Assessing Access to Five Types of Insurance by People with Multiple Sclerosis Using a Cross-sectional Online Survey

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Practice Points

- Most people with MS have health insurance but lack other important insurance coverage, including short-term disability insurance, long-term care insurance, or life insurance, although it is possible to obtain them after an MS diagnosis is made.

- This research suggests that a proportion of those with MS are unsure about their eligibility for Social Security Disability Insurance.

- Health care providers may consider the value of making their patients aware of these insurance types and offer educational resources. Multiple sclerosis advocacy and wellness organizations should consider including information about this important topic as part of their portfolios. The National Multiple Sclerosis Society is a highly reliable source for information about these insurance types and obtaining them.
Abstract

Background: Many individuals with multiple sclerosis (MS) depart the workforce prematurely. In the United States, access to insurance, including health, disability income, long-term care, and life insurance, is largely employment-based or purchased from earnings. Many individuals we see in the clinic experience financial hardship because of a lack of insurance, even if working. We sought to determine the proportion of workers who are financially protected through insurance coverage and the sources of this coverage in a large sample.

Methods: We developed an online survey and opened it to individuals aged 18 to 65 years registered with the North American Research Committee on Multiple Sclerosis, iConquerMS, or the National Multiple Sclerosis Society Minority Advisory Council. Data collected included demographic and disease characteristics, current information about each insurance type (coverage vs no coverage), and when the current insurance policies were obtained relative to MS diagnosis.

Results: Of 2507 survey respondents, 82.9% were female, 3.8% Hispanic/Latino, and 91.2% White. The mean ± SD age was 53.5 ± 8.5 years and disease duration was 16.4 ± 8.5 years after diagnosis. The most frequently held insurance types were health (96.3%) and life (58.8%). Only 9.7% of respondents had long-term care insurance. Except for life insurance, most current policies were obtained after MS diagnosis.

Conclusions: Individuals with MS might not prioritize the possible short- and long-term benefits of these types of insurance. Health care providers can direct patients to nonprofit agencies that educate about of these insurance types and emphasize that others with MS have obtained these insurance types after their diagnosis. Int J MS Care.
Introduction

Working-age adults in the United States most often access health, short-term disability, long-term disability, long-term care, and life insurance through employer-based group insurance plans.\(^1\)\(^-\)\(^3\) When individuals become unable to work, they often lose the income and care protection provided by these insurance policies.\(^3\)\(^-\)\(^7\) Loss of insurance access is a particular concern for individuals with chronic progressive diseases, including multiple sclerosis (MS). A 2016 US study\(^8\) demonstrated that people with MS with even a low level of disability using the Expanded Disability Status Scale (EDSS) may be limited or unable to participate in gainful employment. That study demonstrated that compared with respondents with EDSS scores less than 3 (minimal disability), those with EDSS scores of 3 to 5 (moderate disability affecting daily activities but still able to walk) were twice as likely to be unable to work due to MS, and those with EDSS scores greater than 5 (at least moderate gait impairment) were more than 12 times more likely to be disabled. This loss of employment has lifelong consequences that could be mitigated by having the types of insurance coverage studied herein. In 2011, Noyes\(^9\) estimated that annual indirect costs of having MS for US residents averaged $19,733 (2011 dollars) per individual from missed work, underemployment, and episodes of unemployment due to disability. The estimated indirect yearly cost for individuals with severe disability and who are dependent on personal care assistance has been valued at $100,000.\(^10\)

Significant changes in the economic landscape, particularly after the 2008 recession, have negatively affected employment status, resulting in less access to all forms of insurance.\(^6\)\(^,\)\(^11\) Although passage of the Affordable Care Act ensured access to health insurance coverage
regardless of preexisting illness, there is no mandated coverage for all types of care needs. Furthermore, disabled individuals face barriers to purchasing new short- or long-term disability income insurance policies.\textsuperscript{12,13} Individuals in the United States who become disabled and do not have private short-term disability income insurance must earn less than $1260 per month for 5 months before becoming eligible for Social Security Disability Insurance (SSDI). After that period of minimal or no earnings, an individual who earned $60,000 (2011 dollars) would receive an SSDI benefit of $23,340 (39\% of previous earnings) annually.\textsuperscript{14} Individuals often are unaware that long-term personal care is not covered by health insurance policies. The cost of this care is expensive in terms of paid out-of-pocket dollars and the burden experienced by family or informal caregivers. Only individuals with long-term care insurance have coverage for this potentially overwhelming financial and personal burden. The only option for those without substantial wealth is to deplete their resources and become financially indigent and Medicaid eligible.\textsuperscript{15} For those with MS, access to life insurance may be threatened because life expectancy is reduced in persons with MS by 6 years relative to comparator individuals.\textsuperscript{16} In combination, these types of insurance, including disability and long-term care, are identified as personal insurance because they are intended to protect financial security and access to care in the case of illness.\textsuperscript{17,18} It is critical that those with MS are aware of their options for ensuring health coverage as well as personal and family financial protection.

Although many individuals are aware of SSDI and other federal programs, they may not be aware of waiting periods or limitations on benefits.\textsuperscript{19} Although insurance literacy\textsuperscript{20-23} has received increased attention, studies concerning knowledge about personal insurance options have been sparse. The goals of this study were to determine the health and personal insurance status of community-residing, working-age individuals with MS; identify characteristics of those
at risk for not having such insurance; and determine whether those with insurance obtained coverage before or after their MS diagnosis. These results will help inform health care providers about the importance of these types of insurance and highlight the need for patient advocates and wellness organizations to target educational interventions about these insurance types.

Methods

Survey Development and Testing

A multistage process was used to develop and test an online survey. We began by conducting structured focus groups with people with MS (n = 36) and their support partners (n = 24) in Washington, Texas, Ohio, and North Carolina. The Cleveland Clinic institutional review board approved the protocol for these focus groups. Staff from local chapters of the National Multiple Sclerosis Society (NMSS) recruited focus group members, who received advance copies of the informed consent document and completed in-person consent before the start of the groups. In each group, three major areas of concern emerged: securing coverage, uncertainty about coverage and costs, and consequences of maintaining coverage.

The survey was reviewed by a separate, in-person, expert panel of nine working-age adults diagnosed as having MS (six women and three men). Panel participants were recruited from the NMSS and from iConquerMS of the Accelerated Cure Project for Multiple Sclerosis,24 a research network initially funded by the Patient-Centered Outcomes Research Institute. Informed consent for the panel was similar to that used for the focus groups.
Validation and field testing of the online survey occurred at Cleveland Clinic. Staff at the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry, a voluntary self-report registry for people with MS,25 programmed and managed the survey.

Survey Content

Detailed descriptions of each insurance type were provided. Respondents provided information about their current insurance status, demographic characteristics (age, sex, race, ethnicity, marital status, and employment), and health status (overall health, smoking status, current MS type, MS care provider type, disease duration, and Patient-Determined Disease Steps score). Patient-Determined Disease Steps,26,27 a standardized patient-reported measure based primarily on ambulation status, was used to assess functional disability on an ordinal scale with scores ranging from 0 (normal) to 8 (bedridden). Those with a current policy of each type were asked about the source of that insurance and whether the policy was obtained before or after MS diagnosis. Respondents were then presented only those survey sections relevant to their insurance status. In addition, eligibility for SSDI was asked of all respondents and reported independent of private long-term disability income insurance. The number of items answered on the survey varied by skip logic related to the types of insurance a respondent had. The full survey is available on request.

Inclusion Criteria and Study Support
Inclusion criteria were as follows: US permanent residents and citizens, regardless of work status or types of insurance owned; aged 18 to 65 years; and registered with any one of three groups: NARCOMS, iConquerMS, or the NMSS Minority Advisory Council. They were informed about the survey through the organizations’ typical survey recruitment methods. This was a convenience sample. The online survey was available between August and November 2017. Respondents were limited to completing the survey only once even if they participated in more than one of the organizations. The institutional review board at the University of Alabama at Birmingham considered the study to be minimal risk and granted a waiver of informed consent. Patient rights information was included at the beginning of the survey.

Statistical Analysis

Descriptive measures are presented as number, percentage, mean, and SD, as applicable. Univariate comparisons for those with and without a type of policy were made for categorical covariates using likelihood ratio, $\chi^2$, or Fisher exact tests, and for continuous covariates using analysis of variance or Wilcoxon tests. Because respondents could own more than one type of insurance policy, no statistical comparisons are made across types of policies; only observational results are reported between types of insurance.

Odds ratios (ORs) with 95% CIs for the likelihood of having or not having a type of insurance were estimated using covariate-adjusted nominal logistic regression. Covariates considered for all insurance types included demographics, employment status, and MS and other health characteristics. Demographic variables were categorized as follows: current age (<40, 40-49, 50-59, 60-65 years), sex, race (White vs other), ethnicity (Hispanic/Latino vs non-
Hispanic/non-Latino), and marital status (current long-term partner
[married/cohabitating/domestic partner], previous long-term partner, or never in a long-term
relationship). Employment status was categorized as full-time employment or not full-time
employment. Health characteristic variables included MS type (relapsing-remitting, secondary
progressive, primary progressive, clinically isolated syndrome, or don’t know), MS disease
duration in 5-year increments (0-5, 6-10, 11-15, 16-20, and >20 years), and overall health using a
routinely administered NARCOMS question (excellent/very good, good, fair/poor). Because
most respondents with short-term disability income insurance were employed, models for short-
term disability income insurance were stratified by full-time and non–full-time employment.
Because short-term disability and long-term disability coverage cannot be extended to a spouse,
marital status was not included in those analyses. Because life insurance policies can be extended
past divorce or separation, for these analyses only, marital status was assessed for all three
categories (current, previous, and no long-term partner). Non–statistically significant covariates
were removed for final OR estimation. Statistical analyses were performed using SAS version
9.4 and JMP Pro version 13 (SAS Institute Inc). Significance was set at α ≤ .05.

Results

Cohort Characteristics

Surveys were started by 3066 persons; 2507 respondents (81.8%) met the inclusion
criteria, provided complete demographic data, and were included for analysis (Table 1). These
2507 respondents were predominantly female (82.9%), White (91.2%), and married (69.5%).
Most were either employed full time (32.0%) or not employed or retired due to disability (46.5%). Respondents’ mean ± SD age was 53.5 ± 8.5 years. Most respondents reported relapsing-remitting MS (66.6%), a disease duration of 16 years or more (52.1%), and receiving care from private neurologists (55.4%). Most respondents described being in good health (42.0%), and a minority were current smokers (9.2%).

Types of Insurance Coverage

Health Insurance

Most respondents had health insurance (96.3%), and this group had demographic characteristics similar to the overall cohort (Table 1). For health insurance, 38.6% of respondents obtained their policy through public sources and 75.3% through private sources, with some individuals having both. Most respondents, 65.0%, obtained the health insurance policy that was providing them coverage at the time of the survey after their MS diagnosis. Of those with private coverage, most (81.9%) had employment-based coverage; 7.9% obtained their policy through health exchanges and 8.3% obtained a policy privately outside of an exchange (Table 2). Most respondents with employer-based insurance (65.1%) were eligible based on their own employment status (Table S1, which is published in the online version of this article at ijmsc.org). Of the 81.9% of respondents who reported having health insurance coverage through an employer or a union, 65.1% obtained the insurance through their own employment and 28.7% obtained coverage through their spouse’s employment. Of women who were married and had health insurance, 52.3% carried their own coverage and 43.7% were covered by their spouse.
Because of the dominance of employment status, there were very limited associations between sociodemographic characteristics or disease status and having health insurance. The number of individuals without health insurance was too low (94 of 2507 [3.7%]) for logistic regression analysis to be performed for that group.

**Short-term Disability Income Insurance**

Fewer respondents had short-term disability income insurance (455 of 2507, 18.1%) compared with those with health insurance (2413 of 2507, 96.3%). Patients with secondary progressive MS (20.6% overall) or primary progressive MS (5.8% overall) were less likely to have this insurance (10.1% and 2.9%, respectively). Similarly, individuals in poor/fair health (30.1% overall) were less likely to have this insurance (16.0%) (Table 1). For those who did have this insurance, most (94.5%) obtained it through an employer. More than half of the respondents with this insurance (52.7%) obtained their current policy after their MS diagnosis (Table 2).

Because full-time employment was highly associated with access to this type of insurance, the multivariate regression analysis was stratified across employment status (full time vs part time or not working). Regardless of employment status, being married also was associated with an increased odds of having a short-term disability policy: for those employed full time, the OR was 1.5 (95% CI, 1.1-2.0), and for those not employed full time the OR was 4.4 (95% CI, 1.6-12.3). Generally, those with a disease duration of 20 years or less were more likely to have a short-term disability policy than those with a disease duration longer than 20 years, although the strength of association varied by employment status (Figure 1A).
**Long-term Disability Income Insurance**

Most respondents (74.3%) reported meeting the work requirements for SSDI eligibility, and of that number, 49.5% were receiving those benefits (Table 2). A smaller number of respondents (n = 666) had private long-term disability income insurance either in combination with SSDI (63.5%) or as their only long-term income protection (36.5%). Full-time employment (32.0% overall) was associated with higher rates of private long-term disability insurance (51.2%), but no other individual variables were strongly associated with this insurance type (Table 1). Most respondents (89.9%) with long-term disability income insurance obtained it through their employer. Of the individuals with long-term disability insurance, 390 (58.6%) reported obtaining their current policy after their MS diagnosis (Table 2).

Multivariate analysis demonstrated that access to long-term disability income insurance was associated with being female (OR, 1.6; 95% CI, 1.3-2.1), working full time (OR, 2.3; 95% CI, 1.9-2.7), being aged 50 to 59 years (OR, 1.6; 95% CI, 1.1-2.4), and having a disease duration longer than 6 years (Figure 1B).

**Long-term Care Insurance**

Long-term care insurance was the least frequent type of coverage (9.7%). Respondents with this insurance were more likely to be employed full time (43.8%) and less likely to be not employed or retired due to disability (38.0%) compared with the overall cohort (32.0% and 46.5%, respectively). Respondents who reported being in very good or excellent health more...
frequently had this insurance (33.9%) than the overall sample (26.6%) (Table 1). Most of those few respondents who reported having long-term care insurance either purchased it or obtained it through an employer (73.5%). Again, the number of individuals with this insurance was small, and most obtained their current coverage after the MS diagnosis (62.0%) (Table 2).

Multivariate analysis supported the increased likelihood of having long-term care insurance if employed full time, (OR, 1.4; 95% CI, 1.1-2.0) or being 60 years or older (OR, 4.3; 95% CI, 2.0-9.2). Those reporting excellent or very good health status were more likely to have long-term care insurance (OR, 1.8; 95% CI, 1.2-2.6) (Figure 1C).

**Life Insurance**

Life insurance was the second most common insurance type among respondents (58.8%). Compared with the overall cohort, those who were covered were likely to be married (75.5% vs 69.5%), employed full time (40.9% vs 32.0%), and have a disease duration of 5 years or less (40.5% vs 9.8%) (Table 1). Having life insurance was associated with having a spouse and being employed, although most respondents purchased life insurance privately (62.7%). A current policy for life insurance was the least likely insurance type to be purchased after the MS diagnosis, perhaps because of competing financial responsibilities or underappreciating the long-term consequences to the family (25.1%) (Table 2). The regression modeling supported the bivariate analysis for being married (OR, 2.6; 95% CI, 2.0-3.4) and more likely to be employed full time (OR, 2.4; 95% CI, 2.0-2.9). Also included in the model were non-Hispanic ethnicity (OR, 1.6; 95% CI, 1.0-2.6) and younger age (Figure 1D).
Discussion

This large comprehensive survey identifies a variety of demographic and disease-related factors associated with access to different insurance policies. These factors include employment status, age, disease duration, and general health. Although nearly all respondents had health insurance (96.3%), comparable with the general population, only 18.1% of respondents reported having short-term disability income insurance compared with 39% in the general working population. Those who lacked short-term disability income were in worse overall health, and with more aggressive disease, suggesting the importance of having protections from short- and long-term absences from work. This poses a potential hazard to individuals with MS because there is a mandatory 5-month wait period before SSDI eligibility begins. During this wait period, an individual cannot earn more than $1260 a month on average, and many working-age adults may have no other source of income during this period. Consequently, individuals may not have the financial resources to bridge this wait period: a recent report by the Federal Reserve shows that 39% of US adults would not have the savings needed to cover a $400 unexpected expense in any given month.

The Bureau of Labor Statistics reports that in the general population, 33% of employed individuals are offered private long-term disability income insurance through their employers, whereas 26.6% of the present respondents had private long-term disability insurance. Overall, private long-term disability income insurance is considered the most valuable form of income protection for working-age individuals because it typically pays at a higher proportion of previous earnings than does SSDI.
Long-term care insurance was the least common type of coverage (9.7%). It is reported that 25% of the general US population has long-term care insurance.\textsuperscript{30} This insurance has become both less accessible and, as has been reported by some industry leaders, more expensive due to the increasing cost of policies and limits on benefits.\textsuperscript{31} People with MS would greatly benefit from education about alternative means of funding long-term care, and social advocacy is needed to ensure that support for informal care providers is available.

The Bureau of Labor Statistics reports that 58% of all workers have life insurance, a proportion almost identical to that of the present respondents. The high rate of coverage for life insurance is likely due in part to the variety of term and permanent policies available and the range in costs associated with each type. It is important that individuals with MS become educated about the advantages of different types of life insurance policies. Access to this insurance becomes more essential when patients have dependents needing financial security. Even more important, it is increasingly becoming a vehicle for funding long-term care.\textsuperscript{32}

Among the present respondents, those who did not have current coverage for short-term disability and long-term care insurance shared similar characteristics. That is, they were more likely to have progressive disease and to report being in fair to poor health and not employed full time. As a result, individuals who could be considered to be at the greatest risk for intermittent lost wages in early adulthood and are most likely to need subsequent personal care assistance are at the greatest risk for not having coverage. Patients with MS with these profiles could be considered a targeted group for early education and rehabilitation interventions.

There is no ready explanation why those who are married and not employed full time were reported to be more likely to have short-term disability insurance compared with those who are married and employed full time. This finding warrants more exploration. The second most
common insurance in this survey was long-term disability, most likely because SSDI is associated with having been employed within the past 5 years. Still, there is an opportunity to have targeted education efforts about the work and disability requirements associated with SSDI.

The present survey content was similar to that of Iezzoni and Ngo, although the present sample size was nearly three times larger (2507 vs 937). The cohorts were comparably aged and had comparable proportions of Hispanic/Latino respondents, women, and individuals employed full time and a similar proportion with health insurance (96.3% in the present series vs 96.4%), private long-term disability income insurance (26.6% vs 29.7%), and life insurance (58.8% vs 68.3%). These parallel findings suggest that rates of coverage for health insurance, long-term disability insurance, and life insurance have remained consistent for nearly 15 years, and this, in turn, suggests that there has been limited intervention or advocacy around acquiring or maintaining these essential forms of financial protection.

One of the most unexpected and not previously reported results of this survey was that most respondents who had insurance coverage indicated that they obtained their current coverage after their MS diagnosis. Details of the circumstances and processes involved in obtaining current coverage after receiving an MS diagnosis needs to be explored in detail. Subsequently, public service programming for patient and provider awareness is recommended because it is commonly believed that it is not possible to obtain these types of insurance after MS diagnosis.

A few limitations should be considered. This study does not allow analysis of how the unique demographic and health variables interact to influence which individuals are offered insurance access and, if available, why they do or do not acquire it. Although it cannot be
claimed that the respondents to this survey are representative of the MS population, especially in the case of minority representation, they were a convenience sample drawn primarily from the NARCOMS Registry, which has previously been shown to be representative of the US population with MS. It is recommended that similar future surveys provide more detail about MS.

In conclusion, individuals with MS might not prioritize the possible short- and long-term benefits of having the types of insurance discussed in this study. Health care providers can direct patients to nonprofit agencies that provide education about insurance and emphasize that others with MS have obtained these insurance types after their diagnosis. In terms of future directions, a better understanding is needed of the circumstances under which people with MS can change their policies and if those new policies provide greater or more restrictive coverage.

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Figure 1. Adjusted odds ratios of having each type of insurance: short-term disability income insurance (STD) stratified by employment status (A), private long-term disability insurance (LTD) (B), long-term care insurance (LTC) (C), and life insurance (LI) (D)

Error bars represent 95% CIs. FT, full time; H/L, Hispanic/Latino; MCDP, married, cohabitating, or domestic partner; MS, multiple sclerosis; NM, not currently married.
### Table 1. Demographic characteristics of the 2507 study respondents by type of insurance

| Characteristic                      | All (n = 2507) | Health | Short-term disability | Private long-term disability\(\alpha\) | Long-term care | Life       |
|-------------------------------------|---------------|--------|-----------------------|---------------------------------------|----------------|------------|
| Has insurance                       | 2507 (100)    | 2413 (96.3) | 455 (18.1)          | 666 (26.6)                            | 242 (9.7)       | 1473 (58.8) |
| Age, y (n = 2507)                   | 53.5 ± 8.5    | 53.5 ± 8.5 | 49.8 ± 8.6          | 53.0 ± 8.1                            | 55.2 ± 8.1      | 53.3 ± 8.3  |
| Female sex (n = 2507)               | 2079 (82.9)   | 2004 (83.1) | 371 (15.1)          | 521 (78.2)                            | 193 (79.8)      | 1205 (81.8) |
| Race (n = 2477)                     |               |         |                      |                                       |                |            |
| White                               | 2286 (91.2)   | 2205 (91.4) | 420 (22.3)          | 617 (92.6)                            | 220 (90.9)      | 1351 (91.7) |
| African American                    | 94 (3.8)      | 86 (3.6)   | 12 (2.6)            | 18 (2.7)                              | 10 (4.1)        | 56 (3.8)   |
| Other/multi                         | 97 (3.9)      | 93 (3.9)   | 19 (4.2)            | 20 (3.9)                              | 8 (3.3)         | 47 (3.2)   |
| Hispanic/Latino ethnicity (n = 2490)| 95 (3.8)     | 87 (3.6)   | 22 (4.8)            | 22 (3.3)                              | 7 (2.9)         | 44 (3.0)   |
| Marital status (n = 2475)\(\beta\) |               |         |                      |                                       |                |            |
| Married, cohabiting, domestic partner| 1743 (69.5)  | 1697 (70.3) | 334 (73.4)          | 486 (72.3)                            | 169 (69.8)      | 1112 (75.5) |
| Previous marriage                   | 426 (17.0)    | 402 (16.7) | 59 (13.0)           | 94 (14.1)                             | 36 (14.9)       | 218 (14.8) |
| Never married                       | 306 (12.2)    | 285 (11.8) | 58 (12.6)           | 79 (11.9)                             | 34 (14.1)       | 129 (8.8)  |
| Current smoking (n = 2507)          | 230 (9.2)     | 210 (8.7)  | 36 (7.9)            | 44 (6.6)                              | 14 (5.8)        | 115 (7.8)  |
| Overall health (n = 2475)           |               |         |                      |                                       |                |            |
| Poor/fair                           | 754 (30.1)    | 718 (29.8) | 73 (16.0)           | 181 (27.2)                            | 55 (22.7)       | 407 (27.6) |
| Good                                | 1054 (42.0)   | 1013 (42.0) | 204 (44.8)          | 280 (42.1)                            | 97 (40.1)       | 623 (42.3) |
| Very good/excellent                 | 667 (26.6)    | 651 (27.0) | 174 (38.2)          | 240 (30.6)                            | 82 (33.9)       | 430 (29.2) |
| Employment (n = 2507)               |               |         |                      |                                       |                |            |
| Full time                           | 802 (32.0)    | 794 (32.9) | 403 (88.6)          | 341 (51.2)                            | 106 (43.8)      | 602 (40.9) |
| Part time                           | 262 (10.5)    | 255 (10.6) | 20 (4.4)            | 38 (5.7)                              | 10 (4.1)        | 142 (9.6)  |
| Not employed/retired, not due to disability| 277 (11.0) | 270 (11.2) | 2 (0.4)             | 4 (0.6)                               | 34 (14.1)       | 118 (8.0)  |
| Not employed/retired, due to disability| 1166 (46.5) | 1094 (45.3) | 30 (6.6)           | 283 (42.5)                            | 92 (38.0)       | 611 (41.5) |
| Current MS type (n = 2506)          |               |         |                      |                                       |                |            |
| RRMS                                | 1669 (66.6)   | 1613 (66.8) | 363 (79.8)          | 452 (67.9)                            | 166 (68.6)      | 1000 (67.9) |
| SPMS                                | 516 (20.6)    | 499 (20.7) | 46 (10.1)           | 128 (19.2)                            | 47 (19.4)       | 294 (20.0) |
| PPMS                                | 146 (5.8)     | 136 (5.6)  | 13 (2.9)            | 41 (6.2)                              | 12 (5.0)        | 75 (5.1)   |
| CIS                                 | 51 (2.0)      | 44 (1.8)   | 12 (2.6)            | 14 (2.1)                              | 4 (1.7)         | 29 (2.0)   |
| Don’t know                          | 124 (4.9)     | 121 (5.0)  | 21 (4.6)            | 31 (4.7)                              | 13 (5.4)        | 74 (5.0)   |
| MS care (n = 2502)                  |               |         |                      |                                       |                |            |
| Private neurologist                | 1390 (55.4)   | 1335 (55.3) | 263 (57.8)          | 361 (54.2)                            | 140 (57.9)      | 834 (56.6) |
| MS center                          | 899 (35.9)    | 876 (36.3) | 172 (37.8)          | 265 (39.8)                            | 85 (35.1)       | 529 (35.9) |
| GP/other physician                 | 170 (6.8)     | 158 (6.6)  | 15 (3.3)            | 35 (5.3)                              | 14 (5.8)        | 85 (5.8)   |
| No care for MS                     | 43 (1.7)      | 39 (1.6)   | 4 (0.9)             | 4 (0.6)                               | 2 (0.8)         | 20 (1.4)   |
| MS duration (n = 2481)              |               |         |                      |                                       |                |            |
| 0-5 y                               | 242 (9.7)     | 236 (9.8)  | 66 (14.5)           | 65 (9.8)                              | 17 (7.0)        | 153 (10.4) |
| 6-10 y                              | 358 (14.3)    | 342 (14.2) | 94 (20.7)           | 105 (15.8)                            | 31 (12.8)       | 201 (13.6) |
| 11-15 y                             | 575 (22.9)    | 555 (23.0) | 117 (25.7)          | 166 (24.9)                            | 52 (21.5)       | 343 (23.3) |
| 16-20 y                             | 581 (23.2)    | 561 (23.2) | 104 (22.9)          | 177 (26.6)                            | 60 (24.8)       | 344 (23.4) |
| >20 y                               | 725 (28.9)    | 679 (28.9) | 65 (14.3)           | 146 (21.9)                            | 79 (32.6)       | 418 (28.4) |
| PDDS (n = 2496)\(\delta\)           | 3 [1-5]       | 3 [1-5]   | 1 [0-3]             | 3 [1-5]                               | 3 [1-5]         | 3 [1-5]    |

Note: Data are given as number (percentage), mean ± SD, or median [interquartile range].
Abbreviations: CIS, clinically isolated syndrome; GP, general practitioner; MS, multiple sclerosis; PDDS, Patient-Determined Disease Steps; RRMS, relapsing-remitting MS; PPMS, primary progressive MS; SPMS, secondary progressive MS.
\(\alpha\)Some totals do not equal 100% due to missing/unknown responses.
\(\beta\)With or without Social Security Disability Insurance.
\(\delta\)Previous marriage: separated, divorced, or widowed.
\(\delta\)PDDS scale scores: 0, normal; 1, mild; 2, moderate; 3, early gait disability; 4, early cane use; 5, late cane use; 6, bilateral support; 7, wheelchair/scooter; 8, bedridden.
Table 2. Source, timing, and type of insurance

| Variable                              | Health (n = 2413) | Short-term disability (n = 455) | Private long-term disability (n = 666) | Long-term care (n = 242) | Life (n = 1473) |
|---------------------------------------|-------------------|--------------------------------|--------------------------------------|------------------------|----------------|
| Obtained current policy since MS diagnosis | 1471 (60.9)       | 217 (47.7)                     | 276 (41.4)                          | 135 (55.8)           | 370 (25.1)    |
| Type of insurance<sup>a</sup>          |                   |                                |                                      |                        |                |
| Public                                | 931 (38.6)        | NA                             | NA                                   | NA                     | NA             |
| Public and private                    | 399 (16.5)        | NA                             | 423 (63.5)                          | NA                     | NA             |
| Private                               | 1816 (75.3)       | 455 (100)                      | 243 (36.5)                          | 242 (100)             | 1473 (100)    |
| Private source                        |                   |                                |                                      |                        |                |
| Provided or purchased through employer or union | 1488 (81.9)       | 242 (75.2)                     | 424 (63.7)                          | 40 (16.5)             | 574 (39.0)    |
| Purchased through employer/exchange   | 143 (7.9)         | 105 (23.1)                     | 241 (36.2)                          | 155 (64.0)            | 360 (24.4)    |
| Privately purchased                   | 151 (8.3)         | 25 (5.5)                       | 67 (10.1)                           | 54 (22.3)             | 923 (62.7)    |
| SSDI                                  |                   |                                |                                      |                        |                |
| Not eligible                          | NA                | 240 (9.6)                      | NA                                   | NA                     | NA             |
| Unsure of SSDI eligibility            | NA                | 405 (16.2)                     | NA                                   | NA                     | NA             |
| Eligible: worked 5 of 10 previous years and paid FICA taxes | NA | 1862 (74.3) | NA | NA | NA |
| Benefits status for disability        |                   |                                |                                      |                        |                |
| Currently receiving SSDI benefits, with or without other private policy | NA | 922 (49.5) | 236 (35.4) | NA | NA |
| Currently receiving benefits from private policy, with or without SSDI<sup>a</sup> | NA | 8 (1.8) | 286 (42.9) | 21 (8.7) | NA |

Note: Data are given as number (percentage).
Abbreviations: FICA, Federal Insurance Contributions Act; MS, multiple sclerosis; NA, not applicable; SSDI, Social Security Disability Insurance.
<sup>a</sup>Not mutually exclusive; participants could report more than one policy for health insurance and life insurance.
Table S1. Health insurance policy details

| Has health insurance, any source* | Health insurance (n = 2413) |
|----------------------------------|-----------------------------|
| **Public source of health insurance** |                             |
| Medicaid only                     | 56 (6.0)                    |
| Medicare only                     | 663 (71.2)                  |
| Medicare and Medicaid only        | 84 (9.0)                    |
| Veterans Administration (VA) only | 30 (3.2)                    |
| VA plus any other public          | 78 (8.4)                    |
| Tri-care only                     | 24 (2.6)                    |
| Tri-care plus any other public    | 78 (8.4)                    |
| **Private source of health insurance** | 1816                        |
| Other combination of public insurances | 59 (6.3)                   |
| Provided by or purchased through employer or union | 1488 (81.9) |
| Purchased privately               | 151 (8.3)                   |
| Purchased through health exchange | 143 (7.9)                   |
| **Private policy owner** | 2313                         |
| Private through self              | 1571 (65.1)                 |
| Private through spouse            | 692 (28.7)                  |
| Private through other             | 50 (2.1)                    |
| **Supplemental policies** | 712                           |
| Any supplementary health insurance policy | 178 (7.4)             |
| Any additional prescription drug policy | 537 (22.3)              |

*Not mutually exclusive, participants may have more than one policy.