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# Fear of falling and associated activity curtailment among middle aged and older adults with multiple sclerosis

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The purpose of this study was to identify factors associated with increased likelihood of reporting fear of falling (FoF) among people with multiple sclerosis (MS) and factors associated with activity curtailment among the subset of individuals reporting FoF. Cross-sectional data from telephone interviews with 1064 individuals with MS, aged 45–90 years living in the Midwestern United States were used. Logistic regression models examined factors associated with FoF and with activity curtailment among individuals reporting FoF. Of the participants, 63.5% reported FoF. Increased likelihood of reporting FoF was associated with being female, experiencing greater MS symptom interference during everyday activities, history of a fall in the past 6 months, and using a walking aid. Among participants reporting FoF, 82.6% reported curtailing activity. Increased likelihood of activity curtailment among people reporting FoF was associated with using a walking aid, needing moderate or maximum assistance with instrumental activities of daily living, and having less than excellent self-reported mental health. We concluded that FoF and associated activity curtailment are common among people aged 45–90 with MS. While FoF and associated activity curtailment may be appropriate responses to fall risk, the findings suggest that factors beyond realistic appraisal of fall risk may be operating. *Multiple Sclerosis* 2007; 13: 1168–1175. <http://msj.sagepub.com>

**Key words:** fear of falling; multiple sclerosis; physical activity

## Introduction

Multiple sclerosis (MS) is one of the most common chronic degenerative neurological diseases of the brain and spinal cord seen in the northern latitudes [1]. People with MS (PwMS) experience a range of variable symptoms that may influence their ability to ambulate and transfer safely. These symptoms include loss of balance, weakness, fatigue, cognitive impairment, spasticity and tremor [2]. Although MS can result in considerable disability, it does not significantly reduce life expectancy unless the impairments associated with the disease are severe [3]. Nevertheless, many PwMS face decisions about how to maintain autonomy and control much earlier in their lives in comparison to their cohort peers [4].

Fear of falling (FoF) is a common and modifiable source of excess disability among older adults. Prevalence estimates suggest that at least 24% of community-dwelling elderly experience FoF [5]. Higher prevalence is associated with a fall history [6], advanced age [7], or fall risk factors, such as rheumatoid arthritis or chronic dizziness [8,9]. Many older adults report activity curtailment associated with FoF. The prevalence of FoF and associated activity curtailment (FoFAC) ranges from 19% to 56% among older adults with and without known fall risk factors [5,8,10,11]. FoFAC is not experienced exclusively by older adults. Among people aged 45–65 years, 10–13% report limiting activity due to FoF [12,13].

Prospective studies suggest that both FoF and FoFAC deserve the attention of health care

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providers. FoF can lead to functional decline [14,15], and can precipitate falls, deterioration in perceived health status and increased risk of admission to institutional care [14]. People who limit activity because of FoF are at particularly high risk of becoming fallers [16,17]. Fortunately, evidence from randomized trials suggests that among older adults, both FoF and FoFAC can be mitigated [18,19].

To date, there has been no description of FoF and associated activity curtailment among PwMS, which is surprising given the prevalence of MS and the nature of MS symptoms. Although limited, evidence to date suggests that falls are common among PwMS [20–22]. Work by Finlayson *et al.* [22] demonstrated that FoF is independently associated with fall risk and pointed to the need to further understand this phenomenon among PwMS. This study builds on this previous work and examines risk factors associated with FoF and FoFAC in a sample of 1064 people aged 45–90 with MS living in the Midwest USA.

## Methods

### Selection and description of participants

Participants for this study were part of a larger study focused on identifying and describing the unmet health-related service needs of people aging with MS, and examining systematic variations in needs by age, residential location, and disability level. The study was restricted to individuals living in the states of Minnesota, Wisconsin, Illinois, Indiana and Michigan in the USA. Participants were recruited through advertising, the National Multiple Sclerosis Society, and through the North American Research Committee on Multiple Sclerosis (NARCOMS), a volunteer patient registry. Interested individuals contacted the study office and were screened for eligibility, which included being 45 years of age or older, self-reporting a diagnosis of MS, and being willing to participate in a telephone interview. The study was open to all people who meet these basic criteria; no restrictions were placed based on location of residence (eg, community versus institution).

A total of 2277 people volunteered to participate in the study. Of these individuals, 1498 were between the ages of 45–64. The remaining 779 individuals were aged 65 and over. Due to the focus and hypotheses of the original study, an interview was attempted with all of the 779 volunteers aged 65+ , with 725 completing it. For the 45–64-year old group, 585 volunteers from the pool of 1498 were randomly selected and 557 completed the interview. Across all of the individuals who did not

complete the interview, 16 could not be contacted, nine had died, 25 refused and 31 were unable to complete the interview process due to cognitive impairment or illness. The final sample for the overall study was 1282. Of these people, 1089 answered questions about falls experiences, and 1064 had complete data for the fear of falling variable.

### Procedures

Participants were contacted by telephone by a trained project staff member, consented using a standard verbal protocol as approved by the researchers' university, and then interviewed. The full interview lasted an average of 41 min (median = 39 min).

Contents of the interview guide relevant to this analysis included socio-demographics, MS course and symptoms, use of walking aids, fall experience in the past 6 months, fear of falling and activity curtailment due to fear of falling. The items used were based on existing validated needs assessment survey tools and interview guides for PwMS or older adults [23–25]. The key outcome measures used in this study were drawn from previous published work of Yardley *et al.* [26] (fear of falling) and Howland *et al.* [10] (activity curtailment associated with fear of falling).

An advisory group was involved in review of the interview guide to ensure face and content validity and overall relevance to an MS population. Members of the advisory group included a neurologist specializing in MS, a social worker from an MS day program, staff from the National Multiple Sclerosis Society, informal caregivers/family members of people with MS, and several people with MS.

### Analysis

Data were entered into SPSS DataBuilder and then imported into SAS 9.1 for analysis. Preliminary analysis determined presence of potential data entry errors, which were checked and corrected using the hard copy interview guides.

To examine the prevalence of, and factors associated with FoF among PwMS, participants' responses to the question 'Are you concerned about falling?' was examined. To examine factors associated with activity curtailment, we examined the participants' responses to the question 'Are there things you do not do because you might fall?' for the subset of individuals responding 'yes' to the FoF question. Given the binary nature of the responses to both outcomes of interest, separate logistic regression models were used to examine potential factors associated with them.

A set of 16 variables were selected for inclusion for both logistic regression models. These variables represent six categories of characteristics. The first five categories have been studied in the existing literature on FoF and activity curtailment among older adults: demographics, fall experience, health status functional status and potential for social support. The remaining category focused on the participants' MS status and experiences.

Demographic characteristics considered for analysis were limited to age and sex. The fall experience was captured by asking participants if they had experienced a fall in the past 6 months (yes, no). Health status was examined through four separate variables: osteoporosis diagnosis (yes, no), self-rated health (excellent, good, fair, poor), self-rated mental health (excellent, good, fair, poor) and history of hospitalization in the past 6 months (yes, no). Functional status variables included use of cane or walker (use, don't ever use), use of manual or power wheelchair (use, don't ever use), amount of assistance needed for instrumental activities of daily living (IADLs) (very minimal, minimal, moderate, maximal) and functional status change in the past year (about the same, worse, better). Potential for social support was assessed by whether they lived alone or with others. Finally, MS status and experience were captured by number of years since diagnosis, MS status within the past year (stable or improving, deteriorating, variable), MS course since diagnosis (unpredictable, mild and intermittent, steady and progressive), and the extent of MS symptom interference with everyday activities (very minimal, minimal, moderate, severe).

Both FoF and FoFAC analyses included age and sex as covariates, otherwise model selection was performed by using the stepwise, backward and forward selection method with entry and staying criteria set at 0.05. For both analyses, the three selection methods produced the same final model. The models fit the data relatively well, as evidenced by the Hosmer and Lemeshow Goodness-of-fit test, which produced *P*-values of 0.1130 (FoF model) and 0.5300 (FoFAC model). Multicollinearity among the covariates in the final model was assessed by evaluating the correlation between parameter estimates. No problems were identified.

## Ethics

This project was reviewed and approved by the Institutional Review Board of the University of Illinois at Chicago (approval #2002-0055).

## Results

### Descriptive characteristics of sample

Of the 1064 subjects, 73.6% ( $n = 783$ ) were female and the average age was 63.6 (SD = 9.3) years. Participants had been diagnosed with MS for an average of 20.2 (SD = 11.6) years. Only 3.1% ( $n = 33$ ) reported living in a nursing home or assisted living facility. Use of mobility aids was common, with 59.8% ( $n = 636$ ) using a walking aid (cane or walker) and 56.8% ( $n = 604$ ) using a manual or power wheelchair at least part of the time. Just over half of participants (52.8%,  $n = 559$ ) had experienced a fall in the past 6 months (see Table 1).

### Fear of falling and activity curtailment associated with fear of falling

Across the participants, 63.5% ( $n = 676$ ) indicated that they had concerns about falling. The prevalence of activity curtailment among individuals reporting FoF in this sample was 82.6% ( $n = 546$ ). Descriptive details of the participants by FoF status and FoFAC status are provided in Table 1.

### Factors associated with fear of falling

Table 2 shows the parameter estimates, *P*-values, and odds ratios from the FoF multivariate logistic regression analyses. After adjusting for the other covariates in the model, age was not significantly associated with the likelihood of reporting FoF. Women were more likely to report FoF (OR = 1.74, CI = 1.28–2.36), as were participants who reported a fall in the past 6 months (OR = 1.38, CI = 1.03–1.86) or who reported use of walking aid (OR = 2.57, CI = 1.91–3.46). In addition, the extent of symptom interference was found to be significantly associated with FoF ( $P < 0.0001$ ). Specifically, findings show that the greater the extent of symptom interference, the greater the likelihood of reporting FoF. All but two of the pairwise comparisons were found to be significant for the extent of symptom interference. Pairs that were not significantly different included severe versus moderate symptom interference, and moderate versus minimal symptom interference.

### Factors associated with activity curtailment among individuals who reported fear of falling

Results from logistic regression of activity curtailment among the participants who reported FoF

**Table 1** Basic demographic for people aging with MS with fear of falling and curtailment of activities

Characteristics	Are you concerned about falling?									
	Sample* (n = 1064)		No (n = 388, 36.5%)				Yes (n = 676, 63.5%)			
			Do you curtail your activities?				Do you curtail your activities?			
	n	Col. %	No (n = 200)		Yes (n = 175)		No (n = 115)		Yes (n = 546)	
		n	Row %	n	Row %	n	Row %	n	Row %	
<i>Population characteristics:</i>										
Age <sup>‡</sup>	63.6	9.3	62.7	9.9	63.6	9.0	62.5	8.8	64.2	9.2
Sex										
Male	281	26.4	61	49.6	62	50.4	24	16.0	126	84.0
Female	783	73.6	139	55.2	113	44.8	91	17.8	420	82.2
<i>MS Experience:</i>										
Years since diagnosis <sup>‡</sup>	20.2	11.6	21	12.3	20.6	11.6	19.6	12	19.8	11.3
MS Status in the										
Past year:										
Stable or improving	472	44.5	118	60.8	76	39.2	57	21.8	204	78.2
Deteriorating	365	34.4	52	43.7	67	56.3	28	11.8	209	88.2
Variable	224	21.1	30	48.4	32	51.6	30	18.8	130	81.3
MS course since										
diagnosis:										
Unpredictable	130	12.5	14	35.0	26	65.0	15	17.4	71	82.6
Mild and intermittent	453	43.6	103	60.9	66	39.1	59	21.5	215	78.5
Steady and progressive	455	43.8	77	49.0	80	51.0	37	13.0	247	87.0
Degree of symptoms										
interference:										
Very minimal	244	24.3	90	70.9	37	29.1	33	30.0	77	70.0
Minimal	268	26.7	48	46.6	55	53.4	26	16.3	134	83.8
Moderate	205	20.4	26	44.8	32	55.2	23	16.3	118	83.7
Severe	288	28.7	26	36.1	46	63.9	24	11.5	185	88.5
<i>Fall experience:</i>										
Have you fallen in										
the past 6 months?										
Yes	559	52.8	57	35.8	102	64.2	56	14.2	337	85.8
No	500	47.2	142	66.0	73	34.0	59	22.3	206	77.7
<i>Physical health:</i>										
Do you have										
osteoporosis?										
Yes	221	21.7	31	52.5	28	47.5	21	13.6	133	86.4
No	799	78.3	160	53.2	141	46.8	89	18.5	392	81.5
How would you rate										
your current health?										
Poor	80	7.6	9	50.0	9	50	5	8.5	54	91.5
Fair	279	26.3	40	44.9	49	55.1	27	14.8	155	85.2
Good	496	46.8	95	53.7	82	46.3	53	17.1	257	82.9
Excellent	204	19.3	55	62.5	33	37.5	30	27.8	78	72.2
Have you been										
hospitalized in the										
past 6 months?										
Yes	110	10.5	15	46.9	17	53.1	7	9.2	69	90.8
No	939	89.5	179	53.3	157	46.7	106	18.3	472	81.7
How do you rate										
your mental health										
at the present time?										
Fair	236	22.2	32	50.0	32	50.0	24	14.3	144	85.7
Good	565	53.2	104	51.2	99	48.8	52	15.1	293	84.9
Excellent	261	24.6	63	59.4	43	40.6	39	26.4	109	73.6

\*Denotes the total number of individuals who had complete data for the fear of falling variable.

<sup>‡</sup>Denotes characteristics that are continuous and thus mean and standard deviations are presented instead of frequency and percentage.

**Table 2** Results from final logistic regression modeling fear of falling among people aging with MS

Parameter	DF	Estimate	SE	$\chi^2$	OR	95% CI for OR		P-value
						Lower	Upper	
Intercept	1	-0.6611	0.4917	1.81				0.0182
Age	1	0.0024	0.0076	0.10				<b>0.7569</b>
Sex (REF: male)	1	0.5526	0.1551	12.69	1.74	1.28	2.36	<b>0.0004</b>
Degree of symptoms interference (REF: very minimal interference)	3			23.30				<b>0.0001</b>
Minimal symptoms interference	1	0.4201	0.1878	5.00	1.52	1.05	2.20	0.0253
Moderate symptoms interference	1	0.8081	0.2108	14.70	2.24	1.48	3.39	<0.001
Severe symptoms interference	1	0.8419	0.1955	18.54	2.32	1.58	3.40	<0.001
Fallen in the past 6 months (REF: no)	1	0.3247	0.1501	4.68	1.38	1.03	1.86	<b>0.0306</b>
Use of walking aids (REF: never use walking aids)	1	0.9449	0.1511	39.10	2.57	1.91	3.46	<b>0.0001</b>

**Table 3** Results from final logistic regression modeling activity curtailment for subjects who reported fear of falling among people aging with MS

Parameter	DF	Estimate	SE	$\chi^2$	OR	95% CI for OR		P-value
						Lower	Upper	
Intercept	1	-0.8136	0.7990	1.04				0.3086
Age	1	0.0118	0.0123	0.93				<b>0.3342</b>
Sex (REF: male)	1	-0.1528	0.2643	0.33	0.60	0.51	1.44	<b>0.5631</b>
Use of walking aids (REF: never use walking aids)	1	0.6743	0.2290	8.67	1.96	1.25	3.07	<b>0.0032</b>
Degree of IADL limitations (REF: very minimal assistance)	3			16.44				<b>0.0009</b>
Minimal assistance	1	0.5377	0.2805	3.67	1.71	0.99	2.97	0.0553
Moderate assistance	1	1.2754	0.3356	14.45	3.58	1.86	6.91	0.0001
Maximal assistance	1	0.8883	0.3132	8.04	2.43	1.32	4.49	0.0046
Self-rated mental health (REF: excellent)	2			8.30				<b>0.0158</b>
Poor/fair	1	0.6127	0.3042	4.06	1.85	1.02	3.35	0.0440
Good	1	0.7029	0.2518	7.79	2.02	1.23	3.31	0.0053

showed that the likelihood of reporting FoFAC was associated use of walking aids (ie, canes or walkers) (OR = 1.96, CI = 1.25–3.07) (see Table 3). Participants who reported good mental health were more likely to report FoFAC compared to participants who reported excellent mental health (OR = 2.02, CI = 1.23–3.31), and participants who reported poor or fair mental health were more likely to report activity curtailment than those who reported excellent mental health (OR = 1.85, CI = 1.02–3.35). The degree of IADL limitation was significantly associated with FoFAC such that participants needing maximal or moderate IADL assistance were 2.43 (CI = 1.32–4.49) and 3.58 (CI = 1.86–6.91) times more likely to report activity curtailment than participants requiring very minimal assistance, respectively. In addition, participants who required moderate IADL assistance were more likely (OR = 2.09, CI = 1.12–3.91) to report activity curtailment than participants needing minimal assistance.

## Discussion

This is the first study to report prevalence of FoF and FoFAC in a sample of middle aged and older adults with MS. The rates reported here are high compared to those observed in studies of other populations, and may reflect an appropriate appraisal of and response to high fall risk among PwMS. Our finding that recent fall experience was independently associated with reporting FoF offers some support of this hypothesis, as does the finding that use of a walking aid was independently associated with both FoF and FoFAC.

Our findings also suggest that factors beyond realistic appraisal of fall risk influence FoFAC. Like Howland *et al.* [10] who studied community-dwelling well elderly, we found that recent experience of a fall did not increase the likelihood of activity curtailment despite FoF after controlling for the other factors. In addition, we found that lower self-rated mental health was independently

associated with FoFAC and that 68% of the individuals who reported never needing assistance for IADLs also reported FoFAC. Together, these findings raise the possibility that the disuse-disability cycle (ie, reduced activity and physical deconditioning, with resulting increase in dependency and fall risk), as described by Tinetti and Powell [27], may be operating for some PwMS.

The consequences of activity curtailment driven by FoF (rather than realistic appraisal of fall risk) and subsequent deconditioning may be significant. Delbare *et al.* [28] studied well older adults who had inappropriately high fear based on their fall history and demonstrated the debilitating effects of FoF on dynamic balance capability. It is well documented that deconditioning in persons with MS can increase levels of fatigue which, in turn, can increase the extent of other MS symptoms [29].

In the present study, individuals who received more than minimal assistance with IADLs were more likely to report FoFAC. The likelihood of reporting FoF also increased with the level of symptom interference. Together with previous qualitative research, these findings suggest that the high prevalence of FoF and FoFAC may reflect heightened concerns about future autonomy and control when aging with MS. Both well-elderly and older adults with MS have expressed concerns about losing mobility and independence, becoming a burden on caregivers and having to move to a nursing home [4,30]. If FoF and FoFAC are associated with fear of the future, PwMS may experience these fears with greater intensity because of the variable and progressive nature of their disease. This hypothesis is consistent with the observation by DalMonte *et al.* [31] that aging poses unique challenges to PwMS since the disease appears to compound any decline in function associated with normal aging changes.

Additional qualitative studies are needed to explore the relationship between FoF, FoFAC and concerns about maintaining autonomy in the future among PwMS. However, the evidence to date suggests that caregivers have an important role in supporting PwMS in their efforts to safely maintain or increase activity levels. Caregivers typically spend a considerable amount of time assisting with activities of daily living, and are often an important source of support for PwMS [32]. In our view, interventions designed to enhance caregivers' skills in supporting the autonomy of the PwMS that include training in active listening, activity modification and use of assistive devices may be especially beneficial.

Although the associations between walking aid use and both FoF and FoFAC could be viewed as evidence that FoF or FoFAC are appropriate responses to the fall risks associated with MS, our clinical and research experiences suggests that

alternative interpretations are worth consideration. Consumers can easily access walking aids without professional input. In these situations, lack of training may heighten concern about ambulating safely with the device. For some PwMS, the decision to use a walking aid is made as a reaction to experiencing a fall. For others, the decision to use a walking aid is a strategy to prevent a fall. In either case, PwMS are confronting the psychosocial implications of mobility loss, including altered self image, decreased opportunities to socialize, fear of abandonment and decreased independence [33,34]. Our results highlight the relationship between use of walking aids and FoF and FoFAC, and suggest that important opportunities for patient education regarding FoF and FoFAC may exist when health care professionals train PwMS to use walking aids.

We found that use of a walking aid was associated with both FoF and FoFAC while use of a wheelchair was not. Eighty percent of the subjects in our sample used both walking aids (ie, canes and walkers) and wheelchairs at least some of the time. These individuals may be selecting equipment based upon the level of symptom interference and the activities planned for a given day. Some ambulatory individuals, however, may be reluctant to use a wheelchair in an effort to use and preserve the physical capacity they have to the greatest extent possible. For some, the decision to use a wheelchair can appear equivalent to losing hope [35].

In an unadjusted preliminary analyses, we found that individuals who reported that they never use wheelchairs were more likely to report FoFAC. This finding suggests that in some situations, wheelchair use may facilitate safe engagement in activities and reduce concerns about falling. The finding also underscores the importance of health care providers conducting individualized assessments to select appropriate mobility aid options, exploring the attitudes and beliefs about fall prevention strategies, and promoting safe increases in activity levels.

A limitation of this cross-sectional study is that we cannot determine whether participants reporting no FoF had previously experienced FoFAC. Likewise, because we asked about falls in the past 6 months, previous fall history was not captured. Our measure of FoF was limited to a single item and no performance-based measures were used to assess physical abilities. In addition, we did not assess subjects individually to determine whether or not FoFAC was appropriate based on fall risk factors.

Although our descriptive data correspond with other MS studies, it is possible that the people volunteering for this study are more or less likely to fall than the general MS older adult population. The paucity of descriptions of characteristics of elderly persons with MS makes statements about the generalizability of our sample difficult.

Nonetheless, comparison of our sample to previously described samples of older adults with MS [36–38] suggests general consistencies with respect to average age, gender distribution, most common symptoms experienced, duration of MS, and living arrangements.

In summary, our findings raise many questions about the nature of FoF and FoFAC among people aging with MS, and highlight the need for longitudinal studies to examine the causal relationships among fall risk factors, FoF and FoFAC in this population. Since most of the variables found to be associated with FoF and FoFAC are modifiable, our findings suggest important opportunities for intervention.

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