

Caregiver Burden Among Informal Caregivers Assisting People with Multiple Sclerosis

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Multiple sclerosis (MS) burdens not only patients but also their informal or family caregivers. This study was conducted to identify characteristics of caregivers, caregiving, and MS patients receiving informal care that are associated with caregiving burden. Data were collected through a national survey of informal MS caregivers and analyzed using an ordered logistic regression model to identify factors associated with burden. Burden was found to be significantly greater among male caregivers than among female caregivers. Moreover, greater burden was associated with more frequent patient bladder dysfunction, more hours per week spent providing assistance, and greater restriction on the caregiver's ability to perform daily activities because of caregiving responsibilities. A strong association was found between the mental health status of the caregiver and burden. Health professionals should be sensitive to the impact of caregiving on the mental health of MS caregivers. The results of this study suggest that treating patient bladder dysfunction and facilitating respite care may reduce burden and improve the mental health of informal caregivers of people with MS. Future research should identify programs and services designed specifically to reduce burden experienced by male caregivers. Int J MS Care. 2011;13:76–83.

Multiple sclerosis (MS) is characterized by episodes of neurologic symptoms that are often followed by fixed neurologic deficits, increasing disability, and medical and physical decline over 30 to 40 years.^{1,2} The progress and severity of MS symptoms are unpredictable, however, varying widely among those affected.^{3–5} About 30% of people with MS require some form of supportive assistance at home, with 80% of such care provided by informal or unpaid caregivers, usually the patient's spouse.^{6–10} Informal caregivers provide a range of services to people with MS, including assistance with personal care, homemaking, mobility, and leisure activities.^{8,9,11,12} Assistance from informal caregivers enables people with MS to remain in their homes as their functional dependence and need for assistance with daily activities increase.¹³

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Caregiver Burden and MS Care

One study found that more than 20% of informal caregivers assisting people with MS thought that this caregiving was burdensome either most (11%) or all (10%) of the time.¹⁰ Caregiver burden is a multidimensional reaction to a number of factors associated with providing daily assistance to the person with MS, including physical, psychological, emotional, and social stressors.¹⁴ A study of informal caregivers assisting people with MS in Spain found that emotional and vitality factors in the caregiver and disability level in the person with MS were major predictors of caregiving burden.¹⁵ Khan et al.¹⁶ found that caregiver burden was higher in those assisting people with more severe MS.

Another study concluded that psychiatric symptoms and cognitive impairment in the person with MS were significant contributors to caregiver distress.¹⁷ Forbes et al.¹⁸ found that MS disease impact and patient/caregiver health explained most of the variance in the burden of caregiving. Therapeutic strategies to reduce caregiver burden are needed to improve the health status and health-related quality of life (HRQOL) of informal caregivers as well as people with MS receiving their

assistance.^{16,19} Early recognition of caregiving burden and identification of factors linked with this burden are important to determine appropriate interventions.¹⁴ Thus the objective of the present study was to identify factors associated with burden among caregivers assisting people with MS.

Methods

The data analyzed in this study were collected in a national survey of 530 people providing informal care to individuals with MS, with 430 caregivers providing all the data needed to implement our regression model. The sample of informal caregivers was developed by contacting people with MS who were participating in the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry. The NARCOMS Registry was created in 1993 by the Consortium of Multiple Sclerosis Centers (CMSC); currently, more than 34,000 people with MS participate in routine data collection.²⁰ It is estimated that up to 10% of Americans with MS are in the NARCOMS Registry.²¹ Registry participants are assured that their names will not be disclosed to anyone without the participant's written permission.

Our study focused on caregiving to more functionally impaired people with MS. Functional impairment is measured in the NARCOMS Registry using the Patient-Determined Disease Steps (PDDS) scale, a self-assessment of how well the person with MS walks, with scores ranging from 0 (normal) to 8 (bedridden).²² We included in our study only those Registry participants who needed a cane to walk 25 feet (score of 5), required bilateral support (score of 6), primarily used a wheelchair or scooter (score of 7), or were bedridden (score of 8).

Survey Process

We identified 4943 NARCOMS Registry participants with MS who met our impairment criteria to receive a recruitment letter requesting their assistance in identifying informal caregivers. The letter explained the purpose of the study, stating that we wanted to interview "the person who provides the majority of informal or unpaid care to you to help you cope with the effects of MS on your daily life." The letter requested that the person with MS ask the person who provided the majority of their informal care to call a toll-free telephone number to complete a computer-assisted telephone interview administered by the Public Policy Research Institute (PPRI) at Texas A&M University. The caregiver survey received human subjects approval from the Office of

Regulatory Compliance at Mississippi State University in June 2006 and by the Office of Research Compliance Institutional Review Board at Texas A&M University in July 2006. Mailing of recruitment letters began in September 2006, and the survey was halted in March 2007, when no caregivers called in for 2 weeks.

Calculation of a meaningful participation rate for the survey is difficult because we do not know how many people with MS receiving the recruitment letter had an informal caregiver. It is estimated that about 30% of people with MS require some form of home care assistance and that 80% of that assistance is provided by informal caregivers.^{6,7} Using those estimates, about 25% of people with MS receive home care assistance provided by an informal caregiver, or about 1235 of the 4943 people with MS who were sent recruitment letters. Given the study's focus on more functionally dependent people with MS, an estimate of 1235 informal caregivers may be low. Assuming 1235 informal caregivers, 530 completed interviews yields a participation rate of 43%.

Caregiver Interview Questionnaire

The caregiver survey was designed to record the caregiver's perceptions of the impact of MS on the person receiving their care, the care needs of the person with MS, informal care and services provided, and how assisting the person with MS affected the caregiver. The interview, which averaged about 30 minutes, asked about the caregiver's relationship with the person with MS; the patient's MS disease and symptom characteristics, cognitive decision making, and incontinence; and demographic information about the person with MS and the caregiver. The caregiver was asked to rate on a scale from 0 to 10 the extent to which MS symptoms affected the patient's independence in daily life, with 0 indicating no interference at all and 10 indicating the most severe interference.

The interviewer provided a list of statements designed to assess the caregiver's feelings and attitudes about assisting the person with MS, including "caregiving is burdensome." Caregiver burden was measured using a 5-point Likert item, with possible responses of none of the time, once in a while, some of the time, most of the time, and all of the time. The caregiver was asked to report the average number of hours per week they spent helping the person with MS cope with the effects of their illness. The caregiver was also asked to rate on a scale from 0 to 10 the extent to which assisting the person with MS "affects your ability to perform activities

in daily life that are important to you,” with 0 indicating no negative impact at all and 10 indicating the most severe impact. The caregiver was asked whether any paid caregiver was employed to help the patient perform activities necessary in day-to-day life.

The interview included the 8-item Short Form Health Status Survey (SF-8) to measure caregiver HRQOL.^{23,24} This instrument includes a Mental Component Summary (MCS). Higher scores on the SF-8 indicate better health status. Previous studies documented the validity of the SF-8 in the United States,²⁴ and the instrument meets standard evaluation criteria for content, construct, and criterion-related validity.²³ The MCS was included in our analysis as a measure of the mental health status of the caregiver.

Ordered Logistic Regression Model

An ordered logistic regression model using survey data was developed to analyze the contributions of characteristics of the person with MS and the caregiver to caregiver burden. The analyses included 430 caregivers in the regression model (caregivers who provided all data in their survey responses needed to implement the model). The dependent variable, measured with ordinal data, was the caregiver’s assessment of the burden of providing assistance to the person with MS. Caregiver burden was measured using a 5-point Likert item, with possible responses of none of the time, once in a while, some of the time, most of the time, and all of the time.

The model included 17 independent variables theorized to have predictive power in caregiver burden. These independent variables along with descriptions of how they were coded are presented in Table 1. The independent variables are other survey responses from the informal caregivers, including MS symptoms, demographic and overall health assessments of the person with MS and the caregiver, time spent providing informal care, the impact of providing assistance on the caregiver’s day-to-day life, and the caregiver’s SF-8 MCS. The model identified eight characteristics of the caregiver, caregiving, and the person with MS being assisted that were significantly associated with caregiver burden.

Results

Descriptive Characteristics

People with MS

Table 2 provides descriptive statistics for the people with MS included in our analyses. A large majority of

people with MS in our study were female (64%). Their average age was 58.3 years, and most had 2006 family incomes below \$50,000 per year (70%). Symptoms of MS interfered with independence in day-to-day life for most people with MS in our study, with nearly 95% experiencing at least moderate interference (a response of 4 or higher on the scale of 0 to 10). Large majorities of people with MS in our study had bowel and bladder dysfunction.

Caregivers

As shown in Table 3, 54% of informal caregivers in our study were male, the average age of the caregivers was 59.6 years, and about 83% were the spouse of the person with MS. Nonspousal caregivers included a child, parent, or neighbor/friend of the person with MS. About half of the caregivers said they provided more than 20 hours of assistance each week to the person with MS, while only about 11% said they provided 5 or fewer hours of informal care per week. About 64% of the caregivers replied that assisting the person with MS had at least a moderate impact on their ability to perform daily activities that were important to the caregiver (a response of 4 or higher on the scale of 0 to 10).

Ordered Logistic Regression

As Table 4 demonstrates, we identified three characteristics of the person with MS receiving informal care that were significantly associated with caregiver burden. First was worse overall health. A one-unit deterioration in reported overall health of the person with MS (eg, good health vs. fair health) increased the odds of the caregiver reporting higher levels of burden by 20.1%. A second characteristic was increased frequency of bladder dysfunction. Higher frequency of bladder dysfunction (eg, ≥ 2 times per week but not daily incontinence vs. daily bladder problems with some control) increased the odds of greater caregiver burden by 15.6%. Finally, gender of the person with MS was significantly associated with burden, with female gender reducing the odds of greater caregiver burden by 45.3%.

We identified five characteristics of the caregiver or caregiving that were significantly associated with burden. First was the gender of the caregiver: female caregivers had 41.5% lower odds of reporting greater burden. The average number of hours per week spent assisting the person with MS was also significantly linked to burden, with increased hours associated with greater burden. A one-unit increase in reported number of hours per week

Table 1. Independent variables used in analyses of burden among informal caregivers assisting people with MS

Independent variable	Description/coding of independent variable
Characteristics of the person with MS	
Current overall health	1 = excellent; 2 = very good; 3 = good; 4 = fair; 5 = poor
MS symptoms affect independence in day-to-day life	0 to 10 scale; 0 = no interference, 10 = most severe interference ^a
Cognitive skills for daily decision making	0 = independent; 1 = modified independence; 2 = moderately impaired; 3 = severely impaired
Bowel dysfunction	0 = no dysfunction; 1 = less than weekly; 2 = once a week; 3 = 2–3 times per week; 4 = all or almost all the time
Bladder dysfunction	0 = no dysfunction; 1 = once a week or less; 2 = ≥2 times per week (but not daily); 3 = daily bladder problems, with some control; 4 = multiple daily episodes, inadequate control
Gender	1 = male; 2 = female
Age	Age, using date of birth and date of interview
Family income	1 = <\$25,000; 2 = \$25,000–49,999; 3 = \$50,000–74,999; 4 = \$75,000–99,999; 5 = ≥\$100,000
Characteristics of the caregiver	
Spouse of person with MS	0 = no; 1 = yes
Gender	1 = male; 2 = female
Age	Age, using date of birth and date of interview
Average number of hours per week providing care	1 = <1; 2 = 1–5; 3 = 6–10; 4 = 11–15; 5 = 16–20; 6 = >20
Other unpaid caregivers assist person with MS	1 = yes; 2 = no
Paid caregivers assist person with MS	0 = no; 1 = yes (received any of the following paid services: home health aide, home health nurse, housekeeping/homemaker services, or other paid caregiver)
Caregiving affects caregiver's ability to perform important daily activities	0 to 10 scale; 0 = no negative impact, 10 = most severe limit ^a
Current overall health	1 = excellent; 2 = very good; 3 = good; 4 = fair; 5 = poor
Mental Component Summary of the SF-8	Scores ranged from 20 to 69, with higher scores indicating better mental health-related quality of life

Abbreviations: MS, multiple sclerosis; SF-8, 8-item Short Form Health Status Survey.

^aFor the analyses this scale was collapsed into three groups: Group 1 = 0–3; Group 2 = 4–7; Group 3 = 8–10.

providing care (eg, an increase from 6–10 hours per week to 11–15 hours per week) increased the odds of the caregiver reporting higher levels of burden by 22.4%. Similarly, the more the caregiver perceived that assisting the person with MS limited their ability to perform important activities in their daily lives, the greater the level of burden reported. A one-unit increase in reported impact of caregiving on the ability of the caregiver to perform important daily activities (eg, moderate impact [Group 2] vs. major impact [Group 3]) increased the odds of the caregiver reporting higher levels of burden by 125%.

We found a significant association between the MCS of the SF-8 and burden, with higher scores for this

mental health measure linked to lower levels of burden. A 1-point increase in the MCS reduced the odds of the caregiver reporting greater levels of burden by 6.6%. The use of a paid caregiver to help the person with MS perform activities of daily living increased the odds of informal caregivers reporting greater levels of burden by 62.3%.

Discussion

We identified a number of characteristics of the caregiver, caregiving, and the person with MS receiving care that were significantly associated with caregiver burden. Consistent with the findings of Forbes et al.,¹⁸ we found that worse overall health among people with MS was significantly associated with increased caregiver

Table 2. Characteristics of the person with MS

Survey characteristic	Caregiver response
Demographics	
Female, %	64.2
Age (at time of survey), ^a y	
Mean (SD)	58.3 (9.8)
Minimum	21.9
Maximum	85.1
Family income, %	
<\$25,000	45.1
\$25,000–49,999	25.3
\$50,000–74,999	16.3
\$75,000–99,999	6.0
≥\$100,000	7.2
Health and MS characteristics	
Overall health, %	
Excellent	7.9
Very good	17.2
Good	36.0
Fair	25.1
Poor	13.7
MS symptoms affect independence in day-to-day life, ^b %	
Mean (SD) score	7.3 (2.0)
Minimal interference (Group 1: 0–3)	5.1
Moderate interference (Group 2: 4–7)	41.4
Major interference (Group 3: 8–10)	53.5
Cognitive skills for daily decision making, %	
Independent (daily decisions appropriate)	48.4
Modified independence (some difficulty with new tasks or situations)	29.3
Moderately impaired (decisions poor/supervision required)	16.7
Severely impaired (rarely/never makes decisions)	5.6
Bowel dysfunction, %	
No dysfunction	34.2
Less than weekly	13.5
Once a week	10.9
2–3 times per week	12.6
All or almost all the time	28.8
Bladder dysfunction, %	
No dysfunction	21.4
Once a week or less	14.9
≥2 times per week (but not daily)	10.5
Tends to have daily bladder problems, with some control	22.3
Multiple daily episodes, inadequate control	30.9

Abbreviation: MS, multiple sclerosis.

^aAge is converted from months to years for presentation in this table.

^bA scale of 0 to 10 is used to describe interference, with 0 = no interference at all and 10 = most severe interference. Using possible interview responses of 0 to 10, the scale was collapsed into three groups: Group 1 = 0–3; Group 2 = 4–7; Group 3 = 8–10.

burden. However, in contrast to the findings of Forbes et al., we found that caregiver burden was significantly greater among men than among women. Future research is needed to identify programs and services specifically designed to reduce the burden experienced by male caregivers assisting people with MS. We also found that caregivers of either gender assisting males with MS experienced significantly greater burden. Informal caregivers reporting that a paid caregiver also assisted the person with MS had higher odds of reporting greater burden. The presence of a paid caregiver may be due to greater disability in the person with MS or a flare-up of MS symptoms leading to greater caregiver burden. Our findings indicate that treating bladder dysfunction among MS patients, providing access to respite care, and improving the mental health of caregivers would help reduce caregiver burden.

Bladder Dysfunction

Bladder dysfunction is among the most distressing and socially disabling problems associated with MS, affecting the quality of daily life and leading to social isolation.^{25–27} Consistent with our findings, Bosma et al.²⁸ concluded that bladder dysfunction may increase the burden experienced by the partner or caregiver of the person with MS. However, bladder dysfunction can be prevented or symptomatically treated through various strategies, including pharmacologic therapies and behavioral approaches.^{25–31} Del Popolo et al.²⁹ concluded that behavioral rehabilitation and conservative treatments for bladder dysfunction are sufficient for most MS patients, with innovations in neurourology improving urologic function and QOL for patients not responding to first-line treatments. Options for bladder management in MS care have improved, and more patients are receiving effective treatment, with bladder problems often treated at the same clinic providing neurologic care.³¹ Our findings indicate that reducing bladder dysfunction in people with MS could result in decreased caregiver burden.

Respite Care

We found that burden was significantly associated with the number of hours per week the caregiver provided assistance, as well as with restrictions on the caregiver's ability to perform important daily activities due to caregiving responsibilities. Previous studies found that caregivers experienced high levels of stress and substantial burden, with risk of "burnout" a possibility for those without support.^{32,33} Respite services provide caregivers

Table 3. Characteristics of the caregiver

Survey characteristic	Caregiver response
Demographics	
Male, %	53.7
Age (at time of survey), ^a y	
Mean (SD)	59.6 (11.6)
Minimum	20.1
Maximum	83.8
Spouse of person with MS, %	82.6
Health	
Overall health, %	
Excellent	24.0
Very good	32.1
Good	30.7
Fair	10.9
Poor	2.3
Mental Component Summary of the SF-8	
Mean (SD)	49.5 (8.1)
Minimum	19.6
Maximum	68.8
Caregiving	
Caregiving affects caregiver's ability to perform important daily activities, ^b %	
Mean (SD) score	4.7 (3.0)
Minor impact (Group 1: 0–3)	36.3
Moderate impact (Group 2: 4–7)	42.1
Major impact (Group 3: 8–10)	21.6
Other unpaid caregivers assist person with MS, %	41.6
Paid caregivers assist person with MS, %	46.5
Hours per week informal caregiver provides care to person with MS, %	
<1	2.1
1–5	9.1
6–10	12.6
11–15	10.9
16–20	15.6
>20	49.8

Abbreviations: MS, multiple sclerosis; SF-8, 8-item Short Form Health Status Survey.

^aAge is converted from months to years for presentation in this table.

^bA scale of 0 to 10 is used to describe impact, with 0 = no negative impact at all and 10 = most severe impact. Using possible interview responses of 0 to 10, the scale was collapsed into three groups: Group 1 = 0–3; Group 2 = 4–7; Group 3 = 8–10.

with temporary relief and the opportunity to pursue important activities, which may reduce their perceived burden.^{34,35} Respite services include adult day care, in-home respite, institutional respite, and host respite (in which the care recipient stays in the home of the service provider for short periods).³²

A previous study found that only small proportions of informal caregivers assisting people with MS reported the use of respite services, such as at-home respite care (5.3% of caregivers), adult day care (3.6%), or inpatient respite care (1.5%).¹² That study also found that many informal caregivers not using respite care thought these services were needed, such as at-home respite care (29% of caregivers), inpatient respite care (16%), or adult day care (15%). A study of Dutch informal caregivers found that more than one-third needed but did not ask for respite care,³³ indicating a need to educate caregivers about the availability and benefits of respite care.

Mental Health

This study identified a strong and significant relationship between caregiver burden and mental health dimensions of the caregiver's HRQOL. A previous study of informal caregivers assisting people with MS found that about one in four caregivers reported the need for treatment from a mental health professional in the previous 12 months, but only one-third of caregivers reporting the need for counseling sought this care.¹⁰ Providing informal care to a person with MS can have a negative impact on the caregiver's psychological well-being.^{13,16,17,36} Pozzilli et al.¹⁹ observed that depression in caregivers was linked to the physical, emotional, and health status of the people with MS receiving assistance, concluding that informal caregivers would benefit from access to independent and targeted therapies. A study of informal caregivers assisting people with Alzheimer's disease found that higher burden led to greater feelings of depression among caregivers.³⁷

Interventions and therapeutic strategies to reduce caregiver burden are needed to improve the health status and HRQOL of caregivers and people with MS receiving their assistance.^{16,19} Early recognition of caregiver burden and identification of factors linked with this burden are important to determine appropriate interventions.¹⁴ Health professionals should be sensitive to the impact of caregiving on the mental health dimensions of HRQOL experienced by caregivers. As advocated by Patti et al.,³⁸ informal caregivers assisting people with

Table 4. Factors associated with caregiver burden

Independent variable	Coefficient estimate	Proportional odds ratio	Significance (P value)
Characteristics of the person with MS			
Age, mo	-0.001 (0.001)	0.999 (0.001)	.573
Gender	-0.604 (0.256)	0.547 (0.140)	.019
Family income	0.141 (0.092)	1.151 (0.106)	.126
Current overall health	0.184 (0.093)	1.201 (0.111)	.048
MS symptoms affect independence in daily life	0.177 (0.170)	1.194 (0.203)	.299
Cognitive skills for daily decision making	0.012 (0.125)	1.012 (0.126)	.924
Bowel dysfunction	-0.096 (0.060)	0.908 (0.055)	.109
Bladder dysfunction	0.145 (0.064)	1.156 (0.074)	.024
Characteristics of the caregiver			
Spouse of person with MS	-0.050 (0.240)	0.951 (0.228)	.833
Age, mo	-0.0004 (0.001)	0.9996 (0.001)	.638
Gender	-0.537 (0.243)	0.585 (0.142)	.028
Average number of hours/week providing care	0.202 (0.074)	1.224 (0.090)	.006
Caregiving affects caregiver's ability to perform important activities	0.812 (0.168)	2.252 (0.379)	<.001
Current overall health	-0.003 (0.094)	0.997 (0.094)	.975
Mental Component Summary (SF-8)	-0.069 (0.012)	0.934 (0.012)	<.001
Other unpaid caregiver	0.261 (0.190)	1.299 (0.247)	.170
Paid caregivers	0.485 (0.191)	1.623 (0.310)	.012

Note: Data are given as value (SE).

MS should be referred to supportive programs that may benefit them.

Study Limitations

The survey sample of informal caregivers in this study was developed by contacting people with MS who participated in the NARCOMS Registry. Such participation is voluntary; thus the Registry membership is not a random sample of people with MS, resulting in possible

selection bias. However, the Registry population is large, accounting for an estimated 10% of the MS population in the United States.²² In addition, Registry participants have age at onset of MS symptoms and demographic characteristics comparable to those of people with MS in the National Health Interview Survey and the Slifka Study (a representative national sample of people with MS).^{22,39,40} Another possible limitation of our study is its reliance on caregivers' perceptions of the dependency and care needs of the people with MS, as well as the care provided. A previous study found that caregivers reported providing more frequent care and for a longer duration than people with MS reported receiving.⁸

Conclusion

The results of this study indicate that treating bladder dysfunction of MS patients and providing access to respite care could reduce the burden of informal caregivers, improving their mental health. Future research is needed to identify programs and services specifically designed to reduce the burden experienced by male caregivers. Given the strong association of burden and the MCS of the SF-8, our findings highlight the importance of addressing the mental health needs of informal caregivers assisting people with MS. □

Practice Points

- Caregiver burden in MS is significantly associated with the number of hours per week spent providing assistance, the extent to which caregiving responsibilities restrict the caregiver's ability to perform important daily activities, and the frequency of bladder dysfunction in the person receiving assistance.
- Caregiver burden is also strongly and significantly related to mental health dimensions of the caregiver's health-related quality of life.
- Improved control of bladder dysfunction among MS patients may help reduce caregiver burden.
- Our findings highlight the importance of addressing the mental health needs of informal caregivers assisting people with MS.

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