



P805. Relapse Prevalence, Symptoms, and Health Care Engagement: Insights from Patients with Multiple Sclerosis from the 2017 Multiple Sclerosis In America Survey

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Introduction and Purpose

- Relapses are a characteristic feature of multiple sclerosis (MS)^{1,2} and have been proven to be associated with the occurrence of long-term disability.¹
- Treatment of MS relapse helps to shorten and lessen the disability associated with relapse.^{1,2} Timely detection and evaluation of relapse is therefore critical for long-term prognosis.
- As well, successful treatment of MS relapse helps patients to gain a sense of trust, of being capable to take control over their disease.³
- Understanding the true frequency and severity of MS relapse has been a challenge given known heterogeneity across relapses, patients, and study designs, among other factors. Currently, we may be misestimating the prevalence and impact of MS relapse on patients.

Objective

- To obtain direct insight from patients regarding prevalence and characterization of MS relapse, as well as health care provider (HCP) engagement during and after relapse⁴

Methods

- The *Multiple Sclerosis In America* (MSIA) survey was created by Health Union,⁵ a company that cultivates online communities dedicated to supporting patients with specific health conditions, including multiple sclerosis (e.g. MultipleSclerosis.net).
- The survey was fielded by Health Union during the first quarter of 2017 to patients with MS and their caregivers via multiple online sources including MultipleSclerosis.net and Facebook. [MultipleSclerosis.net is an established online health community of approximately 230,000 unique visitors from the US, and over 110,000 Facebook followers (data from Q1 2017). This community provides critical information and support to those impacted by MS.]
- Patient respondents were required to have been diagnosed with MS by an HCP and to live in the United States.
- 124 patient-directed questions comprised the survey; 17 were used in this research, reflecting information on demographics, health insurance, employment, disability (using the Patient Determined Disease Steps [PDDS]), MS diagnosis and symptoms, relapse history and experience, and HCP engagement.⁵ Certain questions were conditionally fielded based upon prior response (e.g., relapse experience).
- Survey responses were analyzed, generating means for continuous variables and percentages for categorical variables. Responses were recoded to facilitate interpretation. 2-year relapse rates were annualized. Chi-square tests were used to compare patients by HCP follow-up (≤ 1 mo vs. > 1 mo). Results were rounded to 1 significant figure, so they do not always sum to 100%.⁴

Results

	Descriptors	No. (%)
Gender (Q1)	Female	4,477 (84.3%)
	Male	829 (15.6%)
	Other	5 (0.1%)
Age (years) (Q3)	Average age	51.2
	Under 20	9 (0.2%)
	20-39	792 (14.9%)
	40-59	3,230 (60.8%)
	≥ 60	1,280 (24.1%)
Race (Q2) (n=5,210*)	Caucasian	4,655 (89.3%)
	African American	231 (4.4%)
	Hispanic	159 (3.1%)
	Multi-racial	84 (1.6%)
	Other	36 (0.7%)
	Native American Asian/Pacific Islander	29 (0.6%) 16 (0.3%)
Employment Status (Q4)	On disability	2,131 (40.1%)
	Employed	1,865 (35.1%)
	Retired	674 (12.7%)
	Unemployed	376 (7.1%)
	Stay-at-home	225 (4.2%)
	Student	40 (0.8%)
Health Insurance Coverage (Q5)	Group coverage	2,429 (45.7%)
	Medicare	1,763 (33.2%)
	Medicaid	354 (6.7%)
	Affordable Care Act exchange	228 (4.3%)
	Private insurance Military/government Uninsured/unsure	187 (3.5%) 181 (3.4%) 169 (3.2%)

*N=5,311, except where noted

Patient Demographics [Table 1]

- 5,311 respondents completed the survey.
- The mean age of respondents was 51.2 years; 60.8% were 40-59 years; 84.3% were female, and 89.3% were Caucasian.
- More respondents were on disability (40.1%) than were employed (35.1%).
- 96.8% of respondents were covered by health insurance.

MS-Related Characteristics [Table 2]

- 72.2% reported having relapsing-remitting MS (RRMS), 12.1% secondary-progressive MS (SPMS), 9.3% primary-progressive MS (PPMS), 6.5% reported being unsure.
- 14.1% reported severe disability, 49.7% moderate disability, and 36.2% mild disability.
- Symptoms that most affected daily function were fatigue (31.1%), walking or balance (20.2%), and cognitive dysfunction (11.0%).
- 96% of respondents were currently seeing an HCP for their MS, most often a neurologist specializing in MS (69.5%) or a general neurologist (18.9%).
- 74.8% of respondents not reporting a diagnosis of PPMS (n=4819) were currently using a disease-modifying treatment (DMT).

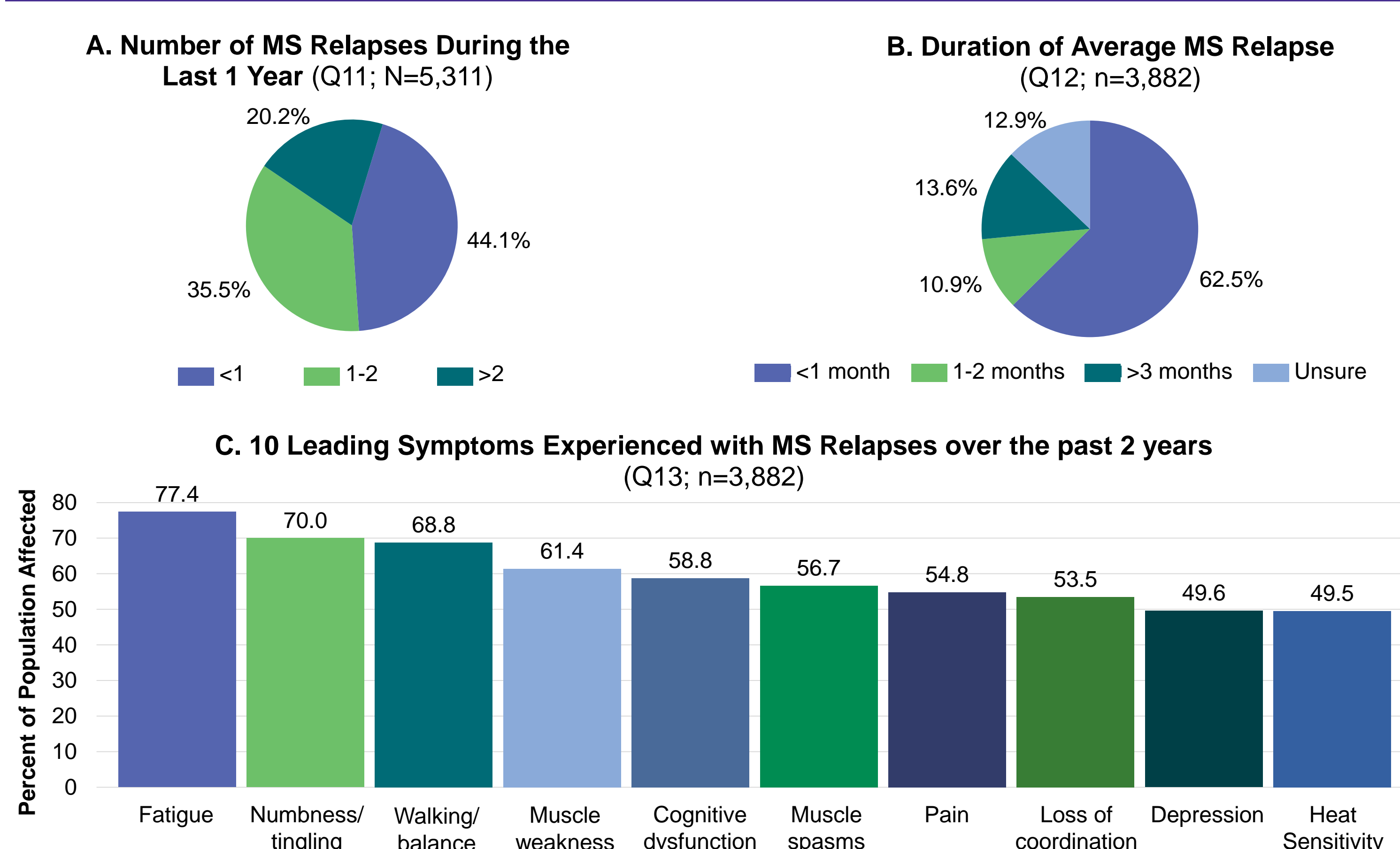
Question	Response	No. [%] of Patients
MS Diagnosis (Q6)	RRMS	3,832 (72.2%)
	SPMS	643 (12.1%)
	PPMS	492 (9.3%)
	Don't know/recall	344 (6.5%)
Using/used DMT for MS management (Q7)	Never Used DMT	6.5%
	Past DMT User	18.7%
	Current DMT User	74.8%
Extent of Disability (based on PDDS) (Q8)	Mild	1,923 (36.2%)
	Moderate	2,641 (49.7%)
	Severe	747 (14.1%)
MS Symptom That Most Affects Daily Function (Q9) (n=5,278* experienced symptom in the past 1 month)	Fatigue	1,642 (31.1%)
	Walking or balance	1,064 (20.2%)
	Cognitive dysfunction	581 (11.0%)
	Pain	352 (6.7%)
	Muscle weakness	216 (4.1%)
	Numbness	196 (3.7%)
	Bladder problems	174 (3.3%)
	Spasticity	157 (3.0%)
	Foot drop	115 (2.2%)
	Heat sensitivity/intolerance	103 (2.0%)
HCP currently being seen for MS (Q10)	Neurologist-MS specialist	3,690 (69.5%)
	Neurologist-general	1,002 (18.9%)
	Not currently seeing an HCP for MS	215 (4.0%)
	Primary care physician/family physician/internal medicine physician	199 (3.7%)
	Nurse practitioner/physician assistant	118 (2.2%)
	All other HCP types surveyed	87 (1.6%)

*N=5,311, except where noted

MS Relapse-Related Findings

- 73.1% of respondents (n=3,882) reported experiencing at least one relapse in the past 2 years. This corresponded to annualized relapse rates amongst all (N=5,311) respondents of: <1/year (44.1%), 1-2/year (35.5%), and >2/year (20.2%). [Figure 1A]
- In those who experienced relapse, the average relapse duration was <1 month for most respondents (62.5%). 24.5% reported an average relapse duration of >1 month. 12.9% were unsure. [Figure 1B]
- Of the most common relapse-related symptoms, fatigue was most reported (77.4% of respondents). Other prominent symptoms included numbness/tingling (70.0%), walking balance/coordination problems (68.8%), muscle weakness (61.4%) and cognitive dysfunction, including memory loss, difficulty concentrating and brain fog (58.8%). [Figure 1C]

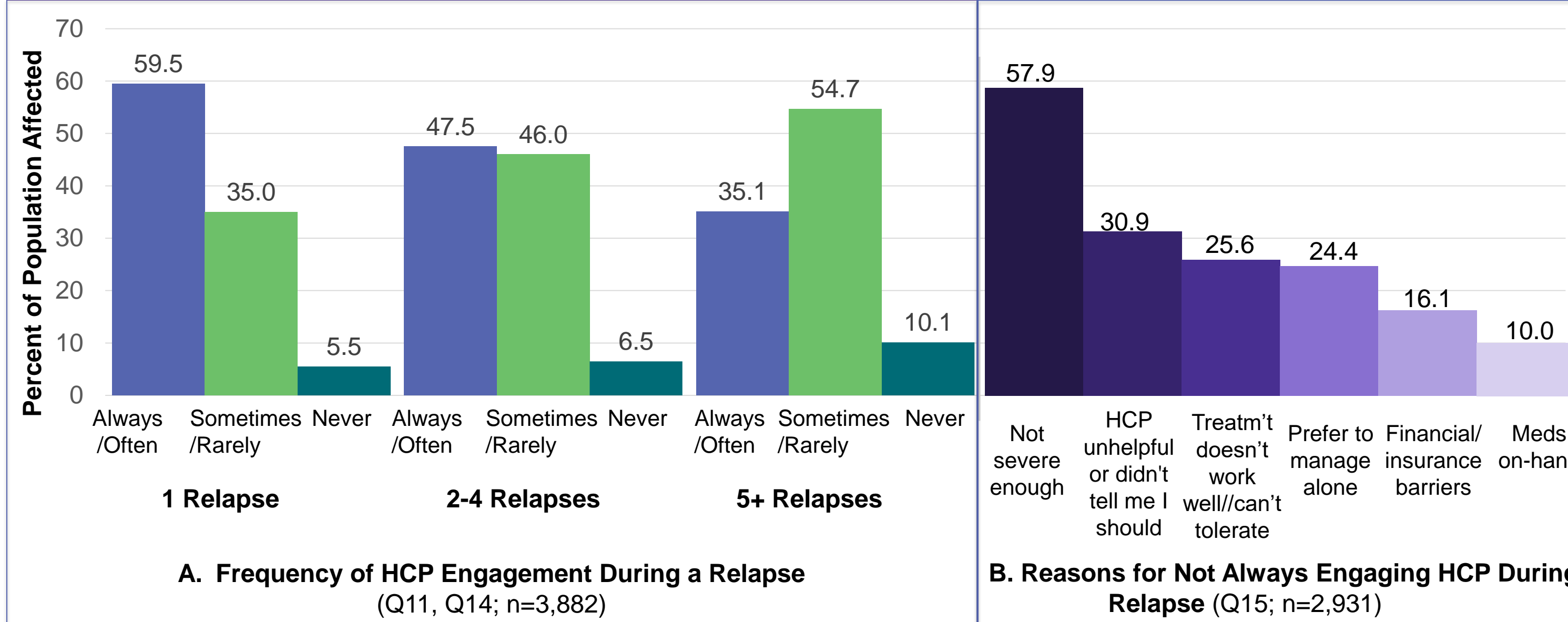
Figure 1. MS Relapse-Related Findings



HCP Engagement During MS Relapse

- 46.9% of respondents reporting relapses said they always/often engage with their HCP during a relapse; 45.8% sometimes (27.3%) or rarely (18.5%), and 7.3% never. [Data not shown]
- Higher 'always/often' engagement with their HCP during relapse was reported by patients having less relapses. The opposite trend was seen in those who 'sometimes/rarely' and 'never' engage with their HCPs during relapse, having more relapses [Figure 2A].
- Common reasons for not always engaging their HCP during a relapse were: relapse is not severe enough (57.9%), HCP is unhelpful / didn't tell me I should (30.9%), medications are ineffective/I can't tolerate (25.6%), preference to manage alone (24.4%), financial/insurance barriers (16.1%), medication on-hand (10.0%). [Figure 2B]

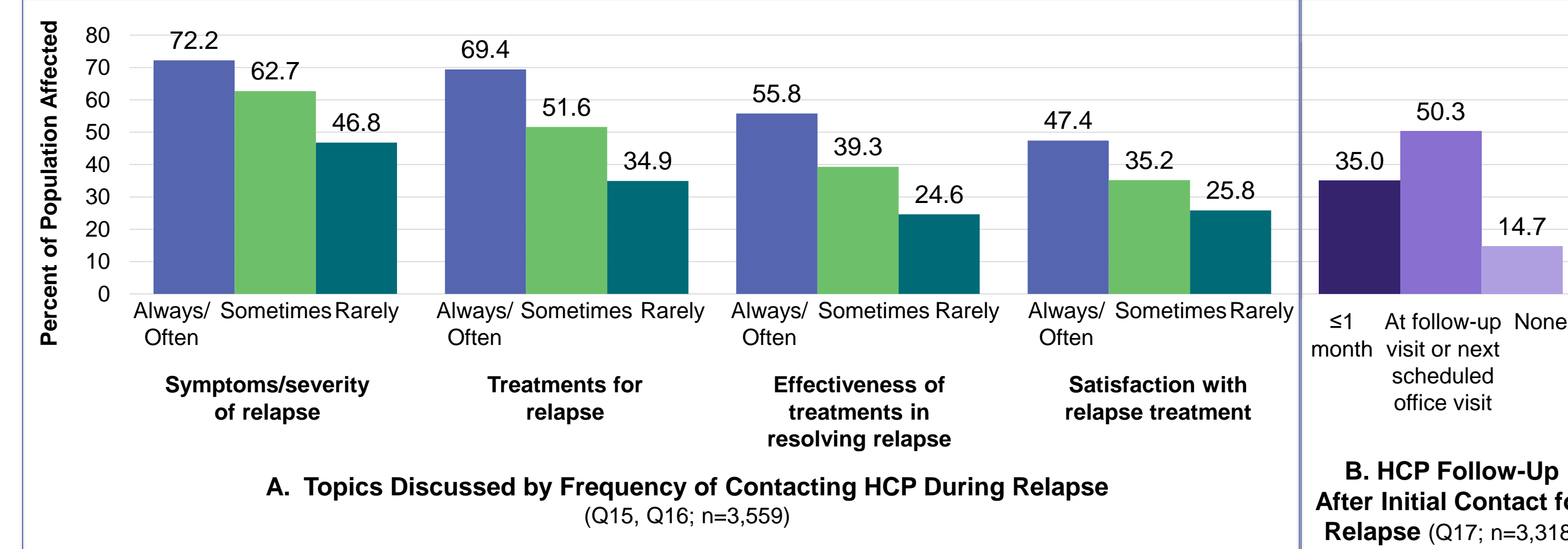
Figure 2. HCP Engagement During MS Relapse



The Patient-Provider Care Partnership

- Respondents who always/often engage their HCP during relapse reported more discussion of key relapse-related topics, relative to those who engaged sometimes and rarely. Those who always/often engage reported the most discussed topics were relapse symptoms and severity (72.2%), relapse treatments (69.4%), effectiveness of treatment in resolving relapse (55.8%), and satisfaction with relapse treatment (47.4%) [Figure 3A]. A similar trend was observed, where those who always/often engage with their HCP during relapse more often discussed MS-related topics (e.g. advancement w/ worsening of disease and changes in treatment plan). [Data not shown]
- 35.0% of respondents reported their HCP followed-up within 1 month of initial contact for the relapse, 50.3% reported at the next visit (a follow-up or the next scheduled), and 14.7% reported no follow-up. [Figure 3B]
- Differences were observed in patients who did (n=1,160) vs. didn't (n=2,158) report HCP follow-up within 1 month of initial contact regarding the relapse. The former were more satisfied with their HCP and their MS treatment plan ($\chi^2=88.3$ and $\chi^2=71.3$, respectively; both $p<0.001$, $df=1$). [Data not shown]

Figure 3. The Patient-Provider MS Care Partnership



Conclusions

- Given the challenges in understanding the frequency and impact of MS relapse, this study contributes valuable insights from the critical perspective of the patient.
- Results indicate patient-reported MS relapse rate may be higher than often thought, despite current DMT use by most respondents. Particular subgroups affected by relapse are identified, i.e. >2 relapses/year, relapse duration of ≥ 1 month, and relapse symptoms that interfere with functioning (e.g. walking / balance).
- Timely and appropriate treatment of relapse is associated with a short-term benefit on the speed of functional recovery from relapse, as well as on an improved long-term prognosis. However, 50% of patients do not regularly engage their HCP during a relapse; those who do, often report they have not received timely follow-up (within 1 month) by their HCP.
- To enhance the patient-HCP MS care partnership, increased engagement and follow-up during and after relapse should be prioritized. 'Always/often' patient engagement of their HCP during relapse is associated with lower relapse frequency, and increased relapse-related and MS-related discussion. HCP follow-up within 1 month is associated with greater patient satisfaction with their MS care provider and MS treatment plan.
- Further insights into the behavior and assumptions of patients and HCPs are needed, particularly with regards to the impact of relapse on overall MS disease and the effectiveness of available relapse treatments.

Limitations

- Surveys reflect convenience samples, and are subject to participation bias and recall bias. Respondents may be different and non-generalizable to the MS adult population.
- Relapse was recalled over a 2 year period. Relapses are more likely to occur over longer timeframes, so recorded 1 year rates may be elevated.
- Validated scales/measures were not used throughout the survey; measurement properties were not formally assessed prior to use, leading to a potential lack of clear interpretability. Such challenges in conducting voice of patient research are not uncommon.

References

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