



## Treatment satisfaction and bothersome bladder, bowel, sexual symptoms in multiple sclerosis



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### ARTICLE INFO

#### Keywords:

Multiple sclerosis  
Bowel symptoms  
Bladder symptoms  
Sexual symptoms  
Quality of life

### ABSTRACT

**Background:** Bladder, bowel, and sexual symptoms are common among persons with multiple sclerosis (MS). We aimed to investigate the frequency and severity of bladder, bowel, and sexual symptoms, the relationships between these symptoms, satisfaction with treatment of these symptoms, and factors associated with symptom severity and treatment satisfaction.

**Methods:** In the fall 2010, we surveyed participants in the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry regarding the severity of being bothered by bladder, bowel, and sexual symptoms, their satisfaction of health providers' inquiry and treatment with these symptoms, and whether their quality of life (QOL) had changed with the treatment. Logistic regression was used to evaluate demographic and clinical factors associated with each outcome.

**Results:** Of 9341 respondents included in the study, 7720 (77.4%) were female and their mean (SD) age was 50.3 (10.5) years. Ninety-one percent of participants were mildly, moderately or severely bothered by bladder, bowel or sexual symptoms. Severity of disability (measured using the Patient Determined Disease Steps), having a relapse in the last 6 months, and catheter use were consistently associated with being bothered (versus not bothered) by each of the three symptoms. Among respondents, 5764 (62.1%) reported that their MS health providers asked about bladder problems, 4523 (51.1%) about bowel problems, and 1890 (20.6%) about sexual problems. At most one-third of participants were completely satisfied with treatment for any of the symptoms. For those who reported how their QOL changed with treatment, 23.0% reported their QOL being better.

**Conclusion:** Bladder, bowel, and sexual problems remain common among persons with MS, and treatment satisfaction is low. Health care providers should consider systematically asking about these symptoms in clinical practice. Greater efforts could be devoted to developing novel, effective therapies to manage these symptoms and thereby improve QOL.

### 1. Introduction

Bladder, bowel, and sexual symptoms are common among persons with multiple sclerosis (MS). Over 70% MS patients report bladder and sexual symptoms and about 35–54% report bowel symptoms (DasGupta and Fowler, 2003), and these are present early in the disease course (Vitkova et al., 2014). Previously we reported that 80% of participants in the North American Research Committee on Multiple Sclerosis (NARCOMS) registry suffered from bladder or bowel symptoms (Mahajan et al., 2010; Marrie et al., 2007). Such symptoms are

associated with reduced quality of life (Nortvedt et al., 2007; Vitkova et al., 2014).

Although the adverse effects of bladder, bowel and sexual symptoms are recognized, they are frequently undertreated (Coyne et al., 2008; Nortvedt et al., 2007). Intensity of treatment of bladder symptoms and frequency of urologic investigations are influenced by racial and socioeconomic characteristics (Marrie et al., 2007). It is not known whether such demographic characteristics influence management of bowel symptoms and sexual dysfunction. Moreover, factors associated with treatment satisfaction for these symptoms are poorly understood.

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We aimed to investigate the severity of bladder, bowel, and sexual symptoms, the relationships between these symptoms, satisfaction with treatment of these symptoms, and factors associated with symptom severity and treatment satisfaction.

## 2. Methods

### 2.1. Study population

Participants in the NARCOMS Registry voluntarily report demographic and clinical information about their MS at enrollment, and semi-annually thereafter using paper or online questionnaires (Marrie et al., 2005). The registry has been collecting information since 1996. The registry was approved by the Institutional Review Board at the University of Alabama at Birmingham at the time of this study. Participants agree to the use of their de-identified information for research purposes. Those participants who completed the fall 2010 update survey and responded to specific questions on severity of bowel, bladder and sexual problems were included in this analysis.

### 2.2. Data collected

Information used in this study was drawn from the enrollment questionnaire and the fall 2010 update survey, and included sociodemographic and clinical characteristics. Sociodemographics obtained from the enrollment questionnaire included sex, date of birth and year of MS diagnosis. Sociodemographic information from the fall 2010 survey included marital status (married, cohabitating/domestic partner, never married, divorced, widowed, separated), and annual income (less than \$15,000, \$15,001–30,000, \$30,001–50,000, \$50,001–100,000, > \$100,000 USD, and I do not wish to answer).

Clinical characteristics drawn from the fall 2010 questionnaire included the presence of a relapse in the prior 6 months (yes vs. no), and level of disability reported using Patient Determined Disease Steps (PDDS). The PDDS is an ordinal rating scale derived from the Disease Steps which ranges from 0 (no disability) to 8 (bedridden) (Hohol et al., 1995). It correlates highly with a physician-scored Expanded Disability Status Scale (Learmonth et al., 2013; Marrie and Goldman, 2007).

In the fall 2010 survey, participants were asked about bladder, bowel and sexual symptoms. Specifically, they reported the degree of bother for each type of symptom on a Likert scale as not at all, mildly bothered, moderately bothered and severely bothered. Second, they reported whether or not health care providers had asked about urinary/bladder symptoms (yes/no), bowel symptoms (yes/no), and sexual symptoms (yes/no). Third, they reported their degree of satisfaction with health care providers' evaluation and treatment of bladder, bowel and sexual complaints as not all, slightly satisfied, moderately satisfied, very satisfied, completely satisfied, and not applicable. Fourth, they reported how their quality of life has changed with the treatment of bladder, bowel and sexual symptoms as much better, better, a little better, no change, a little worse, worse, much worse, and not applicable. Finally, they reported current use of any form of catheterization including indwelling Foley, intermittent catheterization, suprapubic catheter or unsure.

### 2.3. Statistical analysis

We characterized the study cohort using descriptive statistics including frequency (percent), mean (standard deviation [SD]), and median (interquartile range [IQR]). We compared variables between groups using Pearson chi-square tests, analysis of variance, Wilcoxon or Kruskal-Wallis tests as appropriate. We summarized the degree of bother related to bladder, bowel and sexual symptoms using the original Likert scale and any level of being bothered (mildly, moderately or severely). To evaluate the association between being bothered and demographic and clinical factors, separate multivariable logistic

regression analyses (Hosmer and Lemeshow, 2004) were conducted for each symptom, dichotomizing responses related to bother as either 'bothered' (moderately or severely bothered) or 'not bothered' (not at all, mildly bothered). Independent variables included age (continuous), race (Non-Caucasian vs. Caucasian [reference group]), health insurance coverage (no vs. yes [reference group]), disease duration (continuous), relapse in the last 6 months (no vs. yes [reference group]), gender (male vs. female [reference group]), marital status (dichotomized as never married/divorced/widowed/separated vs. married/cohabitating [reference group]), PDDS (categorized as mild (0–2) [reference group], moderate (3–4), and severe (5–8) disability), annual income (less than \$15,000 [reference group], \$15,001–30,000, \$30,001–50,000, \$50,001–100,000, > \$100,000 USD), and catheter use (no vs. yes [reference group]). Using the same approach, we evaluated demographic and clinical factors associated with (i) health care providers inquiring about bladder, bowel and sexual symptoms (yes vs no), and (ii) satisfaction with health providers' evaluation and treatment of these symptoms, (dichotomized as satisfied (Moderately, Very, Completely) or not satisfied (Not at all, Slightly) [reference group]). Based on findings of an association of race with treatment satisfaction, stratification analyses using the same multivariable logistic regression models were conducted to evaluate the association between race and treatment satisfaction for each health insurance coverage status and for each annual income level. Finally, adjusting for the same set of covariates and using ordinal logistical regression with partial proportional odds for gender, catheter use, and PDDS, we evaluated demographic and clinical factors associated with quality of life changes with treatments of these problems (categorized as Better change (Much better, Better), No change (A little better, No change, A little worse), and Worse change (Worse, Much worse)); we did not distinguish changes due to treatment of individual bladder, bowel or sexual symptoms. For each model we reported the associations using odds ratios (OR) and 95% confidence intervals (95% CI). The Hosmer-Lemeshow Goodness of Fit test was used to evaluate the model fit. Model assumptions were tested using standard methods (Hosmer and Lemeshow, 2004).

All analyses were conducted using SAS 9.4 (SAS Institute Inc., Cary, NC). All p-values were based on two-sided tests and  $p < 0.05$  was considered significant.

## 3. Results

Of the 14,475 participants invited to participate in the fall 2010 update survey, 9397 (64.9%) responded. Non-responders (NR) were more likely to be female (NR: 80.0% vs R: 77.4%,  $p = 0.0003$ ), non-Caucasian (NR: 16.7% vs R: 10.0%,  $p < 0.0001$ ), online participants (NR: 79.8% vs R: 69.1%,  $p < 0.0001$ ) and be slightly younger at age of diagnosis (mean [SD], NR: 37.5 [10.3] vs R: 38.5 [10.1],  $p < 0.0001$ ) than responders (R). In the fall 2010 update survey, of the 9397 participants who responded, 9341 (99.4%) answered at least one of the bladder, bowel, and sexual questions, and were included in this study. Three-quarters of respondents were women, and most were Caucasian, with a mean (SD) age of 50.3 (10.5) (Table 1).

### 3.1. Symptom bother

Of the 9341 respondents included, most ( $n = 8511$ , 91.1%) reported being bothered (mildly, moderately, or severely) by at least one of the three symptoms, most often bladder symptoms. Only 776 (8.3%) respondents were not at all bothered by any symptoms and 54 (0.6%) deemed the question not applicable. For the respondents reporting being bothered by at least one symptom ( $n = 8511$ ), 5638 (66.2%) reported being bothered (mildly, moderately, or severely) by both bladder and bowel symptoms, 4662 (54.8%) by both bladder and sexual symptoms, 4071 (47.8%) by both bowel and sexual symptoms, and 3727 (43.8%) by all three symptoms. Being bothered by bladder symptoms was more strongly correlated with being bothered by bowel

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