

# Perceptions of Multiple Sclerosis in 2015: A Public Disease Awareness Survey

Doug Taylor, MBA; Nipa Patel, BS; Philip Sjostedt, BPharm  
Institute for Evidence Based Medicine, New Hope, PA

## Abstract

**Background:** Despite advances in diagnosis, prognosis, treatment, and guidelines, many people remain ignorant of the real-world realities of multiple sclerosis (MS). Patients are often reluctant to discuss their disease with family and friends and scientific advances in MS are rarely discussed outside the medical field. Public surveys of MS provide physicians, patient groups, and industry stakeholders with valuable insights into how the disease is perceived in 2015.

**Objective:** Public perceptions of the impact of MS on patients’ quality of life, family, employment, and economic outlook are explored in this survey. The survey also seeks to determine the public’s knowledge of MS as a medical condition and a factor in daily life.

**Methods:** A virtual survey of 350 respondents from all educational levels and socioeconomic backgrounds was conducted in December 2015. Respondents were polled on their knowledge of MS, including familiarity with the disease, which symptoms they believed were associated with MS, diagnosis and treatment options, quality-of-life impact, and ways to learn new information about MS.

**Results:** A total of 306 respondents (female, 55%, n=169) completed the survey though not all respondents answered every question; 44% reported knowing someone with MS, with more than half (152 of 278, 54%) considering themselves somewhat familiar with the disease. Respondents reported their knowledge of symptoms, their beliefs on the role of MS in daily life, and how impactful they considered the disease for patients. A majority (174 of 278, 63%) believed MS negatively affects patients’ relationships with their families; 77% (214 of 278) of respondents believed MS makes work difficult for patients; and 73% (202 of 278) of respondents considered walking/mobility problems to be the most debilitating factor of MS. Furthermore, 86% (239 of 278) of respondents were unaware of any treatments for MS and 58.6% (163 of 278) of respondents believed the disease to be fatal.

**Conclusions:** Public perceptions of MS are fair, with general understanding of the symptoms associated with the disease and accurate descriptions of how MS can impact patients’ lives. Large gaps remain, however, in public understanding, particularly with regard to knowledge of symptomatology, available treatments, impact on family life, and cost.

## Background

- MS requires a comprehensive and integrated therapeutic approach involving input from patients, healthcare providers, families, and patient support groups.<sup>1</sup>
- Effective communication and coordinated care are critical components of MS treatment that can be improved with greater input from patients and their families.<sup>2</sup>
- Cost containment, accurate and timely diagnosis, and medication adherence are significant concerns for MS patients, their families, and their physicians.<sup>3-5</sup>
- Managing the symptoms associated with MS is a continuous challenge for patients and their caregivers that influences treatment courses, quality of life, and healthcare costs.<sup>4,6</sup>
- MS patients report unsatisfactory communication, understanding, and counseling from their physicians and a disconnect between their experiences with the disease and how MS is managed in clinical practice.<sup>7,8</sup>

## Methods

- A web-based population survey was conducted in 350 American adults across all regions, education levels, and socioeconomic backgrounds in 2015.
- Respondents were asked 18 questions on their familiarity, experience, and perceptions of MS and the disease’s impact on diagnosed patients.
- Data were recorded online and pooled for analysis and presentation in January 2016.

## Results

- 350 respondents received the survey, with 306 total responses collected (55.2% female). Not all respondents answered each question.
- Less than half (44.2%; n=123/278) of respondents knew someone with MS and fewer than one-third (29.2%; n=36/123) of patients discussed their disease with respondents. (**Table 1**)
- The majority of those polled (86.0%; n=239/278) were not aware of specific MS treatments and 68% (n=189/278) believed there was no cure for the disease. (**Table 1**)

Table 1 – Reported Perceptions of MS

Question (n=278)	Yes	No
Do you know anyone with MS?	44.2%	55.8%
If yes, have they ever discussed their MS with you? (n=123)	29.2%	70.8%
Are you aware of treatment currently available for MS?	14.0%	86.0%
Do you beleive there to be a cure for MS?	32.0%	68.0%
Do you beleive MS to be fatal?	58.6%	41.4%

Figure 1 – Reported Familiarity with MS

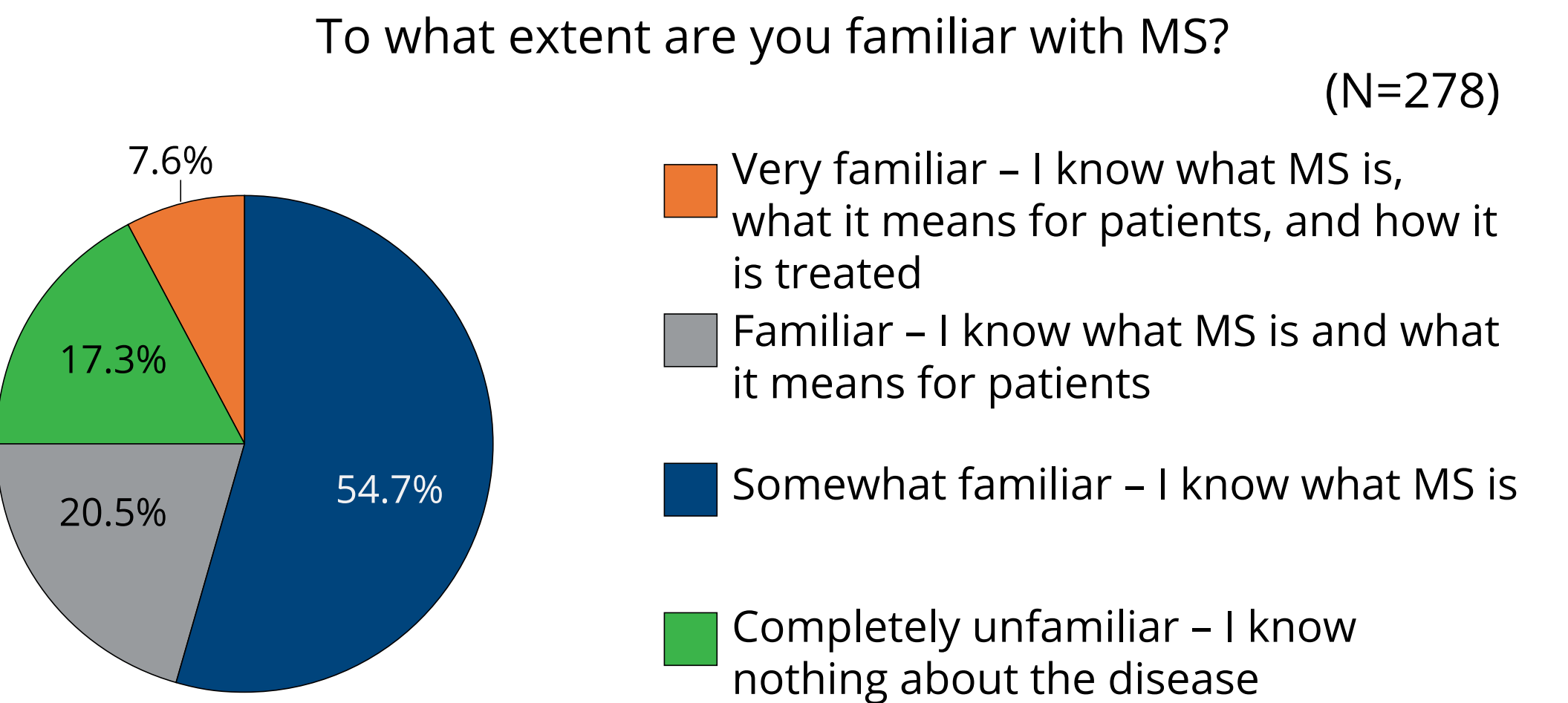


Figure 2 – Most Debilitating Factors of Life With MS

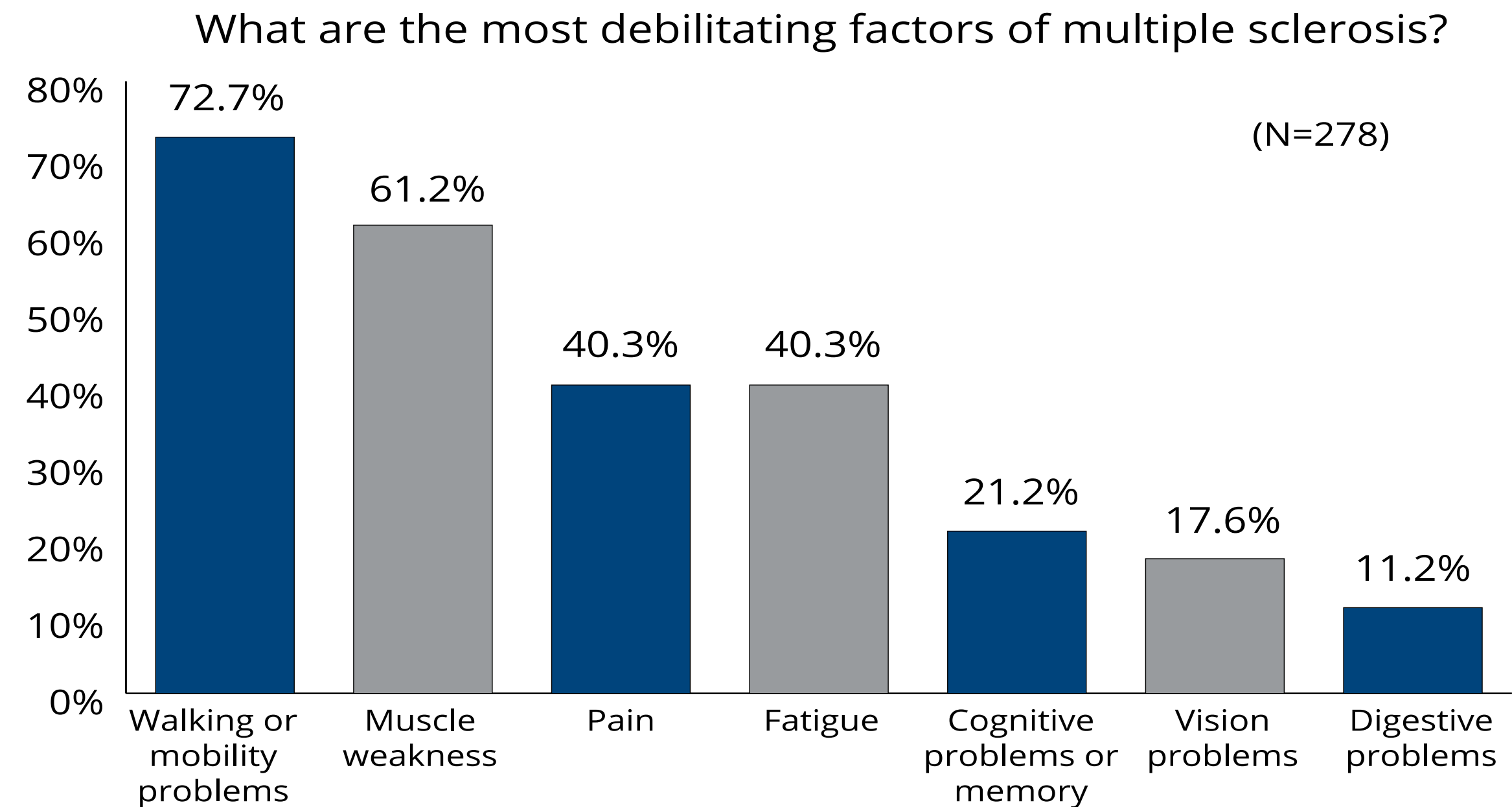


Figure 3 – Most Difficult Aspect of MS Treatment

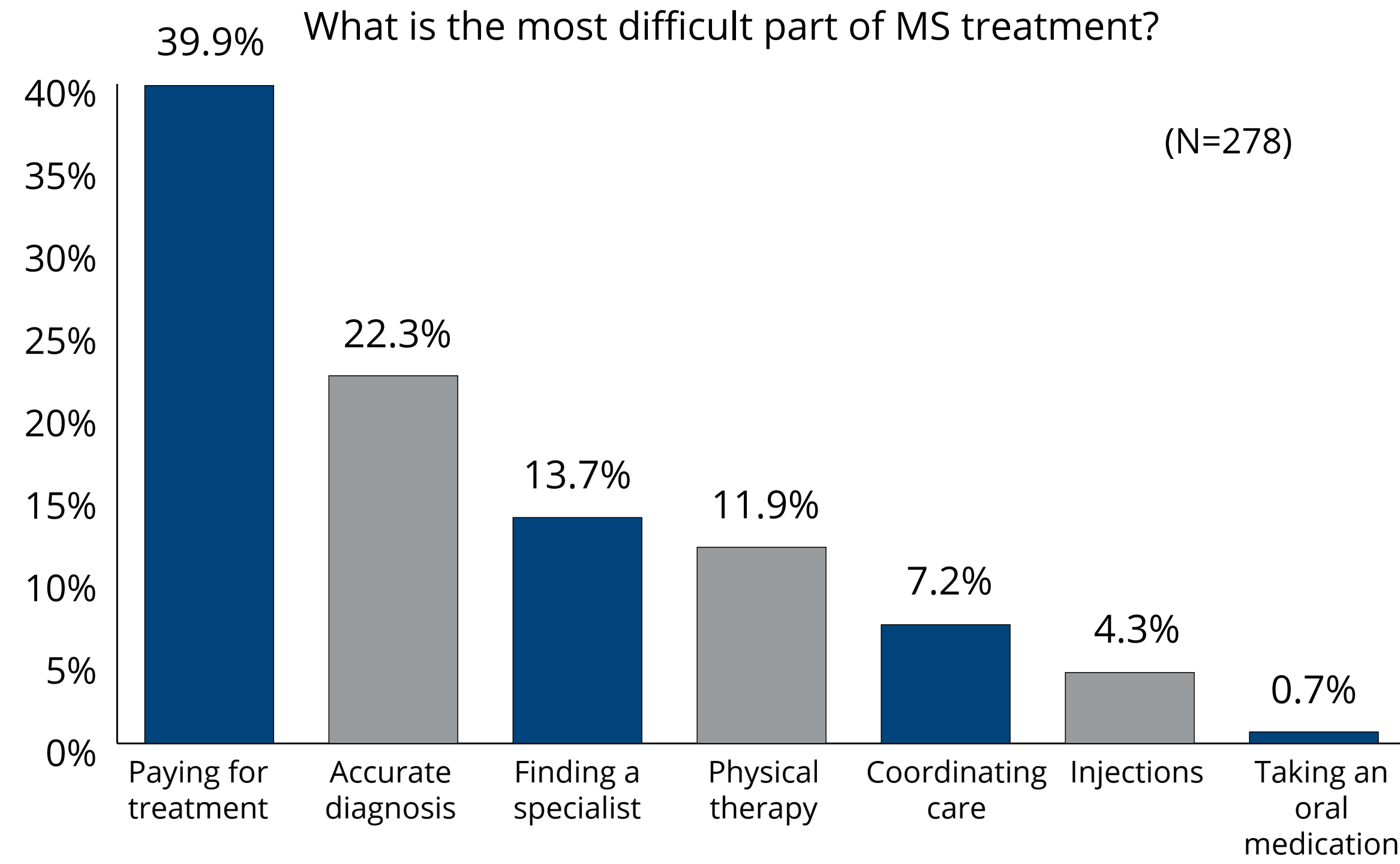


Figure 4 – Impact on Patient Daily Life

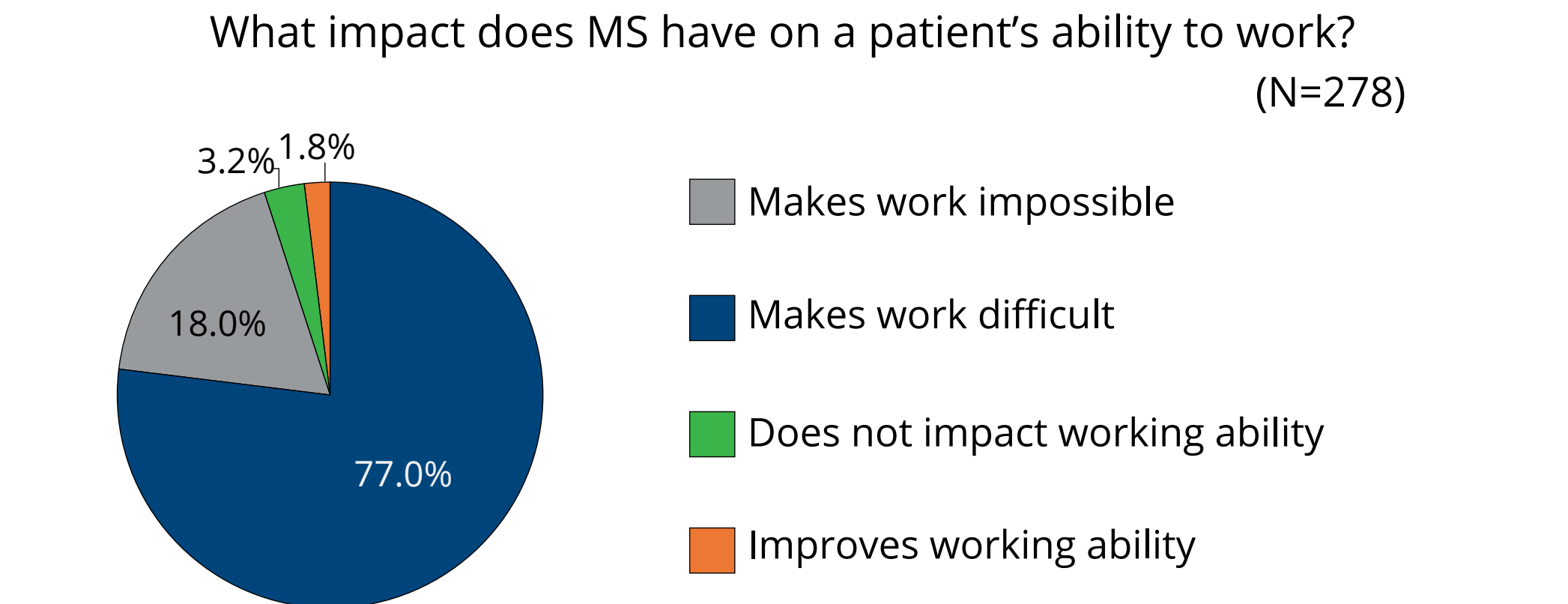
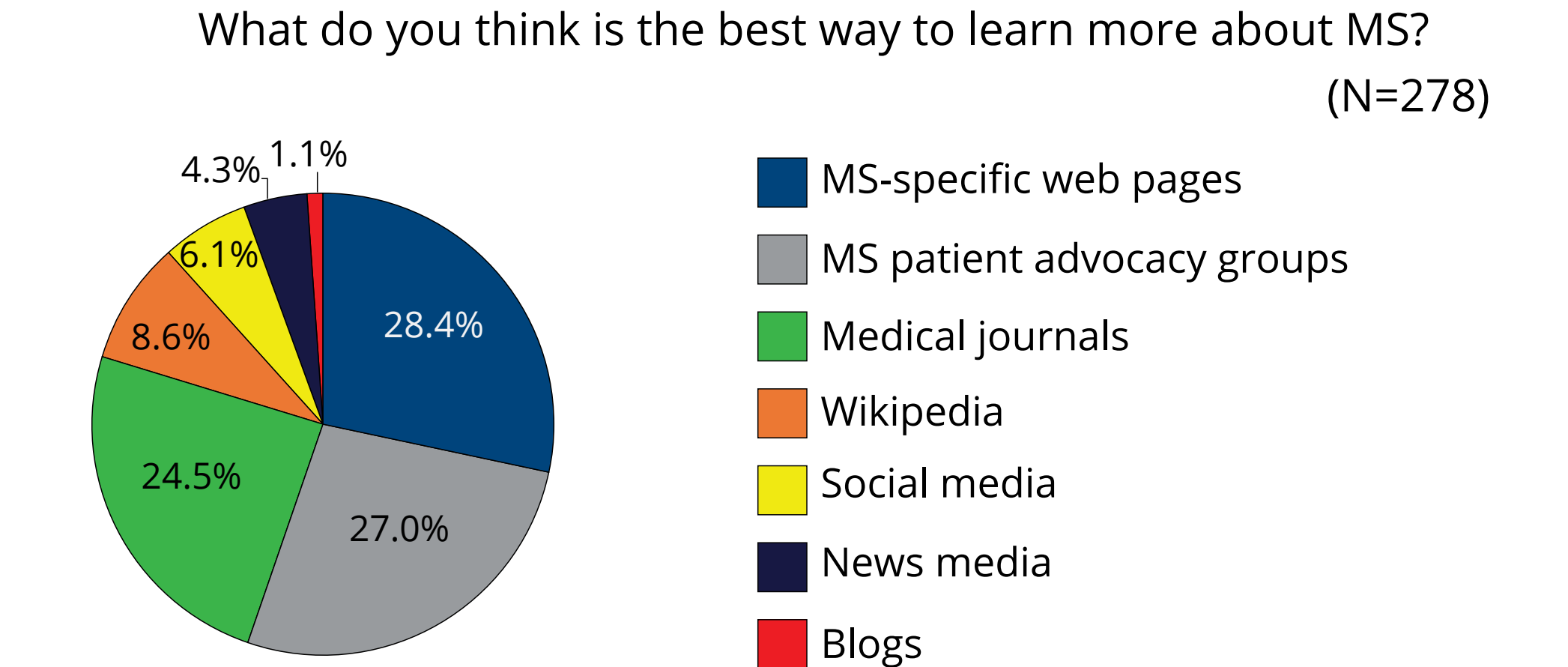


Figure 5 – Impact on Patient Daily Life



## Conclusions

- Most people surveyed are familiar with MS and its impact on patients’ daily lives.
- Perceived symptoms of MS align closely with those reported in clinical studies.
- High costs, correct diagnosis, and identifying the appropriate healthcare provider are believed to be the most difficult aspects of MS treatment.
- Digital forums, MS patient advocacy groups, and peer-reviewed publications are considered the best ways for the general public to learn more about MS.

## References

- Ross AP, et al. Effective multiple sclerosis management through improved patient assessment. *J Neurosci Nurs*. 2008;40(3):150-157.
- Ross AP. Management of multiple sclerosis. *Am J Manag Care*. 2013;19(16 Suppl):s301-s306.
- Ivanova JJ, et al. The cost of disability and medically related absenteeism among employees with multiple sclerosis in the US. *Pharmacoeconomics*. 2009;27(8):681-691.
- de Seze J, et al. Patient perceptions of multiple sclerosis and its treatment. *Patient Prefer Adherence*. 2012;6:263-273.
- Mathis AS & Owens GM. Implications for multiple sclerosis in the era of the Affordable Care Act: the shifting managed care landscape. *Am J Manag Care*. 2014;20(11 Suppl):S242-S253.
- Ytterberg C, et al. Perceived needs and satisfaction with care in people with multiple sclerosis: a two-year prospective study. *BMC Neurol*. 2008;8(1):36-39.
- Forbes A, et al. What people with multiple sclerosis perceive to be important to meeting their needs. *J Adv Nurs*. 2007;58(1):11-22.
- Davies F, et al. “You are just left to get on with it”: qualitative study of patient and carer experiences of the transition to secondary progressive multiple sclerosis. *BMJ Open*. 2015;5(7):e007674-10.

