

Effect of Multiple Sclerosis on Daily Activities, Emotional Well-being, and Relationships

The Global vsMS Survey

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Background: The vsMS survey was conducted to better understand the negative effects of fatigue, cognitive impairment, emotional burden, and decreased physical functioning on the personal, professional, and social lives of individuals with multiple sclerosis (MS).

Methods: The vsMS survey was an online survey conducted in Australia, Canada, France, Italy, Spain, the United Kingdom, and the United States that assessed the impact of MS on individuals' daily activities, emotional well-being, relationships, and employment.

Results: The survey included 1075 participants with relapsing-remitting MS. Almost 42% of participants reported that their ability to perform and manage daily activities had worsened during the previous 2 years. More than 50% reported limitations in daily activities due to fatigue, physical weakness, problems with balance/coordination, heat/cold sensitivity, memory problems, numbness/tingling, trouble concentrating, impaired movement/muscle stiffness, and impaired sleeping. Participants also reported a negative effect on emotional and social factors, including self-esteem, general outlook, well-being, maintaining/starting relationships, ability to progress in their career/keep their job, and ability to cope with life roles.

Conclusions: These data highlight the importance of addressing the impact of MS and the social and emotional disease burdens on daily activities when planning the care of patients with MS. *Int J MS Care.* 2020;22:158-164.

Chronic symptoms of multiple sclerosis (MS), which may be independent of relapse, such as fatigue, cognitive impairment, affective disorders, emotional burden, and diminished physical functioning, considerably affect the daily lives of people with MS and may interfere with social and quality of life (QOL) factors.^{1,2} For example, individuals

with MS report significantly worse health-related QOL (HRQOL) compared with the general population.³ Several aspects of QOL, including friendships, family relationships, and occupational status, are affected by MS.⁴ Low income is more common in people with MS, particularly those with either somatic or psychiatric comorbidities,⁵ and persons with somatic comorbidities have

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increased rates of broken relationships.⁵ Furthermore, individuals with MS may have impaired coping strategies compared with healthy individuals, independent of disability level.^{6,7}

Fatigue is one of the most common symptoms of MS⁸ and can have a profound impact on QOL and activities of daily living (ADLs).⁹ Cognitive dysfunction is another common, debilitating symptom of MS¹⁰⁻¹²; verbal and visual memory, working memory, and executive functions may be impaired in people with MS.¹³ Cognitive dysfunction affects the everyday lives and employment status of people with MS and can be further compounded by depression, anxiety, and fatigue.^{10,14} Cognitive dysfunction and fatigue are important factors in the impact of MS-related physical disability on employment status.¹⁴

The international vsMS survey assessed the impact of MS on ADLs, emotional well-being, and relationships. A better understanding of these aspects of disease burden among health care providers, individuals with MS, and their care partners may enhance patient care and improve patient QOL.

Methods

Enrollment and Protocol

The survey was conducted during July and August 2015. Individuals with relapsing-remitting MS (RRMS) or care partners who assist in the care of someone diagnosed as having RRMS were enrolled. Recruitment of people with RRMS was not limited to those with a care partner who was willing to participate. To be eligible for the study, participants with MS had to self-report via screening questions that they were 18 years or older, literate in the local language, and diagnosed as having RRMS. The survey was completed by 1075 participants with MS and 580 care partners. The data reported herein are for participants with RRMS and do not include those for care partners, which will be published elsewhere. Individuals were identified and enrolled via survey panels managed by a third party, Kantar Health (New York, NY). Panelists were enrolled via Kantar Health through opt-in e-mail, co-registration with MySurvey.com and partners, eNewsletter campaigns, banner placements, and internal and external affiliate networks. Panelists were limited to 12 surveys per year to reduce the likelihood of respondent fatigue. To decrease the likelihood of bias due to self-selection for participation, the details of the study were not shown in the invitation but were first viewed as part of the informed consent. Panelists signed into the survey through a unique e-mail address and password.

The survey was overseen by a steering committee of MS expert clinicians. All study participants provided informed consent electronically, indicating that they had been informed of all pertinent aspects of the study. The vsMS study protocol

was reviewed and granted an exempt determination by Pearl IRB (Indianapolis, IN).

Survey Instrument

The survey questions were developed based on questions and direction provided by the steering committee. Medical representatives from each country where the survey was administered also provided their input on the questions. The steering committee reviewed, edited, and approved the final questionnaire. Information was collected from respondents who met the study inclusion criteria using a self-administered, internet-based questionnaire. The questionnaire began with screening questions to determine eligibility to participate in the study. Qualifying respondents were asked questions about their demographic characteristics, disease history, treatment history, MS symptoms, MS-related QOL, and the effect of MS on activities and relationships. Treatment-related information was collected only from respondents in Australia, Canada, and the United States because treatment-related questions were not permitted by European regulatory committees. The questionnaire took approximately 20 minutes to complete. There were 42 main survey questions and six demographic questions.

Data Processing, Management, and Availability

Data entry was completed instantaneously as the respondents answered the survey questions. The database, which houses the questionnaire responses, allowed for direct export into statistical software. MySurvey.com and its panel partners did not release any identifying information about their panel members other than a single panel ID number; therefore, the working data files contained no other distinguishing information apart from the panel ID number.

Qualified researchers may request access to participant-level data and related study documents. Participant-level data will be anonymized and study documents will be redacted to protect the privacy of participants. Further details on Sanofi's data-sharing criteria, eligible studies, and process for requesting access can be found at the ClinicalStudyDataRequest.com website.

Results

Participant Characteristics

The vsMS survey was completed by 1075 participants with RRMS. Participants were from Australia (5%), Canada (5%), France (6%), Italy (11%), Spain (7%), the United Kingdom (9%), and the United States (56%). In this population, 21.8% of participants were diagnosed less than 5 years before participation in the survey, 25.6% were diagnosed within 5 to 9 years, 21.8% were diagnosed within 10 to 14 years, and 18.2% were diagnosed within 15 to 21 years (Table 1). Of the participants, 12.6% were diagnosed before 1994 (>21 years), the first full year that an MS disease-modifying therapy (DMT) (subcutaneous interferon [IFN]

Table 1. Characteristics of participants with relapsing-remitting multiple sclerosis (N = 1075)

Age at symptom onset, y	
Mean \pm SD	31.2 \pm 10.1
Median [range]	30 [3-65]
Time since diagnosis	
<5 y	234 (21.8)
5-9 y	275 (25.6)
10-14 y	234 (21.8)
15-21 y	196 (18.2)
>21 y	136 (12.6)
Relapses in past 12 mo ^a	
0	507 (47.2)
1	300 (27.9)
2	134 (12.5)
>2	134 (12.5)
Living situation	
Living with spouse/partner	440 (40.9)
Living with spouse/partner and children	333 (31.0)
Living alone	152 (14.1)
Living with parents	62 (5.8)
Other	88 (8.2)
Employment status ^b	
Employed	554 (51.5)
Full-time	380 (35.3)
Part-time	122 (11.3)
Self-employed	52 (4.8)
On long-term disability	195 (18.1)
Retired	181 (16.8)
Homemaker	102 (9.5)
Unemployed	83 (7.7)

Note: Values are given as number (percentage) unless otherwise indicated.

^aSums of values shown do not equal 100% due to rounding.

^bValues exceed 100% because respondents could choose more than one category.

beta-1b) was available in any of the countries in which the vsMS participants resided (Table 1).

Diagnosis and Treatment

Most participants reported consulting a neurologist within a year of first noticing MS-related symptoms (66.6%) and being diagnosed within a year of the first neurologist visit (61.9%) (Table S1, which is published in the online version of this article at ijmsc.org). Participants who did not report diagnosis of MS immediately after consulting their doctor had the option of reporting delay in diagnosis as a subjective determination, along with one or more reasons for such delay. The most common reasons reported for delay in diagnosis were misdiagnosis (32.9%) and inconclusive preliminary testing (30.3%) (Table S1). After diagnosis, 66.0% of participants reported that their neurologist recommended initiating treatment immediately (Table S1). Overall, 38.6%

of participants reported that they began immediate treatment (Table S1). For participants from the United States, Australia, and Canada, the top reasons selected for delaying treatment were no MS medications available when diagnosed (15.8%), neurologist recommended waiting (15.0%), thinking they do not need treatment (12.6%), wanting to see how they felt without taking medication (11.5%), and wanting to avoid medication adverse effects (9.1%). Ninety-six percent of survey respondents had previously used or were currently using a DMT. The most common DMTs used at the time of the survey included glatiramer acetate (19.2%), dimethyl fumarate (15.6%), fingolimod (10.7%), intramuscular IFN β -1a (8.8%), natalizumab (8.2%), and subcutaneous IFN β -1a (7.4%) (Table S1). Fourteen percent of participants reported that they were not receiving any treatment at the time of the survey, and 4.1% were treatment naive (Table S1).

Participants were asked questions to ascertain their level of disease severity and disability. Most participants (64.3%) reported being told during the previous year by their neurologist that they had stable disease (15% were told that their disease had worsened, 15% were not told either way, and 5.8% did not know). Of note, 52.8% of participants reported having one or more relapses in the previous 12 months, and 25% reported having two or more relapses (Table 1). Half of the participants were employed: 35.3% full-time, 11.3% part-time, and 4.8% self-employed (Table 1). A total of 7.7% of participants were unemployed without any disability leave, 16.8% were retired, and 18.1% were on long-term disability leave (Table 1). A total of 71.9% of participants lived with a spouse (with or without children), and 14.1% of the respondents lived alone (Table 1). Among all respondents, 45.2% reported minimal impact on their activities due to MS symptoms, whereas 54.8% reported more substantial impact on their ADLs due to MS symptoms (Table 2). Of note, only 17.2% of ambulatory respondents reported requiring a mobility aid regularly, and 3.7% were limited to a wheelchair as their primary form of mobility (Table 2). The proportion of participants who required walking support or used a wheelchair generally increased with increasing disease duration (Table S2). A wheelchair was the primary form of mobility for 11.8% of patients who were diagnosed as having MS more than 21 years before the survey date, and only 0.9% of patients were diagnosed less than 5 years before the survey date (Table S2).

Table 2. Current disease situation

Description	Patients, %
I may have some mild symptoms, mostly numbness or tingling due to MS, but they do not limit my activity. If I do have an exacerbation, I return to normal when my flare has passed.	25.0
I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle and have required minimal adaptations.	20.2
I do not have any limitations in my walking ability. However, I do have significant memory loss/trouble multitasking and/or fatigue-related problems due to MS that limit daily activities in other ways.	15.4
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 do not need a cane or other assistance to walk, but I might need some assistance when fatigued.	18.4
I use a cane or 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/8 m) 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.	17.2
My main form of mobility is a wheelchair. I may be able to stand and/or take 1 or 2 steps (25 feet/8 m), even with crutches or a walker.	3.7

Abbreviation: MS, multiple sclerosis.

Effects of MS

Activities of Daily Living

Many participants reported that their ability to perform and manage ADLs had recently worsened during the previous 6, 12, and 24 months (Figure 1). A total of 41.7% of participants reported worsening in their ability to perform ADLs during the previous 24 months, whereas 14.1% of respondents reported worsening during the previous 6 months (Figure 1). Patients with longer disease duration were less likely to report improvements at all three time points (Table S3). Participants reported that their ability to perform ADLs was limited by many different disability-related factors. Factors that were reported to limit ADLs in 50% or more of patients included the following (% overall/% severely

limiting): fatigue (75.5%/17.9%), physical weakness (68.3%/9.9%), problems with balance/coordination (60.6%/12.7%), heat/cold sensitivity (59.4%/16.5%), issues with memory (53.5%/8.4%), numbness/tingling (53.0%/7.6%), trouble concentrating (52.4%/7.5%), trouble moving/muscle stiffness (51.9%/9.1%), and trouble sleeping (51.4%/7.6%) (Figure S1). There was a trend for patients with longer disease duration to report a greater impact of physical symptoms such as fatigue, physical weakness, problems with balance and coordination, and heat/cold sensitivity (Table S4). Other factors reported to limit ADLs included trouble multitasking (49.3%), depression or anxiety (47.5%), muscle spasms (46.6%), and mood swings (46.2%) (Figure S1). Approximately half of the participants reported impaired cognitive functions such as memory and concentration that limited ADLs (<23% reported memory and concentration difficulties that did not limit ADLs). Forty-two percent of participants reported a negative impact of MS on information processing (Figure S2). Furthermore, 34.7% of participants reported that urinary problems were a factor in the decisions they made when planning to leave the house.

Physical and Emotional Well-being and Social Interactions

Most participants (70.5%) reported that progression of their disease and potential future disability were their greatest concerns. Since being diagnosed as having RRMS, many participants reported negative changes regarding emotional and social factors, including to their future outlook (48.5%), emotional well-being

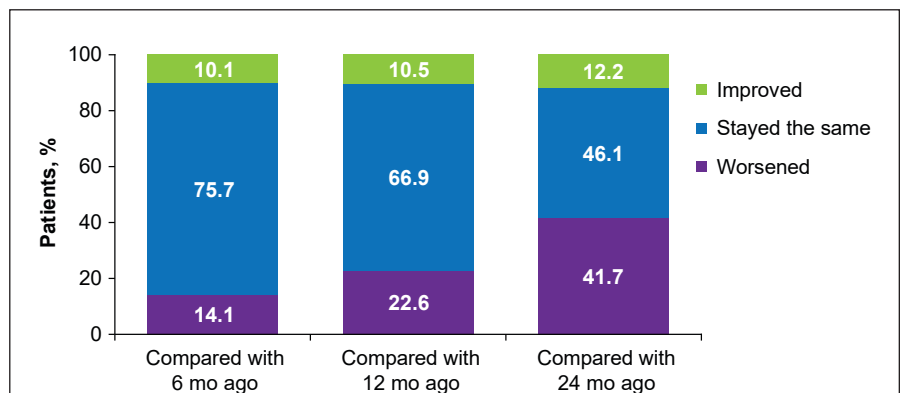


Figure 1. Proportion of participants with changes in activities of daily living (ADLs)

Participants were asked to think about their ability to perform and manage ADLs today and whether it has improved, stayed the same, or worsened compared with 6, 12, and 24 months earlier.

(43.5%), ability to cope with stress (39.3%), self-esteem (34.9%), and relationships with friends (25.1%) and family (15.9%) (Figure S2). Energy level was most commonly reported as being negatively affected (72.7%) (Figure S2). Participants also reported a negative effect on physical functioning (60.3%) (Figure S2). They also reported that MS affected their ability to progress in their career (50.0%) and keep a job (64.2%). Slightly more participants with more than 5 years' disease duration seemed to be affected negatively by energy level, physical functioning, or the ability to progress in their career, but there was no apparent relationship between disease duration and the ability to keep a job (Table S4). A negative impact of RRMS on participants' relationships was reflected in concerns relating to sexual attractiveness (43.9%), fear that their partner may leave (25.5%), and role regarding family, friends, and work (33.9%) (Figure S2). In addition, more than half of all respondents (68.3%) reported that most of their MS symptoms are hidden and that most people do not know that they have MS; and more than one-third (35.3%) of participants reported that they go out of their way to keep their MS private and hidden from most people in their day-to-day life.

Discussion

Neurologists use outcome measures such as relapse rate, physical disability, and magnetic resonance imaging activity to assess disease status and response to treatment for patients with MS. The objective of the present study was to understand the impact of MS symptoms on the daily lives of individuals with RRMS from their perspective, including the symptoms that are most bothersome and the activities that are most affected. The results reported herein demonstrate the extensive effect of MS on the overall well-being of persons with MS, including emotional, cognitive, and social factors in a large sample of individuals with RRMS. Based on respondents' assessments of their current disease level (Table 2), very few participants (3.7%) were wheelchair dependent, and the rest were distributed relatively equally among less severe levels of disease. Although higher levels of disability are associated with worse HRQOL,¹⁵ the results reported herein suggest that common aspects of emotional and social well-being are negatively and substantially affected in individuals across a spectrum of MS-related disability levels. This study shows that relationships and social aspects of life often suffer as a result of MS and, there-

fore, need to be considered when assessing a patient's well-being.

More than half of the participants reported physical symptoms that negatively affected ADLs, such as weakness, problems with balance/coordination, heat/cold sensitivity, numbness/tingling, and trouble moving/muscle stiffness; most patients also reported fatigue and low energy. Fatigue and reduced energy level may exacerbate physical and cognitive symptoms of MS.¹⁴ Consistent with other reports,¹⁶ we observed that cognitive dysfunction developed in approximately half of the participants. Approximately half of the respondents (51.4%) reported trouble sleeping, which may have an effect on energy level and cognitive dysfunction.¹⁷ The fact that fatigue may not be readily apparent to family members and colleagues as a symptom of MS may also add strain to patients' social interactions and work life. Deterioration in the ability to keep a job (64.2%) was the second-most commonly reported negative effect of MS, and 50% of respondents reported that MS negatively affected their ability to progress in their careers. The combined effects of fatigue, cognitive dysfunction, and physical impairment are likely to affect employment status,^{1,9} which may, in turn, be related to a reported detrimental effect of RRMS on financial well-being (40.2%) (Figure S2). In addition to MS disease burden, these results were also likely influenced by how important an occupation/career is to a respondent's identity. Although data on the percentage of respondents who are the primary earner of their household were not collected, it would be interesting to further study whether primary earner status affects perceptions of disease burden. Similarly, fatigue and cognitive dysfunction, which are invisible symptoms of MS, when coupled with physical impairment may negatively influence other factors, such as outlook, emotional well-being, ability to cope with stress, and self-esteem—all of which may affect, and in turn be affected by, employment/career status, especially because individuals with MS are also likely to have impaired problem-solving and coping skills.^{6,7} Indeed, invisible symptoms of MS are more predictive of health distress and can negatively affect the social lives of persons with MS.^{18,19}

Depression and anxiety (47.5%) and mood swings (46.2%) may be directly due to MS pathology or to medication adverse effects (eg, interferon) or may be comorbidities that are influenced by other MS burdens, such as inability to perform ADLs and relationship issues.²⁰ Depression and anxiety may also, in turn, affect

the manifestation of MS symptoms and the performance of ADLs and may accentuate relationship and social concerns. Problems with communication skills and cognitive deficits may underlie some of the social difficulties observed in individuals with MS.^{21,22} These social factors may also affect perceptions of disease burden.

Despite 64.3% of respondents reporting that their neurologists had characterized them as having stable disease in the past year, and most respondents (86%) being treated with a DMT at the time of the survey, 70.5% of participants reported that progression of their disease and potential future disability were their greatest concerns. This likely reflects the anxiety associated with living with a chronic disease.

The results of this study are in line with those of other studies examining the impact of MS on HRQOL but provide a greater understanding of the components that contribute to the burden of MS in a real-world setting.^{1-4,14,23} The insights gained from this study could be used to design additional measures of MS disease activity that specifically measure patients' perceptions of how their disease affects their social status, using factors such as those highlighted in Figure S2. The results of the US survey (56% of the entire vsMS survey population) were comparable with the results from the entire population.²⁴ As with all self-administered questionnaires, a limitation is the necessity for accurate responses. People

with longer disease duration may potentially have recall or selection bias, especially for questions relevant to the time when they were first diagnosed. In addition, the vsMS survey questions were not validated, which limits the generalizability of the results. Last, we limited the survey to individuals with RRMS because the most burdensome symptoms and their effect on ADLs may differ compared with progressive forms of MS.

Health care providers should include emotional and social factors when assessing the overall well-being of their patients with MS and should consider these, in addition to clinical relapse and disability, when delivering optimal care. It is important for providers to understand the full spectrum of disability, including the cognitive and emotional aspects, to facilitate effective communication when planning a treatment regimen. Health care providers should specifically ask about psychosocial issues that may be affecting their patients' well-being, and perhaps spend more time assessing the overall health of their patients with MS than is typical for other neurologic diseases. Patients might not be aware that some of their emotional and social difficulties are due to, or compounded by, their MS. Ultimately, optimal care of patients with MS should incorporate objectives not only for reducing the physical symptoms but also for improving QOL measures such as those reported in this study. A partnership between the multidisciplinary health care team and the patient with MS is key to better understanding and mitigating the multifaceted total burden of disease. □

PRACTICE POINTS

- The vsMS survey was administered to participants with relapsing forms of MS; more than half of all individuals in the vsMS survey reported physical symptoms that negatively affected daily activities, such as fatigue, weakness, and problems with balance/coordination, as well as memory problems and trouble sleeping.
- Participants with relapsing-remitting MS also reported that MS negatively affects their emotional and social well-being, and they expressed concerns about future disability, relationships, and employment.
- These data highlight the need for health care providers to carefully consider emotional and social well-being when assessing the needs of patients with MS, although this could be challenging due to the limited time available for patient visits.

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MISSION STATEMENT

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