

PELVIC FLOOR DISORDERS AND MULTIPLE SCLEROSIS: ARE PATIENTS SATISFIED WITH THEIR CARE?

Hypothesis / aims of study:

Despite recent efforts to educate multiple sclerosis (MS) healthcare providers (HCP) regarding the importance of pelvic floor disorders (i.e. urinary, bowel and sexual dysfunction); no data is currently available to assess outcomes of these efforts with regards to patient satisfaction. As part of the Fall 2010 North American Research Committee On Multiple Sclerosis survey, we conducted a prospective survey-based cohort study (N=14,268) to evaluate patient satisfaction with the current evaluation and treatment of pelvic floor dysfunction.

Study design, materials and methods:

The Consortium of Multiple Sclerosis Centers (www.ms-care.org) administers the North American Research Committee of Multiple Sclerosis (NARCOMS) Registry. The NARCOMS Registry captures self-reported demographic and clinical information from patients with MS at enrollment and semi-annually thereafter. The registry is the largest self-report database of patients with MS worldwide. In the Fall of 2010, the authors created a short 2-page questionnaire for inclusion in the Fall 2010 questionnaire regarding pelvic floor disorders. Patients were queried on: 1) bother from urinary/bladder, bowel, or sexual problems; 2) if they had been evaluated by a HCP about pelvic floor issues in the last 12 months; and 3) satisfaction with the evaluation and treatment received on a 5-point Likert scale. Patients were also asked if their quality-of-life (QoL) had changed with these treatments (7-point Likert scale). The Patient Determined Disease Steps (PDDS), a validated measure of disability based on self-report, was also administered. Data analysis used SAS version 9.1 (SAS Institute Inc., Cary, N.C.) and descriptive statistics, chi-square tests for frequency data and calculation of correlation coefficients and 95% confidence intervals were constructed as appropriate.

Results:

The Fall of 2010 NARCOMS questionnaire was delivered to 14,268 participants of whom 9397 (65.8%) responses were returned. Respondents were primarily white (89%), women (77.4%), with an average age of 55 (SD 10.5) years. Moderate to severe pelvic floor complaints were reported by a significant number of respondents (Figure 1): bladder (40.3%; 95% CI [39.3, 41.3]) and bowel (29.7%; 95% CI [28.8, 30.7]). Despite a significant number of respondents opting not to answer questions about sexual dysfunction (718 respondents or 8%), a sizeable number reported moderate to significant sexual problems (3644 respondents or 38.8%; 95% CI [37.8, 39.8]). Increased disability as gauged by the PDDS was significantly correlated with the presence of bladder ($r=0.483$; 95% CI [0.468, 0.498]), bowel ($r=0.364$; 95% CI [0.347, 0.381]) and sexual dysfunction ($r=0.140$; 95% CI [0.120, 0.159], all $p<0.001$). Respondents were much more likely to have been asked about bladder (61%) and bowel (50%) dysfunction than sexual dysfunction (20%) by their HCP in the last one year (Table 1). The majority of patients reported moderate to complete satisfaction with the treatment and evaluation of their bladder (83%; 95% CI [82.2, 84.0]) and bowel (i.e. fecal incontinence, diarrhea and constipation), with 4766 (79.6%; 95% CI [78.6, 80.6]) complaints. However satisfaction was much lower among sexual dysfunction with only 61.6% (95% CI [60.2, 63.0]) reporting moderate to complete satisfaction with their care, although only 50% of respondents completed this question. Increased bother from bladder, bowel or sexual problems was inversely correlated with satisfaction with provider evaluation ($r=-0.206$; 95% CI [-.228, -.184] bladder, $r=-0.339$; 95% CI [-.361, -.317] bowel; $r=-0.400$; 95% CI [-.423, -.376] sexual - all $p<0.001$).

Interpretation of results:

Patients with significant pelvic floor symptoms were more likely to have been assessed for these complaints than respondents on the whole. Most respondents were moderately-to-very satisfied with the evaluation and treatment of bladder and bowel complaints, but significantly less satisfied with the care of sexual dysfunction they had received to date. Treatment of pelvic floor dysfunction tended to positively impact (47%) or have no effect (43%) on quality of life (QoL) for the majority of patients; 11% of respondents believed treatment of their pelvic floor complaints had adversely affected their QoL.

Concluding message:

Despite significant efforts to educate patients, families and healthcare providers on the importance of bowel, bladder and sexual dysfunction in MS patients, the impact of these efforts remains unclear. Our results demonstrate that moderate to severe pelvic floor complaints are extremely common among MS patients, with 40% reporting bladder, 30% reporting bowel and 40% reporting sexual dysfunction. Patient satisfaction with current levels of evaluation and treatment of bladder and bowel dysfunction in patients with MS is high. However, continued improvement is needed regarding sexual dysfunction issues.

Figure 1. Degree of bother from pelvic floor symptoms reported by all respondents (1= not at all; 2= mildly bothered; 3= moderately bothered; 4= severely bothered; and 5= declined to answer).

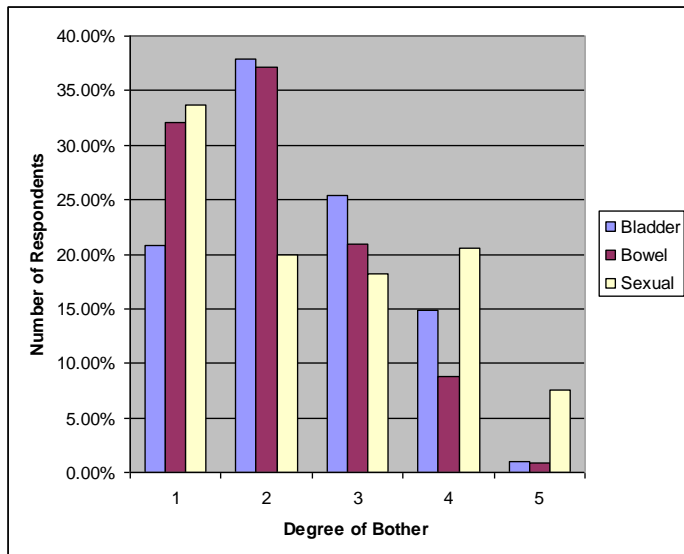


Table 1. Provider assessment and patient satisfaction with provider evaluation and treatment of bladder, bowel and sexual problems

	Bladder	Bowel	Sexual
Degree of Bother from Symptoms			
Not at all	1953 (20.8%)	3014 (32.1%)	3165 (33.7%)
Mildly bothered	3561 (37.9%)	3500 (37.2%)	1870 (19.9%)
Moderately bothered	2391 (25.4%)	1965 (20.9%)	1713 (18.2%)
Severely bothered	1396 (14.9%)	829 (8.8%)	1931 (20.5%)
Not answered	96 (1%)	89 (0.9%)	718 (7.6%)
Satisfaction with provider evaluation/treatment			
Not at all	542 (5.8%)	571 (6.1%)	1140 (12.1%)
Slightly satisfied	641 (6.8%)	648 (6.9%)	600 (6.4%)
Moderately satisfied	1562 (16.6%)	1258 (13.4%)	884 (9.4%)
Very satisfied	2107 (22.4%)	1620 (17.2%)	876 (9.3%)
Completely	2156 (22.9%)	1888 (20.1%)	1178 (12.5%)
Not applicable or Not answered	2389 (25.4%)	3412 (36.3%)	4719 (50.2%)

Disclosures

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