

# Health, disability, and life insurance experiences of working-age persons with multiple sclerosis

LI Iezzoni and L Ngo

Working-age Americans with multiple sclerosis (MS) may face considerable financial insecurities when they become unable to work and lack the health, disability, and life insurance typically offered through employers. In order to estimate the rates of having these insurance policies, as well as how insurance status affects reports of financial stress, we conducted half-hour telephone interviews with 983 working-age persons across the US, who reported being diagnosed with MS. The interviews occurred from May through November 2005, and among the sampled individuals contacted and confirmed eligible, 93.2% completed the interview. The study population was largely female (78.9%), Caucasian (86.4%), married (68.6%), with at least some college education (71.5%), and unemployed (60.2%). Overall, 96.3% had some health insurance (40.3% with public health insurance, primarily Medicare), 56.7% had long-term disability insurance (36.4% with public programs), and 68.3% had life insurance. Notably, 27.4% indicated that, since being diagnosed with MS, health insurance concerns had significantly affected employment decisions. In addition, 16.4% reported considerable difficulty paying for health care, 27.4% put off or postponed seeking needed health care because of costs, and 22.3% delayed filling prescriptions, skipped medication doses, or split pills because of costs. Overall, 26.6% reported considerable worries about affording even basic necessities, such as food, utilities, and housing. *Multiple Sclerosis* 2007; 13: 534–546. <http://msj.sagepub.com>

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**Key words:** disability insurance; health insurance; life insurance; multiple sclerosis; poverty; uninsured

Beyond its clinical consequences, multiple sclerosis (MS) can disrupt lives on many different levels. MS-related debility can derail education, halt careers, challenge familial relationships, and leave persons profoundly uncertain about their financial well-being and futures [1–10]. The standard tools working-age Americans use to ensure economic security for themselves and their families – health, disability, and life insurance offered by many employers – may be unavailable to persons unable to work because of MS [11]. Private insurers can reject or impose restrictions on applicants with chronic health conditions, such as MS [12]. Since the US does not provide universal health or disability insurance, this leaves persons dependent upon public programs with strict eligibility requirements

– for health insurance, Medicare (a federal program for elderly persons, which also covers working-age disabled individuals who contributed to social security while employed), and Medicaid (a joint federal and state program that covers, among others, disabled persons who are poor); and for income support, Social Security Disability Insurance (SSDI; for persons who were formerly employed) and Supplemental Security Income (SSI; for impoverished persons) [13]. These public programs, the so-called ‘social safety net’, nevertheless, often provide only minimal support, and sometimes fail altogether to meet persons’ needs [14,15].

In the US, MS clinicians and advocacy organizations report frequently fielding questions from patients facing unemployment, financial distress,

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Department of Medicine, Division of General Medicine and Primary Care, Harvard Medical School, Beth Israel Deaconess Medical Center, the Charles A Dana Research Institute, and the Harvard-Thorndike Laboratory, Boston, MA, USA

**Author for correspondence:** Dr Lisa I Iezzoni, Department of Medicine, Division of General Medicine and Primary Care, Beth Israel Deaconess Medical Center, 330 Brookline Avenue RO-137, Boston, MA 02215, USA. E-mail: [liezzoni@bidmc.harvard.edu](mailto:liezzoni@bidmc.harvard.edu)

Received 26 May 2006; accepted 16 August 2006

gaps or lapses in health insurance, and related economic concerns. These anecdotal reports identify potential problems, but they give little sense of magnitude – how often working-age persons with MS actually confront such economic hardships. These financial pressures could possibly contribute to depression, heighten anxiety, and affect patients' ability to adhere to MS treatments and obtain supportive services. Understanding how often MS patients confront these problems and their perceptions of associated stress could help clinicians and patient advocates anticipate needs and consider appropriate responses.

This study examined health, disability, and life insurance coverage, as well as associations with economic and related worries, for working-age US residents with MS. We focused on these three insurance types because: (a) each fills critical economic needs; (b) policies are frequently tied to employment, often at risk for persons disabled by MS; and (c) some insurers erect barriers specifically targeting persons with chronic medical conditions. In addition, some persons gain access to health insurance through the policies of spouses or partners – relationships that disabling MS can strain. To explore these issues, we conducted half-hour telephone surveys with working-age adults with MS living in communities (ie, outside institutions) nationwide.

## Methods

### Sampling frame

We aimed to survey nationwide, approximately 1000 non-institutionalized, US residents, age 18–64, with MS. Funded by the National Multiple Sclerosis Society (NMSS), we used its 2004 mailing list as our initial sampling frame, as have other investigators [16–18]. The NMSS mailing list contained 322 630 records representing members of the national society, its local chapters, and other individuals interested in MS; NMSS and chapter membership is free. A 1998 analysis found that the NMSS mailing list contained approximately two-thirds of Americans with MS, but may under-represent persons who are less disabled (eg, newly diagnosed), lower income, rural, or southern residents [19]. Other researchers have used NMSS mailing lists to construct national samples of persons with MS [17,18].

We excluded 38 624 records (participants in other NMSS studies; persons flagged as institutionalized or uninterested in research), as well as 1655 records lacking essential contact information; 282 338 records remained as our sampling universe. Given our survey topics [20], we wanted to include

relatively large numbers of persons with low incomes. We used the 2000 US Census data to identify zip codes where 40% or more of residents lived at or below the poverty line (784 of the 33 178 zip codes nationwide). Among the 282 338 records, only 1117 persons lived in high poverty zip codes. By over-sampling, we aimed for 20% of our survey respondents to reside in high poverty zip codes. Although not all residents in these zip codes would be poor, this strategy increased our likelihood of including low-income participants. To account for the over-sample of persons from high poverty zip codes, we reweighted all results, as described below.

### Designing the questionnaire

We aimed to design a questionnaire suitable for a 30-minute, English language, telephone interview about health, disability, and life insurance, as well as demographic characteristics, brief MS history, and related topics (eg, use of MS medications, health care services). Although several, recent, large-scale surveys considered health insurance concerns of persons with disabilities [21–26], no existing survey instrument encompassed our range of topics. To create our questionnaire, we began by conducting focus group interviews with convenience samples of persons with MS recruited by local MS Society chapters. We conducted three focus groups by telephone (mid-Atlantic, four participants; Minnesota, three participants; and Southern California, three participants) and one in-person (Central New England chapter, 12 participants). Drawing upon these findings and literature reviews, we drafted a questionnaire, which we tested with cognitive interviews of six subjects using two interviewers. After revising the instrument, we programmed it into computer-assisted telephone interviewing (CATI) software, and then conducted two rounds of pretests, including cognitive interviews, with 21 participants, before finalizing the questionnaire.

The questionnaire contained 18 sections, including sections on health insurance, financially-related experiences obtaining MS medications, and various health items and services (eg, physician services, home care, physical and occupational therapy, mobility aids, complementary and alternative therapies), public and private long-term disability insurance, and life insurance. Extensive skip patterns ensured that respondents answered only questions relevant to their individual circumstances. The questionnaire is available upon request.

### Survey process and response rates

We selected simple, random, samples from the two zip code strata (high poverty versus other zip codes), and mailed them a letter, describing the study and our plans to call them shortly for an interview. As expected, when sampling from organizational mailing lists, we could not locate 31% of our overall sample, even after extensive efforts (ie, letters were undeliverable, multiple attempts to find valid telephone numbers failed), and 6% were deceased. Of the remaining sample, 55.2% were eligible (had MS, were age 18–64, resided outside institutions, and spoke English), 22.1% were ineligible (57% of these reported not having MS), and we could not determine the eligibility status of 22.7% (ie, although we believed we had valid telephone numbers, we could not reach the individual). Among those whom we reached and confirmed eligible, 93.2% completed the interview. The interviews, which averaged 30.4 minutes, occurred from May through November 2005.

### Data analysis

We used SAS Version 9.1 (Cary, NC) for data analysis. All analyses used sampling weights and one-level stratification design effect to reflect our over-sampling of respondents from high poverty zip codes – in the final sample of 983 respondents, 170 came from high poverty zip codes. We computed sampling weights based on the product of the probability of selection and the response rate. This allows us to generalize our findings to the population of working-age NMSS members reporting having MS.

For descriptive statistics, we calculated weighted percentages with standard errors (SE). The survey asked many questions about different types of ‘stress’. To examine whether individuals offered consistent responses across these various stresses, we examined Spearman correlation coefficients for pairs of questions.

We also performed weighted multivariable logistic regressions using demographic and other characteristics to predict various dichotomous outcomes (eg, having specific types of insurance). Multivariable models predicting insurance status controlled for the following factors: age category (21–39, 40–49, 50–59, 60–64); sex; race (Caucasian, African-American, other and unknown); Hispanic ethnicity; living in zip code with high poverty rate; education (high school or less, some college, college graduate, postgraduate education); employment (currently working for pay, not working because of health, not working for other reason); marital status (married/living with partner, divorced or separated, widowed, never married);

overall health (excellent, very good, good, fair, poor); and years since MS diagnosis (0–5, 6–10, 11–15, 15–20, >20). Multivariable models predicting various ‘stresses’ added dummy variables for a specific insurance type to determine the effect of insurance status on reports of stress. We performed many analyses. We, therefore, only considered associations statistically significant with  $P$ -values <0.01.

## Results

Table 1 shows the demographic characteristics of the study population (ie, working-age NMSS members reporting MS) and presents the percentage (SE) of persons with different types of insurance by demographic attributes. The study population was largely female (78.9%), Caucasian (86.4%), married or living with a partner (68.6%), with at least some college education (71.5%), and unemployed (60.2%). Most (72.7%) reported having relapsing-remitting MS, with half (50.9%) stating they had the disease for >10 years.

### Demographic characteristics and insurance

Overall, 96.3% had at least some health insurance, 40.3% had public health insurance (Table 1). In contrast, 56.7% had some long-term disability insurance, with 36.4% having public programs, and 68.3% had life insurance. Percentages with all forms of insurance varied by certain demographic characteristics, notably sex, education, marital status, residence in a high poverty zip code, and employment (Table 1). Table 2 provides more details about insurance types and experiences. Medicare was the most common, single, public health insurance program (22.7% of the study population). Among those who only had private health insurance, 84.4% obtained it through an employer or former employer, and 43.9% had this insurance under someone else’s name. Most with public disability insurance had SSDI only (27.8% of the study population). Of those with life insurance, 70.3% obtained their major policy before being diagnosed with MS, as did 61.5% of persons with private long-term disability insurance.

Table 3 shows the adjusted odds ratios (AOR; 95% confidence intervals) for having specified types of insurance after accounting for various characteristics (some AORs for ‘any health insurance’ had very wide confidence intervals because of the small numbers lacking insurance). Across insurance types, sex, education, employment, and marital status were generally the most significant predictors. In particular, females were significantly

**Table 1** Demographic characteristics of study population and percent with various types of insurance

Demographic or other characteristic	All <sup>a</sup>	Health insurance <sup>b</sup>			Disability insurance <sup>c</sup>			Life insurance <sup>d</sup>
		Any	Public	Private	Any	Public	Private	
No. of survey respondents	983	946	431	683	562	374	279	639
			Weighted percent (standard error)					
All	100.0	96.3 (0.7)	40.3 (1.7)	74.0 (1.5)	56.7 (1.7)	36.4 (1.7)	29.7 (1.6)	68.3 (1.6)
Age								
21–39	15.0 (1.2)	95.8 (1.8)	32.3 (4.2)	75.0 (3.9)	53.8 (4.5)	25.9 (4.0)	33.8 (4.3)	62.7 (4.4)
40–49	31.0 (1.6)	96.0 (1.2)	36.0 (3.0)	72.3 (2.8)	64.8 (3.0)	38.8 (3.1)	35.5 (3.0)	68.2 (2.9)
50–59	38.5 (1.7)	96.7 (1.0)	41.4 (2.8)	74.3 (2.5)	53.3 (2.8)	37.7 (2.8)	27.2 (2.5)	70.1 (2.6)
60–64	15.5 (1.3)	98.3 (1.1)	53.9 (4.4)	75.3 (3.8)	53.3 (4.5)	39.7 (4.3)	21.3 (3.7)	70.3 (4.1)
Sex								
Male	21.1 (1.4)	95.4 (1.6)	51.2 (3.8)	65.1 (3.6)	67.2 (3.6)	47.3 (3.8)	31.2 (3.5)	70.6 (3.5)
Female	78.9 (1.4)	96.7 (0.7)	37.4 (1.9)	76.4 (1.7)	53.9 (2.0)	33.6 (1.7)	29.3 (1.8)	67.6 (1.8)
Race								
Caucasian	86.4 (1.2)	96.2 (0.7)	38.2 (1.8)	76.8 (1.6)	55.6 (1.9)	35.2 (1.8)	29.7 (1.7)	67.7 (1.8)
African-American	5.4 (0.8)	97.6 (2.2)	60.7 (7.2)	62.0 (7.2)	75.5 (6.5)	54.9 (7.9)	36.2 (7.3)	81.6 (5.8)
Other and unknown	8.2 (1.0)	96.9 (2.1)	48.7 (6.1)	52.8 (6.1)	56.6 (6.2)	38.2 (6.1)	25.4 (5.4)	66.0 (5.8)
Hispanic ethnicity								
Yes	3.9 (0.7)	93.6 (4.3)	39.0 (8.6)	67.5 (8.3)	48.7 (8.8)	29.1 (8.0)	22.7 (7.4)	48.2 (8.8)
No	96.1 (0.7)	96.4 (0.7)	40.4 (1.8)	74.6 (1.6)	57.1 (1.8)	37.0 (1.7)	29.9 (1.7)	69.2 (1.7)
Lives in high poverty zip code								
Yes	0.4 (0.0)	95.9 (1.5)	61.2 (3.7)	47.1 (3.8)	66.1 (3.7)	47.6 (3.8)	25.3 (3.4)	51.5 (3.9)
No	99.6 (0.0)	96.3 (0.7)	40.2 (1.7)	74.2 (1.5)	56.7 (1.8)	36.4 (1.7)	29.7 (1.7)	68.4 (1.6)
Education								
High school or less	28.5 (1.6)	95.2 (1.4)	55.5 (3.3)	67.6 (3.1)	51.0 (3.3)	37.1 (3.2)	21.2 (2.7)	63.8 (3.2)
Some college	33.3 (1.7)	94.8 (1.3)	56.0 (3.0)	69.4 (2.8)	58.5 (3.0)	41.6 (3.0)	24.6 (2.7)	68.5 (2.8)
College degree	26.3 (1.5)	97.7 (1.0)	61.9 (3.3)	78.8 (2.8)	59.3 (3.4)	35.1 (3.3)	37.7 (3.3)	71.7 (3.1)
Postgraduate education	11.9 (1.1)	100.0 (0.03)	74.9 (8.4)	91.6 (2.8)	59.4 (5.0)	24.0 (4.4)	45.8 (5.1)	71.8 (4.6)
Employment								
Currently working for pay	39.8 (1.7)	95.6 (1.1)	11.0 (1.7)	89.3 (1.7)	45.6 (2.8)	6.6 (1.4)	39.6 (2.7)	79.6 (2.6)
Not working because of health	50.0 (1.8)	97.0 (0.8)	67.6 (2.3)	59.9 (2.4)	72.1 (2.3)	64.6 (2.4)	25.8 (2.2)	61.2 (2.4)
Not working for other reason	10.2 (1.1)	95.1 (2.4)	19.6 (4.4)	84.0 (4.0)	27.4 (4.9)	15.0 (3.9)	13.8 (3.8)	63.3 (5.3)
Marital status								
Married/living with partner	68.6 (1.6)	97.5 (0.7)	32.4 (2.0)	83.4 (1.6)	52.8 (2.1)	29.6 (1.9)	31.8 (2.0)	75.8 (1.8)
Divorced or separated	18.2 (1.3)	93.9 (2.0)	62.5 (4.0)	48.5 (4.1)	68.6 (3.8)	58.2 (4.4)	21.3 (3.4)	51.4 (4.1)
Widowed	3.1 (0.6)	92.0 (5.4)	64.0 (9.5)	51.8 (9.9)	40.1 (9.7)	32.0 (9.3)	12.1 (6.5)	44.1 (9.9)
Never married	10.1 (1.0)	93.8 (2.6)	48.4 (5.5)	63.8 (5.2)	66.2 (5.2)	45.1 (5.5)	35.6 (5.3)	55.4 (5.4)
Overall health								
Excellent	6.9 (0.9)	98.2 (1.8)	23.2 (5.6)	87.5 (4.4)	45.5 (6.7)	19.6 (5.3)	32.8 (6.3)	76.7 (5.6)
Very good	25.1 (1.5)	96.6 (1.3)	19.7 (2.8)	86.2 (2.4)	47.8 (3.5)	17.3 (2.6)	35.5 (3.3)	76.9 (2.9)
Good	34.3 (1.7)	96.4 (1.1)	41.8 (2.9)	75.8 (2.6)	54.6 (3.0)	34.1 (2.8)	29.8 (2.7)	66.2 (2.8)
Fair	25.7 (1.5)	95.2 (1.5)	55.8 (3.4)	61.9 (3.3)	66.8 (3.3)	54.6 (3.5)	28.7 (3.2)	66.9 (3.3)
Poor	8.0 (0.9)	96.9 (2.1)	61.7 (6.0)	56.8 (6.1)	69.9 (5.7)	61.9 (6.1)	19.1 (4.9)	46.0 (6.2)
Years since MS diagnosis								
0–5	21.9 (1.5)	96.0 (1.5)	32.1 (3.5)	78.7 (3.1)	51.2 (3.8)	25.5 (3.3)	29.2 (3.5)	70.7 (3.3)
6–10	27.2 (1.6)	95.9 (1.3)	34.6 (3.2)	77.3 (2.8)	56.0 (3.4)	30.8 (3.1)	33.0 (3.2)	60.7 (3.2)
11–15	19.3 (1.4)	96.1 (1.6)	41.0 (3.9)	73.2 (3.6)	64.9 (3.9)	43.7 (4.0)	36.4 (3.9)	71.2 (3.6)
16–20	14.0 (1.2)	97.3 (1.5)	51.0 (4.7)	67.8 (4.2)	56.3 (4.7)	46.0 (4.7)	20.7 (3.8)	64.1 (4.6)
>20	17.6 (1.3)	97.1 (1.4)	51.8 (4.2)	68.0 (3.9)	58.0 (4.2)	45.4 (4.2)	25.4 (3.7)	66.6 (4.0)
MS pattern								
Relapsing-remitting	72.7 (1.6)	95.7 (0.8)	33.7 (2.0)	77.0 (1.7)	52.0 (2.1)	29.2 (1.9)	30.1 (1.9)	69.1 (1.9)
Secondary progressive	22.4 (1.5)	98.9 (0.8)	56.2 (3.7)	69.6 (3.4)	70.7 (3.4)	55.1 (3.7)	31.2 (3.5)	66.4 (3.5)
Other	4.9 (0.8)	99.9 (0.1)	71.9 (7.1)	58.7 (7.8)	69.6 (7.6)	64.0 (7.9)	18.9 (6.4)	61.3 (7.7)

<sup>a</sup>Weighted percent (standard error) of the population with demographic and other characteristics.

<sup>b</sup>Weighted percent (standard error) of the population with different types of health insurance, by demographic and other characteristics.

<sup>c</sup>Weighted percent (standard error) of the population with different types of disability insurance, by demographic and other characteristics.

<sup>d</sup>Weighted percent (standard error) of the population with life insurance, by demographic and other characteristics.

**Table 2** Specific insurance types and experiences

Insurance type and experiences	Percent <sup>a</sup>
<b>Health insurance: public</b>	
Medicare only <sup>b</sup>	22.7 (1.5)
Medicaid only <sup>b</sup>	3.5 (0.6)
Medicare and Medicaid only <sup>b</sup>	3.5 (0.6)
Veterans Administration, CHAMPUS/TRICARE <sup>c</sup>	4.9 (0.8)
Other government program <sup>c</sup>	4.3 (0.7)
Medicare or Medicaid and other government program <sup>c</sup>	1.9 (0.5)
<b>Health insurance: private</b>	
Insurance through employer or former employer <sup>d</sup>	84.4 (1.5)
Insurance through union or private insurance bought directly by respondent or family member <sup>d</sup>	15.6 (1.5)
Insurance is in respondent's name <sup>d</sup>	52.6 (2.0)
Insurance is in someone else's name <sup>d</sup>	43.9 (2.0)
Private insurance or Medigap plan in addition to public health insurance <sup>e</sup>	45.8 (2.7)
<b>Disability insurance: public</b>	
SSDI only	27.8 (1.6)
SSI only	3.9 (0.7)
SSDI and SSI	4.7 (0.7)
<b>Long-term disability insurance: private</b>	
Has private disability insurance	29.1 (1.6)
Got long-term disability insurance before MS diagnosis <sup>f</sup>	61.5 (3.2)
<b>Life insurance</b>	
Has at least one policy	67.9 (1.6)
Got life insurance through an employer <sup>g</sup>	56.7 (2.1)
Got major life insurance policy before MS diagnosis <sup>g</sup>	70.3 (1.9)

<sup>a</sup>Weighted percent (standard error) of entire population, unless otherwise noted.

<sup>b</sup>Persons fall uniquely into one of these three categories.

<sup>c</sup>Persons could fall into more than one of these three categories.

<sup>d</sup>Asked only of persons who report having only private health insurance.

<sup>e</sup>Asked only of persons with private in addition to public health insurance.

<sup>f</sup>Asked only of persons with private long-term disability insurance.

<sup>g</sup>Asked only of persons with life insurance.

more likely than males to have private health insurance (AOR = 2.5). In contrast, females were much less likely to have long-term disability insurance (AOR = 0.5), especially public disability insurance (AOR = 0.4). Findings relating to marital status suggest that persons who were married or living with partners depended much less often on public health and disability insurance programs compared with persons who were unmarried for various reasons, while they more often had private health and disability insurance than unmarried individuals. The association of employment with insurance status followed expected patterns.

### Worries and stresses

We posed seven 'stress' questions on how economically-related concerns affected various decisions

and actions, and then asked about respondents' worries concerning 13 issues. Most questions had four response categories, ranging from 'none' to 'a lot'. Table 4 shows the percentage (SE) reporting 'a lot', in addition to 'yes' answers to several questions about obtaining care. Table 4 also presents these percentages when persons had specified types of insurance. Notably, 27.4% indicated that, since being diagnosed with MS, concerns about health insurance had affected decisions about their work life 'a lot'. In addition, 16.4% reported 'a lot' of difficulty paying for health care, and of these persons, 21.3% had spent less on food, heat, and other necessities in order to meet health care expenses. Over one-quarter (27.4%) had put off or postponed seeking the health care they needed because of the expense, and 22.3% delayed filling prescriptions, skipped doses of medications, or split pills because of costs.

The percentages reporting 'a lot' of worries varied across the 13 concerns, with 34.2% worried 'a lot' about losing or not having health insurance. Very basic concerns also intruded, with 26.6% worried 'a lot' about not having money for necessities, such as food, housing, and utilities, while 43.6% worried 'a lot' about burdening their families. Not surprisingly, responses were highly correlated across these 13 'worry' questions, with all Spearman correlation coefficients across the 156 correlations significant at  $P < 0.0001$ .

After accounting for demographic and other characteristics, *not* having any health insurance generally significantly increased the likelihood that persons would report 'a lot' of worries or stress (Table 5). For instance, the AOR of postponing seeking care associated with being uninsured was 10.9 (4.1, 29.3) and for skimping on medications was 2.6 (1.1, 6.1). However, not having public or private health insurance, specifically, demonstrated relatively few significant effects. Life insurance was also often significant ( $P < 0.01$ ) – persons without life insurance were much more likely than those with life insurance to report high levels of worry and stress.

To understand better which persons reported 'a lot' of worries or stress, we also looked at the role of demographic and health characteristics without accounting for insurance. Most variables were not significant, but age, sex, marital status, and self-reported overall health were important in certain situations. For instance, compared with married persons, those who were divorced or separated were much more likely to report 'a lot' of difficulty paying for care (AOR = 3.5 [2.1, 5.8]); compared with those reporting excellent health, persons in poor health were more likely to report these difficulties (AOR = 12.1 [2.5, 59.7]). Persons aged 60–64 were much less likely than the youngest group to worry about paying for basic necessities

**Table 3** Adjusted odds ratio of having various types of insurance<sup>a</sup>

Demographic and other characteristics	Health insurance			Disability insurance			
	Any	Public	Private	Any	Public	Private	Life insurance
<b>Age</b>							
21-39	1.0	1.0	1.0	1.0***	1.0	1.0	1.0
40-49	0.8 (0.3, 2.7)	0.5 (0.3, 1.0)	1.4 (0.7, 2.6)	1.2 (0.7, 1.9)	0.9 (0.5, 1.7)	1.1 (0.6, 1.8)	1.8 (1.1, 3.0)
50-59	1.0 (0.3, 2.9)	0.6 (0.3, 1.1)	1.7 (0.9, 3.2)	0.6 (0.3, 1.0)	0.7 (0.4, 1.3)	0.7 (0.4, 1.2)	2.2 (1.3, 3.8)
60-64	2.2 (0.3, 14.2)	0.6 (0.3, 1.3)	2.0 (0.9, 4.2)	0.6 (0.3, 1.1)	0.6 (0.3, 1.4)	0.5 (0.3, 1.1)	2.3 (1.2, 4.5)
<b>Sex</b>							
Male	1.0	1.0	1.0**	1.0***	1.0**	1.0	1.0
Female	1.8 (0.7, 4.6)	0.7 (0.4, 1.1)	2.5 (1.5, 4.0)	0.5 (0.4, 0.8)	0.4 (0.2, 0.7)	1.0 (0.6, 1.5)	0.9 (0.6, 1.4)
<b>Race</b>							
Caucasian	1.0	1.0	1.0***	1.0	1.0	1.0	1.0
African-American	1.4 (0.1, 14.0)	2.8 (1.2, 6.4)	0.6 (0.3, 1.2)	2.2 (0.9, 5.1)	2.2 (0.9, 5.4)	1.3 (0.6, 2.8)	4.1 (1.6, 10.9)
Other and unknown	1.2 (0.2, 7.0)	1.1 (0.5, 2.4)	0.3 (0.2, 0.6)	0.7 (0.4, 1.2)	0.6 (0.3, 1.2)	0.7 (0.3, 1.5)	1.2 (0.6, 2.2)
<b>Hispanic ethnicity</b>							
No	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Yes	0.7 (0.1, 3.2)	0.3 (0.1, 1.2)	0.9 (3.4, 2.3)	0.7 (0.3, 1.9)	0.5 (0.1, 1.8)	0.7 (0.3, 1.8)	0.5 (0.2, 1.2)
<b>Lives in high poverty zip code</b>							
No	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Yes	1.4 (0.4, 5.3)	0.9 (0.5, 1.6)	0.8 (0.5, 1.3)	0.8 (0.6, 1.6)	0.7 (0.4, 1.3)	0.9 (0.5, 1.5)	0.6 (0.3, 0.9)
<b>Education</b>							
High school or less	1.0*	1.0	1.0***	1.0***	1.0	1.0*	1.0
Some college	0.8 (0.3, 2.2)	1.5 (0.9, 2.5)	0.9 (0.6, 1.4)	1.7 (1.1, 2.5)	1.9 (1.1, 3.1)	1.2 (0.8, 1.9)	1.1 (0.7, 1.7)
College degree	2.2 (0.7, 6.5)	1.3 (0.8, 2.2)	1.3 (0.8, 2.3)	2.1 (1.3, 3.2)	1.6 (1.0, 2.7)	2.4 (1.5, 3.8)	1.2 (0.8, 2.0)
Postgraduate education	115.2 (22.7, 585.3)	1.2 (0.6, 2.4)	3.7 (1.6, 8.6)	2.3 (1.3, 4.2)	1.1 (0.5, 2.2)	3.1 (1.8, 5.5)	1.1 (0.6, 2.0)
<b>Employment</b>							
Currently working for pay	1.0	1.0*	1.0*	1.0*	1.0*	1.0**	1.0**
Not working because of health	2.2 (0.8, 6.1)	17.6 (9.7, 31.8)	0.2 (0.1, 0.4)	3.7 (2.4, 5.5)	28.1 (15.6, 50.6)	0.7 (0.5, 1.1)	0.5 (0.3, 0.7)
Not working for other reason	0.6 (0.2, 2.0)	3.3 (1.5, 7.4)	0.4 (0.2, 0.7)	0.5 (0.3, 1.0)	3.7 (1.7, 8.3)	0.2 (0.1, 0.5)	0.3 (0.2, 0.6)

Table 3 (Continued)

Demographic and other characteristics	Health insurance			Disability insurance			Life insurance
	Any	Public	Private	Any	Public	Private	
Marital status							
Married/ living with partner	1.0*	1.0*	1.0*	1.0	1.0*	1.0	1.0*
Divorced or separated	0.4 (0.2, 1.1)	3.8 (2.3, 6.2)	0.2 (0.1, 0.3)	1.6 (1.1, 2.5)	3.0 (1.8, 5.0)	0.7 (0.4, 1.1)	0.4 (0.2, 0.5)
Widowed	0.2 (0.03, 1.0)	3.4 (1.2, 9.6)	0.2 (0.1, 0.4)	0.6 (0.2, 1.6)	0.6 (0.2, 1.8)	0.5 (0.1, 1.6)	0.2 (0.1, 0.5)
Never married	0.3 (0.1, 1.2)	2.8 (1.5, 5.3)	0.3 (0.2, 0.5)	1.4 (0.8, 2.5)	2.6 (1.3, 5.1)	0.8 (0.5, 1.5)	0.4 (0.2, 0.6)
Overall health							
Excellent	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Very good	0.5 (0.1, 4.0)	0.8 (0.3, 1.9)	1.0 (0.4, 2.5)	1.4 (0.7, 2.8)	1.0 (0.5, 2.2)	1.2 (0.6, 2.5)	1.1 (0.5, 2.4)
Good	0.5 (0.1, 3.6)	2.0 (0.9, 4.5)	0.8 (0.3, 2.0)	1.4 (0.7, 2.8)	1.6 (0.8, 3.3)	1.1 (0.6, 2.3)	0.8 (0.4, 1.6)
Fair	0.3 (0.04, 2.6)	1.8 (0.8, 4.0)	0.6 (0.2, 1.6)	1.6 (0.8, 3.3)	1.8 (0.8, 3.8)	1.2 (0.6, 2.5)	0.9 (0.4, 2.0)
Poor	0.4 (0.04, 4.9)	1.3 (0.5, 3.4)	0.8 (0.3, 2.4)	1.3 (0.5, 3.1)	1.4 (0.6, 3.3)	0.7 (0.3, 1.8)	0.4 (0.2, 0.9)
Years since MS diagnosis							
0–5	1.0	1.0	1.0	1.0	1.0	1.0	1.0
6–10	0.9 (0.3, 2.7)	0.9 (0.5, 1.5)	1.0 (0.6, 1.8)	1.0 (0.6, 1.5)	0.8 (0.4, 1.5)	1.3 (0.8, 2.1)	0.8 (0.5, 1.3)
11–15	0.8 (0.2, 3.2)	1.2 (0.7, 2.3)	0.7 (0.4, 1.4)	1.6 (1.0, 2.8)	1.9 (1.0, 3.8)	1.7 (1.0, 2.8)	0.9 (0.5, 1.6)
16–20	1.3 (0.3, 5.7)	1.4 (0.7, 2.8)	0.7 (0.3, 1.3)	0.9 (0.5, 1.7)	1.6 (0.8, 3.4)	0.7 (0.4, 1.3)	0.7 (0.4, 1.3)
>20	1.2 (0.3, 5.6)	1.2 (0.6, 2.3)	0.6 (0.3, 1.2)	1.0 (0.6, 1.8)	1.2 (0.6, 2.4)	1.2 (0.7, 2.1)	0.7 (0.4, 1.3)

\* $P < 0.0001$ .\*\* $P < 0.001$ .\*\*\* $P < 0.01$ .

<sup>a</sup>Multivariable logistic regression models predicting having insurance controlled for: age category, sex, race, Hispanic ethnicity, living in zip code with high poverty rate, education, employment, marital status, overall health, and years since MS diagnosis.

**Table 4** Weighted percent (standard error) reporting ‘a lot’ on questions relating to stress and worries

Stresses and worries <sup>b</sup>	Health insurance				Disability insurance			Life insurance
	All	Any	Public	Private	Any	Public	Private	
Since diagnosed with MS, concerns about type of health insurance have affected ‘decisions you have made about your work life’	27.4 (1.6)	27.4 (1.6)	26.7 (2.8)	26.1 (1.8)	28.5 (2.1)	26.2 (2.6)	32.0 (3.0)	24.6 (1.8)
Difficulty paying for ‘expenses relating to health care’ <sup>c</sup>	16.4 (1.3)	15.3 (1.3)	26.3 (2.9)	12.0 (1.3)	18.5 (1.9)	23.5 (2.6)	13.9 (2.3)	11.7 (1.4)
‘Did you have to spend less on food, heat, and other necessities in order to pay for your health care needs?’ <sup>c,d</sup>	21.3 (1.5)	20.0 (1.5)	30.4 (3.0)	17.3 (1.6)	23.8 (2.1)	30.9 (2.8)	16.0 (2.4)	16.7 (1.6)
‘In order to pay for your health care needs, did you make any other kinds of changes in your life?’ <sup>c,d</sup>	44.0 (2.2)	43.6 (2.2)	46.6 (3.8)	42.9 (2.5)	43.3 (2.9)	43.9 (3.5)	47.0 (4.1)	41.5 (2.6)
‘Put off or postponed seeking health care you felt you needed’ <sup>e</sup>	27.4 (1.6)	25.5 (1.6)	31.7 (2.9)	23.5 (1.7)	27.4 (2.1)	30.7 (2.7)	25.1 (2.8)	23.8 (1.8)
‘Went without additional treatments you felt you needed’ <sup>e</sup>	25.3 (1.5)	23.4 (1.5)	32.5 (2.9)	20.8 (1.6)	25.8 (2.0)	31.1 (2.7)	17.3 (2.5)	20.8 (1.7)
‘Did not fill a prescription, skipped doses of medicine, or split pills’ <sup>e</sup>	22.3 (1.5)	21.5 (1.5)	35.1 (3.0)	18.0 (1.6)	24.4 (2.0)	32.1 (2.7)	15.2 (2.3)	18.1 (1.6)
‘Worry about losing or not having health insurance’ <sup>f</sup>	34.2 (1.7)	33.1 (1.7)	33.9 (3.0)	32.3 (1.9)	33.1 (2.2)	36.2 (2.8)	28.8 (2.9)	29.6 (1.9)
‘Worry about the cost of your health insurance’ <sup>f</sup>	32.9 (1.6)	32.0 (1.7)	36.1 (3.0)	30.9 (1.9)	32.9 (2.2)	34.8 (2.8)	31.8 (3.0)	28.3 (1.9)
‘Worry the your [health] insurance coverage might change’ <sup>f</sup>	35.6 (1.7)	35.7 (1.7)	41.8 (3.1)	35.4 (1.9)	37.4 (2.3)	39.8 (2.8)	35.6 (3.1)	31.9 (2.0)
‘Having to spend time with your insurer to get them to pay for the care that you need’ <sup>f</sup>	16.4 (1.3)	16.4 (1.3)	20.5 (2.5)	15.2 (1.5)	17.3 (1.8)	21.1 (2.4)	12.4 (2.1)	12.9 (1.4)
‘Worry about not being able to get MS medications when you need them’ <sup>f</sup>	22.4 (1.5)	21.4 (1.5)	27.4 (2.8)	19.4 (1.6)	23.2 (2.0)	28.0 (2.6)	16.1 (2.4)	18.9 (1.7)
‘Being able to see the doctors you want to see’ <sup>f</sup>	15.8 (1.3)	14.8 (1.3)	17.6 (2.4)	13.3 (1.4)	14.5 (1.6)	17.5 (2.2)	10.6 (2.0)	12.9 (1.4)
‘Being able to afford the equipment you need for mobility’ <sup>f</sup>	15.4 (1.3)	14.8 (1.3)	23.0 (2.6)	13.0 (1.4)	18.9 (1.8)	23.1 (2.5)	12.9 (2.2)	12.8 (1.4)
‘Being able to get the physical or occupational therapy you need’ <sup>f</sup>	12.8 (1.2)	11.7 (1.1)	16.8 (2.3)	10.7 (1.3)	13.6 (1.6)	15.8 (2.1)	8.5 (1.8)	10.2 (1.3)
‘Being able to get other treatments or alternative therapies for MS’ <sup>f</sup>	16.9 (1.3)	16.0 (1.3)	19.2 (2.5)	15.2 (1.5)	17.2 (1.8)	19.6 (2.3)	13.1 (2.2)	12.4 (1.4)
‘Worry about not having money for necessities like food, utilities, and housing’ <sup>f</sup>	26.6 (1.5)	25.6 (1.6)	37.4 (3.0)	21.0 (1.7)	29.5 (2.1)	35.9 (2.8)	19.6 (2.6)	20.5 (1.7)
‘Worry about being a burden on your family’ <sup>f</sup>	43.6 (1.7)	42.7 (1.8)	51.3 (3.1)	40.1 (2.0)	44.5 (2.3)	50.9 (2.9)	36.1 (3.1)	38.7 (2.1)
‘Worry about not being able to take care of your family’ <sup>f</sup>	38.3 (1.7)	37.5 (1.7)	43.1 (3.1)	35.8 (2.0)	40.3 (2.3)	44.5 (2.9)	33.8 (3.1)	34.3 (2.0)
‘Worry about leaving your family provided for in the event of your death’ <sup>f</sup>	26.9 (1.6)	25.9 (1.6)	32.2 (2.9)	23.9 (1.7)	29.5 (2.2)	33.6 (2.8)	24.1 (2.8)	22.1 (1.8)

<sup>a</sup>Unless otherwise indicated, response categories for these questions were: ‘a lot’, ‘some’, ‘a little’, and ‘not at all’.

<sup>b</sup>Quotation marks indicate verbatim language from survey.

<sup>c</sup>Question asks about ‘the past 12 months’.

<sup>d</sup>Asked only of persons who reported that it was very, somewhat, or a little difficult affording expenses related to health care; response categories: yes/no.

<sup>e</sup>‘In the past 12 months was there a time when you’ [READ ITEM] ‘because of cost concerns’. Response categories: yes/no.

<sup>f</sup>For each of the following, tell me how much it adds to the stress in your life’.



**Table 5** Adjusted odds ratio of reporting ‘a lot’ of stresses or worries by insurance type<sup>a</sup>

Stresses and worries <sup>b</sup>	Health insurance			Disability insurance			Life insurance
	Any	Public	Private	Any	Public	Private	
	Adjusted odds ratio (95% confidence interval)						
Health insurance concerns affect work decisions	1.0 (0.4, 2.4)	1.2 (0.8, 1.8)	1.3(0.8,2.0)	1.0 (0.7, 1.5)	1.3 (0.9, 2.1)	0.8 (0.6, 1.2)	1.4 (0.9, 2.1)
Difficulty paying for health care	5.5 (2.1, 14.8)**	0.7 (0.4, 1.2)	2.1 (1.2, 3.6)***	1.0 (0.6, 1.6)	0.9 (0.5, 1.5)	1.1 (0.6, 1.8)	2.0 (1.2, 3.2)***
Spent less on food, heat, necessities	4.8 (1.8, 12.9)***	0.9 (0.5, 1.4)	1.4 (0.9, 2.3)	0.9 (0.6, 1.5)	0.6 (0.3, 1.0)	1.5 (0.9, 2.4)	1.8 (1.2, 2.8)***
Made other life changes	1.3 (0.5, 3.2)	0.8 (0.5, 1.4)	1.0 (0.6, 1.6)	1.0(0.7,1.6)	0.9 (0.6, 1.5)	0.7 (0.5, 1.1)	1.3 (0.8, 2.0)
Postponed seeking health care	10.9 (4.1, 29.3)*	1.1 (0.7, 1.7)	1.5 (1.0, 2.4)	1.3 (0.9, 2.0)	1.1 (0.7, 1.7)	1.2 (0.8, 1.7)	1.5 (1.0, 2.2)
Went without additional treatments	10.5 (3.6, 30.9)*	1.0 (0.6, 1.5)	1.6 (1.0, 2.4)	1.3 (0.9, 1.9)	1.0 (0.7, 1.6)	1.8 (1.2, 2.8)***	1.6 (1.1, 2.4)
Skimped on medications	2.6 (1.1, 6.1)***	0.5 (0.3, 0.8)***	1.6 (1.0, 2.5)	1.0 (0.7, 1.5)	0.6 (0.4, 0.9)	1.8 (1.1, 2.8)	1.6 (1.0, 2.3)
Worries about losing health insurance	3.2 (1.3, 8.1)***	1.5 (1.0, 2.3)	1.1 (0.7, 1.7)	1.4 (1.0, 2.0)	1.1 (0.7, 1.6)	1.5 (1.1, 2.2)	1.6 (1.1, 2.3)***
Worries about cost of health insurance	2.3 (1.0, 5.6)	1.1 (0.7, 1.6)	1.1 (0.8, 1.7)	1.1 (0.8, 1.5)	1.0 (0.7, 1.6)	1.0 (0.7, 1.5)	1.6 (1.1, 2.3)***
Worries about health insurance changes	0.8 (0.3, 1.8)	0.7 (0.5, 1.1)	0.8 (0.6, 1.3)	0.9 (0.6, 1.3)	0.8 (0.5, 1.2)	1.0 (0.7, 1.4)	1.5 (1.1, 2.2)
Worries about obtaining MS medications	3.4 (1.4, 8.3)**	1.0 (0.6, 1.5)	1.3 (0.8, 2.1)	1.3 (0.8, 1.9)	0.7 (0.5, 1.2)	1.8 (1.2, 2.9)***	1.4 (1.0, 2.2)
Affording mobility equipment	2.4 (1.0, 5.9)	0.8 (0.5, 1.4)	0.9 (0.5, 1.6)	0.5 (0.4, 1.1)	0.6 (0.3, 1.0)	1.1 (0.6, 1.8)	1.2 (0.7, 1.9)
Not having money for necessities	2.9 (1.2, 6.8)	0.7 (0.5, 1.2)	1.6 (1.0, 2.5)	1.0 (0.6, 1.4)	0.6 (0.4, 1.0)	1.7 (1.1, 2.5)	1.9 (1.3, 2.8)***
Burdening family	2.9 (1.1, 7.9)	1.1 (0.7, 1.6)	1.2 (0.8, 1.8)	1.4 (1.0, 1.9)	1.1 (0.7, 1.6)	1.5 (1.1, 2.2)	1.6 (1.1, 2.3)***
Not being able to care for family	2.5 (1.0, 6.3)	1.0 (0.7, 1.6)	1.0 (0.7, 1.6)	1.0 (0.7, 1.5)	0.9 (0.6, 1.4)	1.3 (0.9, 1.9)	1.5 (1.0, 2.1)
Leaving family provided for when dies	2.7 (1.1, 6.3)	0.9 (0.6, 1.4)	1.1 (0.7, 1.7)	0.9 (0.6, 1.3)	0.7 (0.4, 1.1)	1.1 (0.7, 1.7)	1.8 (1.2, 2.7)***

\* $p < 0.0001$ .

\*\* $p < 0.001$ .

\*\*\* $p < 0.01$ .

<sup>a</sup>We looked at selected items from Table 4. Multivariable logistic regression models predicting stresses controlled for: age category, sex, race, Hispanic ethnicity, living in zip code with high poverty rate, education, employment, marital status, overall health, years since MS diagnosis, and specific insurance type. Separate models were run for each insurance type; not having insurance is reference category.

<sup>b</sup>See Table 4 for question wording and response categories.

(AOR = 0.3 [0.1, 0.6]); widowed individuals expressed more such worries than married persons (AOR = 4.6 [1.7, 12.2]).

## Discussion

This survey of working-age, US residents, who are NMSS members reporting MS, produced several key findings. First, this population has very low rates of lacking health insurance compared with the general population. As expected, uninsured persons reported difficulties (eg, postponing care, skimping on medications) much more often than others. Second, this high insurance level is achieved largely by dependence on public programs, primarily Medicare. Not surprisingly, since working-age persons generally gain Medicare coverage through SSDI, we also found high use of public disability insurance, specifically SSDI. Thus, this population depends heavily on governmental programs (the 'social safety net') for both health insurance and income support. Third, despite having health insurance, significant fractions of persons report high levels of stress and worries about affording health care services. These findings suggest that health insurance is often inadequate to meet persons' needs. Approximately one-quarter have postponed seeking care, skimmed on medications, or worried 'a lot' about affording food, utilities, or housing. Only 41.1% reported 'no' worries about paying for basic necessities, such as food.

To assess the generalizability of our findings, the first question is whether our 983 respondents closely resemble the US MS population. The absence of firm nationwide figures about US residents with MS makes answering this question difficult. Although registries of MS patients are growing, most recruit from specific care settings or geographic regions, raising their own concerns about generalizability [27–31]. The Sonya Slifka Longitudinal Multiple Sclerosis Study, initiated in 2000, represents the most significant effort to identify a nationally-representative cohort of US residents with MS [16,17]. Although it also began sampling using NMSS membership files, the Slifka Study supplemented its cohort to account for the presumed under-representation of persons who are less disabled, lower income, rural, and southern residents [16,19]. Our population had remarkably similar demographic characteristics to those of the Slifka Study [16], suggesting that our results might generalize nationally.

Our findings indicate that persons with MS have higher rates of demographic attributes associated with social advantages in the US, than other populations with disabling conditions. Using the 2004 US Census data, one study found that 59.1%

of disabled persons, regardless of cause, had high school education or less, compared with 28.5% of our MS population [32]. In addition, 24.8% of persons nationwide reporting physical disabilities had family incomes below the poverty level, and 16.2% received SSI, an indicator of low income [32]. Only 8.6% of our study population received SSI, and just 0.4% (weighted percent) lived in high poverty zip codes, suggesting possible socioeconomic disadvantage.

Another advantage for our working-age MS population is their remarkably high rate of health insurance. Across all ages, an estimated 45.8 million Americans (15.7% of the population) had no health insurance during 2004 [33]. Among adults, younger persons are least likely to be insured: 25.9% of persons age 25–34 and 18.7% of persons age 35–44 lacked health insurance in 2004 [33]. Our overall uninsured rate of 3.7% is dramatically lower than that of working-age Americans nationally, across all age ranges. But our study population also has much higher rates of public health insurance (40.3%) than for the general public. For instance, only 3.7% of persons nationwide, age 44–54, had Medicare in 2004, compared with over one-quarter of our total study population; 6.7% nationally had Medicaid, as did at least 7% of our population [33]. Just 11.6% of 44–54 year olds nationwide had some form of public health insurance (including military and veterans coverage), a much lower percentage than among our population at similar ages.

Finding comparable population-based figures for disability and life insurance coverage in the US is more difficult than for health insurance. Since Medicare eligibility for persons under age 65 directly ties to SSDI, our population obviously had higher rates of SSDI than the general public. Approximately 2.7% of Americans had SSDI in 2004 [34], compared with >30% of our population. Nationwide statistics for private disability and life insurance coverage relate primarily to employed populations. In 2005, more private industry employees had life insurance (52%) through their employers than long-term disability insurance (30%), but these rates varied by job type [35]. Just 5% of part-time private industry workers nationwide had long-term disability insurance, compared with 38% of full-time employees [35]. While 59% of white-collar workers and 55% of blue-collar workers had life insurance, only 28% of service industry workers had life insurance; 12% of part-time workers had life insurance, compared with 64% of full-time employees [35]. These figures offer imperfect comparisons with our MS population, which was 60% unemployed.

Thus, the insurance picture for working-age NMSS members with MS is complicated. On the one hand, persons had much higher rates of health

insurance, albeit often from public programs, than the general public. That should provide important advantages. Unmarried individuals were most at risk of lacking health insurance, presumably because they were less likely to obtain insurance through an employed spouse. On the other hand, persons also had higher rates of public disability insurance (primarily SSDI), provided only to individuals who were too medically impaired to work. As other studies have shown [36,37], males had higher rates of public disability insurance (probably relating to being more likely than females to have worked and paid sufficiently into the Social Security Trust Fund), as did persons with higher educational attainment (for similar reasons). The bottom line is, though, that regardless of whether or not individuals had health, disability, or life insurance, many reported substantial worries and stress about financially-mediated concerns, including obtaining health care. This suggests that benefit coverage was inadequate to assuage persons' financial fears about meeting health care needs.

With substantial percentages of persons reporting various worries and stresses, questions arise about whether this MS population is more or less worried than other populations nationwide. Another national telephone survey identified US residents with a disability, variously defined, and found that 28% had postponed care, 18% had gone without needed medical care in the prior year, and 9% had not filled medication prescriptions [24]. Our population expressed the latter two concerns (going without care, skimping on medications) more often. Yet another nationwide survey focused on non-elderly persons receiving SSDI or SSI or reporting physical or mental disabilities, with socio-demographic attributes suggesting considerable social disadvantages (ie, only 11% were employed, 49% earned <\$12,000 annually, and 69% reported fair or poor health) [25]. Not surprisingly, the survey found very high rates of problems: 37% had put off or postponed care because of costs, 36% skipped medication doses, split pills, or did not fill prescriptions, and 36% spent less on basic needs (eg, food, heat) [25,38]. In addition, 25% reported being 'very worried' about possible difficulties paying for basic needs, such as food or rent, and 19% were 'very worried' about burdening their families [38]. Our study population expressed similar worries at higher rates. These comparisons, albeit imperfect, suggest that our MS population faces financial and other challenges at higher or similar rates to persons with disabilities, broadly defined, nationwide.

Our study has important limitations. Given our sampling frame, we cannot ensure that we identified a nationally representative population of working-age US residents with MS, although the

comparability of demographic traits with the Slifka Study was reassuring. We could not find 31% of our original sample; these persons may differ systematically in important ways from persons we did interview. We did not independently verify that respondents actually had MS, relying solely upon their self-report of the diagnosis. Due to privacy concerns and fears about compromising our survey completion rate, we did not specifically ask respondents about their incomes – questions well-known to upset survey participants. Through over-sampling from high poverty zip codes, we surveyed a relatively large number of racial and ethnic minority participants: for example, we interviewed 102 persons who self-identified as African-American, although after reweighting, our population prevalence of African-American individuals was only 5.4% (similarly, we interviewed 55 Hispanic persons for a reweighted prevalence of 3.9%). Having these large numbers of respondents allowed us to produce relatively rigorous estimates for African-American and Hispanic persons in our analyses. Nonetheless, having specific information on household incomes would have offered advantages over this indirect measure. Finally, we did not interview persons without MS. National surveys repeatedly find high anxiety about health insurance and financial stresses among many Americans, and our study cannot determine how much MS contributes to such worries.

Despite these limitations, this survey is the largest ever undertaken to explore insurance-related concerns of US residents reporting MS. The findings strongly convey both the relatively high dependence of working-age persons with MS on 'safety net' health and disability insurance programs, as well as the considerable worries and stresses experienced by approximately one-quarter to one-third of these individuals. Simply having health insurance does not ensure that persons can meet their health care needs. Clinicians caring for Americans with MS should be aware that even persons with health insurance may not be able to afford – or may worry greatly about affording – treatments prescribed by their physicians. Persons who are alone (eg, divorced or separated) and those without adequate employment histories (ie, to confer SSDI eligibility and thus, eventually, Medicare) may be particularly at risk. At a minimum, these stresses could weigh heavily on patients' mental health; negative consequences for physical health, especially when persons postpone or skimp on treatments, could potentially follow. Persons who are unable to afford such basic necessities as food, utilities, and shelter, could certainly suffer deleterious physical effects.

After initiating treatment plans, clinicians should, therefore, follow up with patients, not

only to check for potential clinical concerns (eg, medication side effects), but also to ensure that patients have not delayed or avoided care because of financial or insurance-related concerns. Working closely with social workers or other resource specialists, knowledgeable about local, regional, or national patient assistance programs, could help avert or address such problems [39–41]. Despite increasing treatment options, MS remains an incurable disease that patients will live with throughout their lives. Our findings confirm that dealing with the physical consequences of the disease is only one aspect of living with MS. The financial consequences also loom large, potentially posing threats to emotional health, equanimity, and well-being.

## Acknowledgements

We thank Mary Ellen Colten, PhD, Anthony Roman, MSc, and other staff at the Center for Survey Research, University of Massachusetts, Boston, for their expertise and professional conduct of the telephone survey. We are especially grateful to survey participants who willingly and generously shared their views with us. This research was supported by the National Multiple Sclerosis Society, Contract No. HC 0062.

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