occurrence. For 34%, spasticity is constant, while 40% describe multiple periods of spasticity during each day (Table 1). Spasticity is also variable throughout the day in severity and duration for 70% and from day to day for 63%. They reported that their spasticity is often worse in the evening (31%) and throughout

FIGURE 1B. Self-Reported Barriers to Discussion With Physician About Multiple Sclerosis Spasticity (n = 534[a])

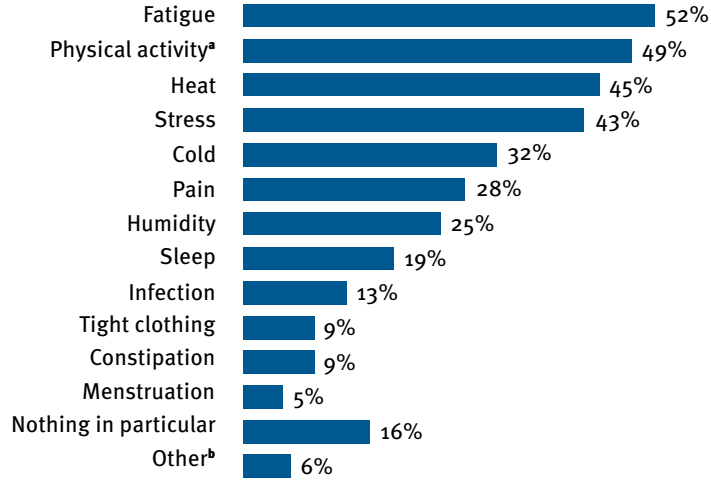
(B) Survey question:
What kept you from discussing your spasticity symptoms with your physician sooner?



[a]Among those wishing they had discussed sooner.
[b]Other: There were 86 unique responses/barriers to physician discussion that did not fall into any of the key responses noted above.

FIGURE 1C. Variable Triggers of Spasticity (N = 1177)

(C) Survey question:
What triggers your spasticity or makes your spasticity worse? Select all that apply.



[a]Physical activity triggers included movement/daily activities, exertion, sitting/standing for too long.
[b]Other triggers included skin lesions, full bladder, alcohol, stretching or changing position, weather or barometric changes.

the day (30%), compared with overnight (18%), in the morning (17%), or in the afternoon (4%).

Spasticity is triggered by a range of factors, most commonly fatigue (52%), physical activity (49%), heat (45%), and stress (43%) (**FIGURE 1C**).

Implications of the Variable Nature of Spasticity

From day to day, 90% reported that they were not able to predict when their spasticity would occur or how severe it would be, and 65% agreed or strongly agreed that the day-to-day variability of their spasticity prevented them from doing things they would like to do.

Depending on how troubling the spasticity symptoms were on a given day, 49.7% shared that they changed the way they used their spasticity treatment by dose or frequency. Twenty-five percent did not believe that their physician understood how many aspects of their lives were impacted by spasticity.

DISCUSSION

The SEEN-MSS survey reveals that spasticity in MS can have a highly variable presentation in onset, duration, and severity; that it can be triggered by a number of different factors; and that individuals with MSS describe spasticity in many different ways. Findings also highlight a communication disconnect between individuals with MS and physicians. Possible MS symptoms are not always relayed in a timely manner, and spasticity is not always included in that conversation. Individuals with MSS are hesitant to initiate a discussion about spasticity symptoms with physicians because they may be uncertain of the proper language to describe the symptoms they are experiencing; furthermore, they may not recognize these symptoms as spasticity and have doubts about whether they should proactively initiate a discussion about these symptoms with their physician.

Although effective treatments for spasticity in MS do exist, this lack of awareness and recognition of spasticity and delays in the patient-physician dialogue limit the availability of treatment for those individuals with MSS who may benefit. Previous studies have shown that early and effective treatment of MS-related spasticity is important; it minimizes the consequences of spasticity-related symptoms, it improves patients' quality of life, and it alleviates some of the economic burden on health care systems.[10]

Physicians and individuals with MSS may benefit from using a common language and the survey results underscore the importance of education, which enables earlier recognition, diagnosis, and treatment of spasticity in MS. The patient-clinician dialogue may be improved by the development and use of spasticity symptom trackers and assessments of outcome. Although several questionnaires are currently available, they are not commonly used outside of a clinical research setting. Tools that ask the right questions about potential symptoms and manifestations of spasticity, using easy-to-understand terminology at earlier and regular time points, may open up communication between patients and physicians, although acceptance and application within the clinic setting would be necessary. Additionally, capturing a profile of specific symptoms for each patient, accounting for day-to-day and individual variability of spasticity, may also provide the opportunity for more flexible, customizable management plans.

Due to the inherent nature of survey-related research, the findings presented should be interpreted, while keeping in mind the following limitations. Due to the anonymity of survey responses, verification of reported data is not possible. Although this was a large, inclusive sample with a sufficient base size and representation across subgroups to project findings to the broader population, this is a survey and not a stratified sample; also, a clinician survey was not included. The current survey is also subject to potential sampling bias because it was available online only and administered in English. Thus, it has limited potential to reach certain populations including non-English speakers and those with limited access to the internet. These findings were not reported in comparison to any control group. Although the survey questions used were original in nature, customized to the study objectives, and validated through pretesting, the survey itself was not derived from existing validated instruments.

We acknowledge that patient-driven surveys are subjective in nature; however, they do help provide the patients' experience, which is essential to understanding where gaps may be in the comprehensive care for individuals with MS. A long-standing patient registry, the North American Research Committee on Multiple Sclerosis registry, has published data from multiple patient surveys that have provided useful information for clinical practice. For future consideration, the inclusion of a clinician survey to assess perceived impact of spasticity on the lives of individuals with MSS also may be beneficial.

Spasticity can be highly variable in its onset, duration, and severity and can be triggered by a number of different factors. Although results from the SEEN-MSS survey have highlighted that the negative impacts of spasticity are wide-reaching across multiple aspects of life and cause substantial burden for individuals with MSS, many people with this disease may lack awareness that spasticity may manifest as part of MS. Individuals with MSS have demonstrated that they have uncertainty about how to describe symptoms and whether they should initiate a discussion with their physician. ■

PRACTICE POINTS

The variable nature of multiple sclerosis (MS) spasticity necessitates customized treatments based on the severity, timing, and duration of spasticity symptoms.

Clinicians must take the lead: Individuals with MS may be unaware that spasticity could be a symptom of their MS, and they may be uncertain about whether to initiate a conversation with their doctor and how to describe their symptoms. ■

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