Understanding the Burden of Caring for Patients with Multiple Sclerosis: A US Caregiver Survey

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BACKGROUND

- Multiple sclerosis (MS) is associated with a broad spectrum of symptoms such as weakness, fatigue, difficulty walking, pain, and spasticity, in addition to varying degrees of visual dysfunction, depression, and cognitive impairments[1]
- Studies suggest that MS is more common in populations with northern European ancestry; however, minority populations in the United States, particularly the Black/African American population, may have a higher incidence and risk of MS compared to their ancestral countries of origin; that said, little is reported about the burden of MS in these populations, potentially due to under-representation in studies[2]
- Among the diverse symptoms associated with MS, fatigue is considered one of the most common and debilitating, independent of the extent of neurologic impairment. Eighty percent of patients with MS experience fatigue, with 65% of patients affected daily[3,4]
- In addition to the progressive, disabling nature of MS for patients, around 30% of them rely on caregivers and it is estimated that around 80% of caregivers for these patients are informal or unpaid[5]
- Furthermore, because MS is usually diagnosed between the ages of 20 and 50,[6] a caregiver's role may persist for years or decades
- Despite this, there is a paucity of literature looking at the burden of caregiving for patients with MS, in general and especially in minority populations as well as for patients with MS-related fatigue

OBJECTIVES

- To describe the characteristics of caregivers for adult patients with MS for all caregivers and for subgroups categorized by race and by MS-related fatigue severity
- To describe the burden and quality of life of the caregivers of adult patients with MS from a caregiver perspective for all caregivers and by subgroups of MS-related fatigue severity

METHODS

Data Collection

- A 20-minute online double-blind survey was administered in 2 rounds: once in November 2021 to eligible respondents (first-round sample) and once in January 2022 specifically targeting minority caregivers (second-round sample)
  - Eligible participants in both rounds were ≥18 years of age, living in the United States, and were currently unpaid primary caregivers of patients with MS aged ≥18 years
  - The first round was inclusive of all races but in the second round, survey respondents were additionally screened for self-identifying as a minority (i.e., Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian, or other Pacific Islander)
- Survey respondents in both rounds of administration were recruited from an anonymous online panel via a third-party vendor (Dynata, LLC) and provided their informed consent prior to participating in the survey

Study Measures

- Demographic and socioeconomic characteristics, as well as the duration of time caregivers had been in a caregiver role and their relationship to the patient with MS, were collected
- Caregivers also provided demographic and clinical information such as the duration and severity of the patient's MS and the severity of fatigue symptoms in the patient with MS for whom they provided care
- Caregiver burden and quality of life were evaluated using standardized tools
  - Caregiver burden: Caregiver Burden Inventory (CBI©)[7]
  - Mental health: Hospital Anxiety and Depression Scale (HADS©)[8]
  - Work productivity: Work Productivity and Activity Impairment: Specific Health Problem (WPAI:SHP©)[9]
  - Life satisfaction: Satisfaction With Life Scale (SWLS©)[10]
- The positive aspects of caregiving were assessed via additional questions

Statistical Analysis

- Caregivers' responses from the survey were described and summarized using means, medians, and standard deviations (SD) for continuous variables and frequencies and proportions for categorical variables
- Demographic, socioeconomic, and clinical characteristics from the first- and second-round samples were pooled to present baseline results by race and from White and minority caregivers
- Results were presented descriptively for the first-round sample, which allowed for qualitative assessment of the natural fallout across caregiver characteristics, and for subgroups of patient MS-related fatigue as reported by caregivers on an 11-point scale of 0 ("not severe; happens rarely and/or does not affect their daily physical or social activities") to 10 ("severe; happens often and/or has a considerable impact on their daily physical or social activities"; subgroups were fatigue assessments of 0-6, 7-8, and 9-10)

RESULTS

Characteristics of Patients with MS and their Caregivers

- In the first-round sample, a total of 300 caregivers completed the survey
  - Of the caregivers, 82.3% were male, 86.2% were ≥35 years old, and 96.0% were White; of the patients, 40.0% were male, 76.0% were ≥35 years old, and 96.0% were White (**Table 1**)
  - A total of 43 caregivers (14.3%) reported fatigue severity scores for the patients they care for from 0-6, 88 caregivers (29.3%) reported fatigue scores from 7-8, and 169 caregivers (56.3%) reported scores from 9-10; these were assigned to their respective fatigue subgroups
- In the pooled sample (first- & second-round samples), a total of 352 caregivers completed the survey for the baseline results description by race (n = 286 White and n = 64 minority caregivers)
  - Two participants who self-identified as White and another race in the second-round sample were excluded
  - Of caregivers in the White subgroup, 83.9% were male, 87.4% were ≥35 years old, and 84.6% were employed full-time; of patients in the White subgroup, 40.2% were male, and 75.8% were ≥35 years old (**Table 1**)
  - Of caregivers in the minority subgroup, 57.8% were male, 59.3% were ≥35 years old, 73.4% were Black or African American, and 68.8% were employed full-time; of patients in the minority subgroup, 35.9% were male, 79.7% were ≥35 years old, and 67.2% were Black or African American (**Table 1**)

Table 1. Demographic and Socioeconomic Characteristics of Patients with MS and their Caregivers[a]

	First-round sample		First-round sample subgroups: Level of patient fatigue						Pooled sample subgroups: Caregiver race			
			0-6		7-8		9-10		White		Minority	
	Caregivers N = 300	Patients with MS[b] N = 300	Caregivers N = 43	Patients with MS[b] N = 43	Caregivers N = 88	Patients with MS[b] N = 88	Caregivers N = 169	Patients with MS[b] N = 169	Caregivers N = 286	Patients with MS[b] N = 286	Caregivers N = 64	Patients with MS[b] N = 64
Age at survey date, n (%)												
18-34 years	41 (13.7)	72 (24.0)	5 (11.7)	11 (25.6)	13 (14.8)	9 (10.2)	23 (13.6)	52 (30.8)	36 (12.5)	69 (24.1)	26 (40.6)	13 (20.3)
35-44 years	196 (65.3)	112 (37.3)	18 (41.9)	10 (23.3)	53 (60.2)	30 (34.1)	125 (74.0)	72 (42.6)	191 (66.8)	109 (38.1)	26 (40.6)	14 (21.9)
45-64 years	50 (16.6)	83 (27.7)	11 (25.6)	13 (30.3)	21 (23.8)	37 (42.1)	18 (10.7)	33 (19.6)	47 (16.4)	77 (26.9)	10 (15.6)	30 (46.9)
≥65 years	13 (4.3)	33 (11.0)	9 (20.9)	9 (20.9)	1 (1.1)	12 (13.6)	3 (1.8)	12 (7.1)	12 (4.2)	31 (10.8)	2 (3.1)	7 (10.9)
Male, n (%)	247 (82.3)	120 (40.0)	25 (58.1)	17 (39.5)	71 (80.7)	36 (40.9)	151 (89.3)	67 (39.6)	240 (83.9)	115 (40.2)	37 (57.8)	23 (35.9)
Race, n (%)												
White	288 (96.0)	288 (96.0)	40 (93.0)	40 (93.0)	81 (92.0)	80 (90.9)	167 (98.8)	168 (99.4)	286 (100.0)	284 (99.3)	0 (0.0)	8 (12.5)
Black or African American	5 (1.7)	5 (1.7)	1 (2.3)	1 (2.3)	3 (3.4)	3 (3.4)	1 (0.6)	1 (0.6)	0 (0.0)	1 (0.3)	47 (73.4)	43 (67.2)
American Indian or Alaska Native	4 (1.3)	3 (1.0)	1 (2.3)	1 (2.3)	3 (3.4)	2 (2.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	8 (12.5)	8 (12.5)
Asian, Native Hawaiian or other Pacific Islander	5 (1.7)	3 (1.0)	2 (4.6)	0 (0.0)	3 (3.4)	3 (3.4)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.3)	10 (15.6)	7 (10.9)
Employment status, n (%)												
Employed, full-time	249 (83.0)	88 (29.3)	24 (55.8)	9 (20.9)	71 (80.7)	10 (11.4)	154 (91.1)	69 (40.8)	242 (84.6)	85 (29.7)	44 (68.8)	9 (14.1)
Employed, part-time	18 (6.0)	28 (9.3)	3 (7.0)	5 (11.6)	6 (6.8)	7 (8.0)	9 (5.3)	16 (9.5)	16 (5.6)	28 (9.8)	6 (9.4)	5 (7.8)
Retired	14 (4.7)	58 (19.3)	10 (23.3)	12 (27.9)	2 (2.3)	22 (25.0)	2 (1.2)	24 (14.2)	14 (4.9)	53 (18.5)	1 (1.6)	15 (23.4)
Self-employed	9 (3.0)	6 (2.0)	2 (4.7)	0 (0.0)	4 (4.5)	2 (2.3)	3 (1.8)	4 (2.4)	5 (1.7)	6 (2.1)	4 (6.3)	4 (6.3)
Unemployed	5 (1.7)	56 (18.7)	1 (2.3)	6 (14.0)	3 (3.4)	29 (33.0)	1 (0.6)	21 (12.4)	4 (1.4)	51 (17.8)	6 (9.4)	26 (40.6)
Homemaker or student	3 (1.0)	55 (18.3)	1 (2.3)	9 (21.0)	2 (2.3)	16 (18.2)	0 (0.0)	30 (17.8)	3 (1.0)	54 (18.9)	2 (3.2)	4 (6.3)
Pre-tax household income categories, n (%)												
<$59,999	29 (9.7)	53 (17.7)	10 (23.3)	13 (30.3)	14 (15.9)	27 (30.7)	5 (3.0)	13 (7.8)	25 (8.7)	47 (16.4)	24 (37.5)	31 (48.4)
$60,000-$99,999	32 (10.6)	36 (12.0)	10 (23.2)	11 (25.6)	17 (19.3)	15 (17.1)	5 (3.0)	10 (5.9)	27 (9.4)	32 (11.1)	25 (39.0)	15 (23.4)
$100,000-$149,999	118 (39.3)	107 (35.7)	15 (34.9)	11 (25.6)	27 (30.7)	20 (22.7)	76 (45.0)	76 (45.0)	114 (39.9)	104 (36.4)	9 (14.1)	6 (9.4)
≥$150,000	121 (40.3)	84 (28.0)	8 (18.7)	4 (9.3)	30 (34.1)	20 (22.8)	83 (49.1)	60 (35.5)	120 (42.0)	84 (29.4)	5 (7.8)	3 (4.7)
Mean duration of caregiver role ± SD, years (median)	11.6 ± 12.9 (6.0)	-	14.6 ± 18.1 (6.0)	-	8.7 ± 8.0 (5.3)	-	12.4 ± 13.2 (7.3)	-	11.8 ± 13.1 (6.1)	-	6.3 ± 8.8 (3.5)	-
Relationship of caregiver to MS patient, n (%)												
Spouse or ex-spouse	145 (48.3)	-	19 (44.2)	-	35 (39.8)	-	91 (53.8)	-	143 (50.0)	-	17 (26.6)	-
Parent	63 (21.0)	-	10 (23.3)	-	21 (23.9)	-	32 (18.9)	-	61 (21.3)	-	10 (15.6)	-
Child	41 (13.7)	-	5 (11.6)	-	14 (15.9)	-	22 (13.0)	-	37 (12.9)	-	14 (21.9)	-
Other (sibling, friend, grandparent, or grandchild)	50 (16.7)	-	9 (20.9)	-	17 (19.3)	-	24 (14.2)	-	45 (15.7)	-	19 (29.7)	-

SD, standard deviation; MS, multiple sclerosis.
[a]Results may not add up to 100% because the small sample-size response categories for "other," "unknown," and "unsure/prefer not to answer" are not shown in this table.
[b]Reported from the perspective of the caregiver.

- Caregiver-reported clinical information for the patients they cared for is shown in **Table 2**
  - The most commonly reported MS symptoms for patients in the past month in the first-round sample, White subgroup, and minority subgroup were cognitive impairments, emotional change, fatigue or tiredness, and pain
  - MS symptoms that were observed more frequently with higher levels of fatigue included cognitive impairments, MS hug (tightness/pressure around stomach or chest), vision impairments, and difficulty speaking

Table 2. Clinical Characteristics of Patients with MS[a,b]

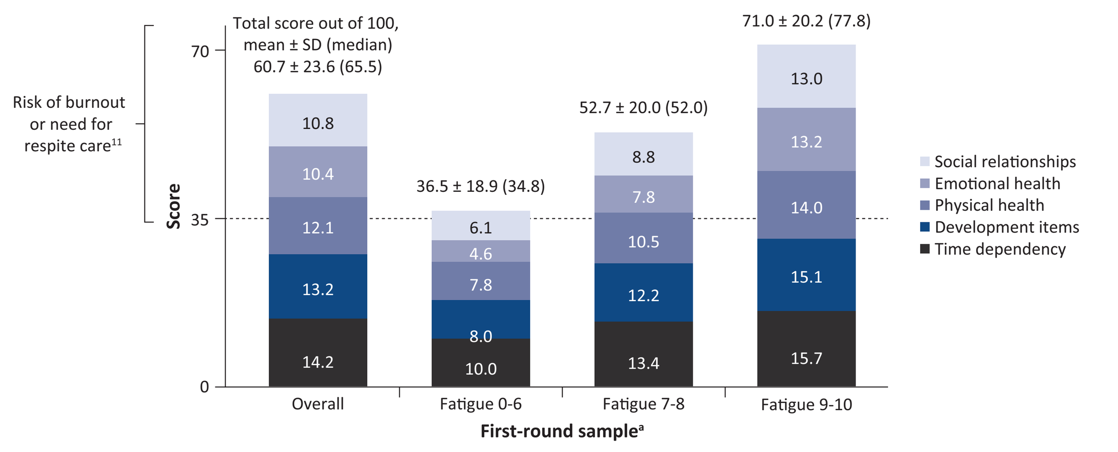
	First-round sample	First-round sample subgroups: Level of patient fatigue			Pooled sample subgroups: Caregiver race	
		0-6	7-8	9-10	White	Minority
	N = 300	N = 43	N = 88	N = 169	N = 286	N = 64
Duration of MS (years), n (%)						
≤5	124 (41.4)	18 (41.9)	38 (43.1)	68 (40.3)	119 (41.6)	39 (60.9)
6-10	103 (34.3)	7 (16.3)	27 (30.7)	69 (40.8)	96 (33.6)	13 (20.3)
>10	71 (23.7)	16 (37.2)	23 (26.1)	32 (18.9)	69 (24.1)	9 (14.1)
MS severity, n (%)						
No disability/able to function normally	28 (9.3)	6 (14.0)	9 (10.2)	13 (7.7)	28 (9.8)	0 (0.0)
Mild or minimal disability	31 (10.3)	8 (18.6)	8 (9.1)	15 (8.9)	31 (10.8)	8 (12.5)
Moderate disability with no impairment to walking and self-sufficient	62 (20.7)	11 (25.6)	19 (21.6)	32 (18.9)	58 (20.3)	14 (21.9)
Significant disability but up and about much of the day, able to work a full day, may require minimal assistance	61 (20.3)	6 (14.0)	18 (20.5)	37 (21.9)	58 (20.3)	22 (34.4)
Severe disability impairing or precluding full daily activities, may require one or two walking aids (e.g., canes, crutches)	56 (18.7)	8 (18.6)	22 (25.0)	26 (15.4)	54 (18.9)	11 (17.2)
Unable to walk even a short distance, relies on wheelchair or remains in bed much of the day	22 (7.3)	3 (7.0)	8 (9.1)	11 (6.5)	18 (6.3)	9 (14.1)
Remains in bed and may or may not be able to eat without help and unable to communicate effectively	40 (13.3)	1 (2.3)	4 (4.5)	35 (20.7)	39 (13.6)	0 (0.0)
MS symptoms in the past month, n (%)						
Cognitive impairments	149 (49.7)	12 (27.9)	44 (50.0)	93 (55.0)	144 (50.3)	29 (45.3)
Emotional changes	118 (39.3)	15 (34.9)	37 (42.0)	66 (39.1)	112 (39.2)	29 (45.3)
Fatigue or tiredness	117 (39.0)	26 (60.5)	37 (42.0)	54 (32.0)	107 (37.4)	38 (59.4)
Pain (generalized or localized)	110 (36.7)	18 (41.9)	43 (48.9)	49 (29.0)	100 (35.0)	34 (53.1)
MS hug	104 (34.7)	4 (9.3)	26 (29.5)	74 (43.8)	102 (35.7)	9 (14.1)
Bladder or bowel problems	92 (30.7)	13 (30.2)	26 (29.5)	53 (31.4)	86 (30.1)	23 (35.9)
Depressive symptoms	91 (30.3)	16 (37.2)	33 (37.5)	42 (24.9)	84 (29.4)	25 (39.1)
Walking (gait) difficulties	89 (29.7)	16 (37.2)	42 (47.7)	31 (18.3)	82 (28.7)	27 (42.2)
Involuntary movements	81 (27.0)	11 (25.6)	19 (21.6)	51 (30.2)	75 (26.2)	13 (20.3)
Numbness or tingling	77 (25.7)	20 (46.5)	27 (30.7)	30 (17.8)	72 (25.2)	26 (40.6)
Vision problems	75 (25.0)	6 (14.0)	25 (28.4)	44 (26.0)	69 (24.1)	19 (29.7)
Difficulty speaking	76 (25.3)	5 (11.6)	21 (23.9)	50 (29.6)	70 (24.5)	21 (32.8)
Spasticity	75 (25.0)	9 (20.9)	17 (19.3)	49 (29.0)	67 (23.4)	18 (28.1)
Weakness (generalized or in one or more limbs)	64 (21.3)	13 (30.2)	31 (35.2)	20 (11.8)	56 (19.6)	31 (48.4)
Vertigo, lightheadedness, and dizziness	59 (19.7)	11 (25.6)	22 (25.0)	26 (15.4)	51 (17.8)	27 (42.2)
Mean severity of fatigue symptoms ± SD in the past month (median)	8.3 ± 2.0 (9.0)	4.5 ± 1.7 (5.0)	7.6 ± 0.5 (8.0)	9.7 ± 0.5 (10.0)	8.4 ± 2.0 (9.0)	6.2 ± 2.1 (6.0)

SD, standard deviation; MS, multiple sclerosis.
[a]Results may not add up to 100% because the small sample-size response categories for "other," "unknown," and "unsure/prefer not to answer" are not shown in this table.
[b]Data were reported from the perspective of the caregiver.

Quality of Life Measures

- Caregivers in the first-round sample and fatigue subgroups reported mean total CBI scores of more than 35, suggesting a need for respite care/risk of burnout[11] (**Figure 1**)
  - There was a notable numeric increase in total CBI scores between the fatigue 0-6 subgroup and the fatigue 9-10 subgroup

Figure 1. Caregiver Burden Inventory Scores

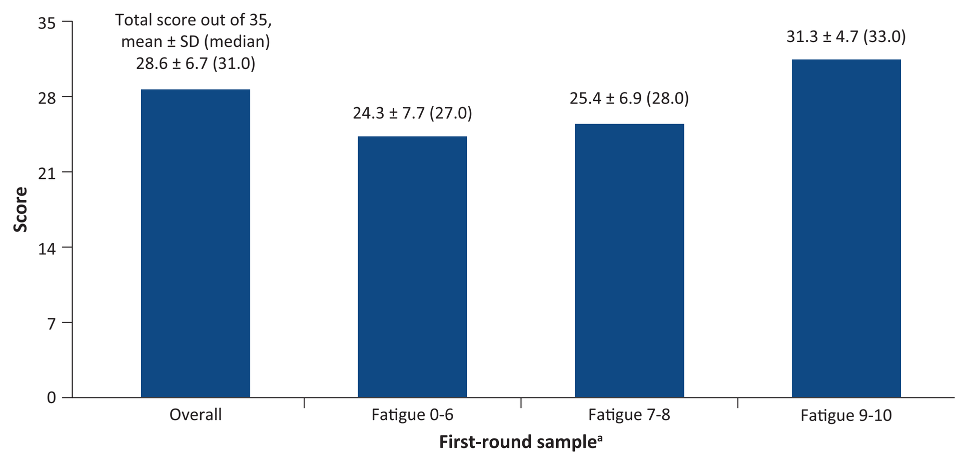


[a]Fatigue subgroups were defined by patient MS-related fatigue as reported by caregivers on a scale of 0 ("not severe; happens rarely and/or does not affect their daily physical or social activities") to 10 ("severe; happens often and/or has a considerable impact on their daily physical or social activities").

- Caregivers in the first-round sample reported "moderate" anxiety (mean score ± SD: 13.3 ± 4.4) and "normal" depression (6.0 ± 3.2), based on the HADS questionnaire
  - There was a numeric increase in anxiety scores between the fatigue 0-6 subgroup (9.1 ± 4.0) and the fatigue 9-10 subgroup (14.9 +/− 3.9), but depression scores remained relatively consistent for all subgroups

- Caregivers in the first-round sample reported high degrees of overall work impairment (mean percentage ± SD: 81.2 ± 27.4) and regular activity impairment (75.0 ± 30.0) due to their caregiver role
  - There was a numeric increase in the percentages of overall work impairment (fatigue 0-6 subgroup: 51.6 ± 29.7, fatigue 9-10 subgroup: 91.9 ± 19.2) and regular activity impairment from the fatigue 0-6 subgroup to the fatigue 9-10 subgroup (fatigue 0-6 subgroup: 44.9 ± 29.1, fatigue 9-10 subgroup: 87.5 ± 25.3)
- Caregivers in the first-round sample reported a "high" life satisfaction, with a mean score of 28.6 based on the SWLS instrument (**Figure 2**)
  - There was a numeric increase in the reported average life satisfaction from the fatigue 0-6 subgroup to the fatigue 9-10 subgroup

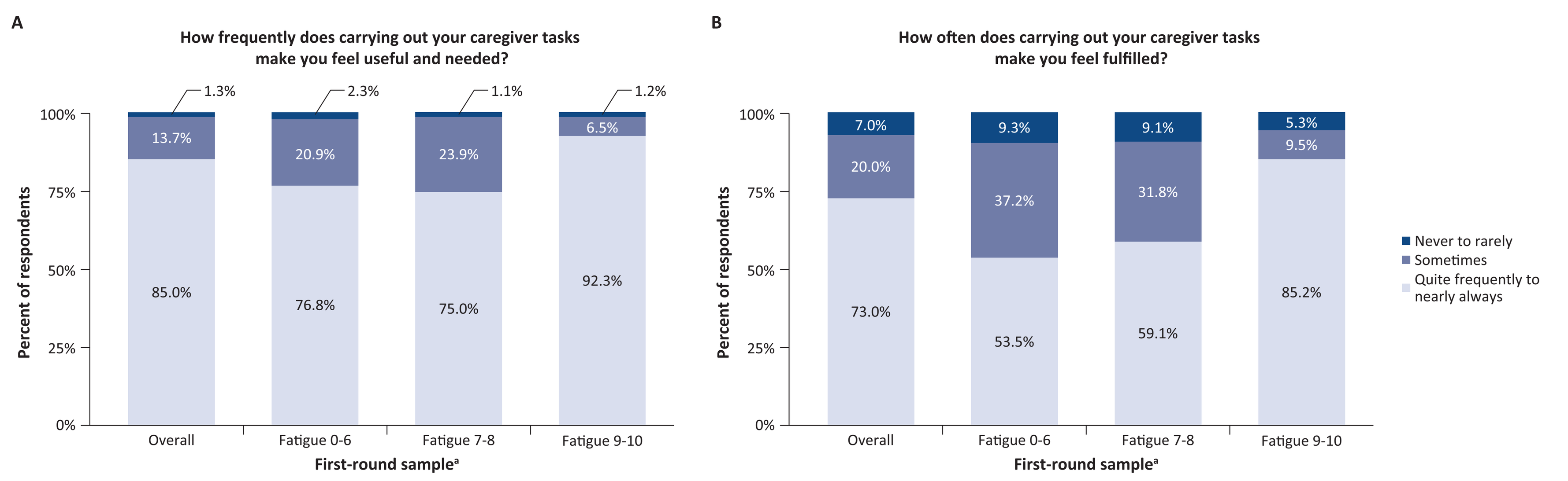
Figure 2. Satisfaction With Life Scale Scores



[a]Fatigue subgroups were defined by patient MS-related fatigue as reported by caregivers on a scale of 0 ("not severe; happens rarely and/or does not affect their daily physical or social activities") to 10 ("severe; happens often and/or has a considerable impact on their daily physical or social activities").

- Most caregivers reported that carrying out their caregiver tasks made them feel useful and needed quite frequently or nearly always (85.0% in the first-round sample, 76.8% in the fatigue 0-6 subgroup, 75.0% in the fatigue 7-8 subgroup, and 92.3% in the fatigue 9-10 subgroup; **Figure 3A**)
- Nearly three-quarters (73.0%) of caregivers reported that carrying out their caregiver tasks made them feel fulfilled quite frequently or nearly always
  - There was a numeric increase in the proportion of caregivers who reported quite frequently or nearly always feeling fulfilled from the fatigue 0-6 subgroup (53.5%) to the fatigue 9-10 subgroup (85.2%) (**Figure 3B**)

Figure 3. Positive Aspects of Caregiving



[a]Fatigue subgroups were defined by patient MS-related fatigue as reported by caregivers on a scale of 0 ("not severe; happens rarely and/or does not affect their daily physical or social activities") to 10 ("severe; happens often and/or has a considerable impact on their daily physical or social activities").

LIMITATIONS

- Data for this analysis were self-reported by caregivers and may be subject to recall bias
- Although attempts were made to minimize selection bias (e.g., enrolling a relatively large number of participants from a nationwide panel), there remains a potential for bias given that caregivers' decision to be on a panel and to contribute to the survey is not random. Hence, the results of this study may not be generalizable to caregivers outside this survey panel
- As the clinical characteristics and demographic information for patients were reported from the perspective of the caregiver, inaccuracies in this information compared to the diagnosis and clinical information from physician visits is possible
- Race and other socioeconomic characteristics may have an impact on the burden of caregiving and needs to be studied further. Moreover, results were descriptive in nature; further research with adjusted comparisons is needed to assess if observed numerical differences between subgroups are statistically significant

CONCLUSIONS

- Surveyed caregivers of patients with MS reported a high caregiver burden with risk of burnout, moderate anxiety levels, and high productivity impairment due to caregiving responsibilities
- Despite this, the majority reported high satisfaction with life and feeling useful, needed, and fulfilled due to their caregiving role, suggesting that meaningfulness found in caregiving may offset some burden
- There were important numeric differences within the reported severity of fatigue results, particularly in measures of caregiver burden, anxiety, work productivity, life satisfaction, and the percentage who felt fulfilled by carrying out caregiver tasks
- Socioeconomic characteristics appeared to differ between White and minority caregivers; further research is needed to assess the impact that race or ethnicity and socioeconomic factors may have on the burden of caring for patients with MS

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Disclosures

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