The prevalence of urinary catheterization in women and men with multiple sclerosis

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Context/objective: To determine the prevalence of urinary catheterization in patients with multiple sclerosis (MS).

Design/intervention: After obtaining Institutional Review Board exemption, results from the Fall 2005 North American Research Committee on Multiple Sclerosis (NARCOMS) survey were reviewed.

Participants: Respondents to the fall 2005 NARCOMS survey.

Outcome measures: Responses to the Urogenital Distress Inventory (UDI-6), the Short Form-12 (SF-12), the Patient Determined Disease Steps measure of physical disability, and urologic history were analyzed using descriptive statistics, the χ^2 and Student's *t*-tests, and multivariable logistic and linear regression.

Results: Of 9702 (58%) responses were returned, excluding respondents with prior bladder surgery, 9676 participants were reviewed: primarily white (92.9%), women (75.3%), with average age of diagnosis of 30.2 (SD 10.0) years. Urinary catheterization was reported by 2514 (26%) respondents, with 1091 (11%) reporting current and 1423 (15%) past catheter use. Among all catheter types (possibly ≥ 1), intermittent self-catheterization was most common (81%), followed by transurethral Foley catheterization (43%) and suprapubic catheterization (8%). Males were more likely to catheterize than females (32 versus 24%, $P < 0.001$) and use indwelling methods ($P < 0.001$). Catheterizing patients reported longer disease duration, greater physical disability, increased overactive bladder symptoms, and reduced quality of life (QoL) scores (all $P < 0.001$).

Conclusions: This is the first study to demonstrate significant rates (1 in 4) of urinary catheterization in patients with MS. Although thought to be common, the true rates of catheter use among MS patient were previously unknown. Urinary catheterization appears to be associated with reduced QoL, increased physical disability and longer disease duration as well.

Keywords: Myelopathy, Urinary catheter, Multiple sclerosis, Neurogenic bladder, Disability, Voiding dysfunction, Quality of life, Incomplete emptying, Detrusor overactivity, Urinary catheterization

Introduction

Lower urinary tract dysfunction is a commonly recognized symptom in men and women with multiple sclerosis (MS).¹ Among patients with MS, 50–80% report symptoms of urinary retention, urinary incontinence, or both during their disease course.² Previously, our unit described the significant under-treatment of lower urinary tract symptoms in patients with MS.³ Although urinary catheterization remains the treatment of choice for patients with incomplete bladder emptying, due to its wide availability and minimally invasive nature, the number of MS patients who utilize this has

to date been unknown. Furthermore, any correlations between urinary catheter use, disease severity, and quality of life (QoL) have been unknown.

The goal of this study was to determine the frequency of catheter utilization among men and women with MS based on responses from a large sample of volunteers. We also aimed to examine associations between catheter use, gender, degree of disability, and QoL.

Materials and methods

This study was a secondary analysis of data provided by the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry (www.cmscnarcoms.org). The NARCOMS Registry captures self-reported demographic and clinical information from MS patients

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at enrollment and semi-annually thereafter, via questionnaires administered either online or by mail, per participant preference. The registry is the largest self-report registry for MS worldwide, with more than 16 000 active participants. The registry is approved by the Western Institutional Review Board (IRB) and the IRB at the University of Alabama at Birmingham. We obtained an exemption from University Hospitals Case Medical Center IRB for this study. De-identified data were supplied by NARCOMS in the form of a excel spreadsheet with a data dictionary.

At enrollment, participants provide demographic information, and clinical information including age at MS onset. Each semi-annual NARCOMS questionnaire includes an assessment of disability status and QoL. The Patient Determined Disease Steps (PDDS) measures disability based on self-report and has been validated in large MS populations against the physician-scored Expanded Disability Status Scale.⁴⁻⁶ It is scored from 0 to 8, with 0 defined as no disability and 8 as bed bound.⁷ Participants also complete the Medical Outcomes Study Short Form-12 (SF-12), a validated measure of health-related QoL based on the Short Form 36 (SF-36). The SF-12 is often used in large study populations,⁸ and consists of 12 items, each capturing an aspect of one of the eight subscales in the SF-36. An aggregate Physical Component Scale (PCS-12) score summarizes physical health-related QoL, with scores ranging from 0 (worst) to 100 (best), while an aggregate Mental Component Scale (MCS-12) summarizes mental health-related QoL. The PCS-12 and MCS-12 are standardized to reflect a general population mean of 50 and a standard deviation of 10.

The Fall 2005 questionnaire included questions regarding lower urinary tract symptoms and related treatment history.⁹ The Urogenital Distress Inventory-Short Form (UDI-6) was also included and consists of six questions to assess bother from urinary symptoms, including frequency, urge incontinence, stress incontinence, urine leakage of any kind, difficulty with bladder emptying, and abdominal pain. Each symptom is scored on a scale of 0–3, where 0 indicated no complaints and 3 indicates severe symptoms.¹⁰ Because it is a common symptom in MS, an additional question regarding nocturia was added to the questionnaire and scored similarly. The UDI-6 has demonstrated good validity, sensitivity and internal consistency in neurologically normal and MS populations with urinary symptoms.^{10,11} Further, its brevity minimizes burden on participants. Volunteers were asked to respond based on their current symptom complaints to all questions. A total overactive bladder (OAB)

symptom score was calculated by summing individual responses to the frequency, urgency, incontinence, and nocturia questions. Patients with at least one symptom score ≥ 2 were denoted as having moderate-to-severe urinary symptoms.

History of lower urinary tract treatment, per patient report, was evaluated using: (1) history of urinary catheter use; (2) form of catheterization utilized, including intermittent straight catheterization (ISC), suprapubic catheterization (SC), and transurethral Foley catheter (TFC); and (3) history of urologic evaluations and treatments, including physician visits, radiologic, and functional studies as well as pharmacologic therapies.⁹

All responses to the Fall 2005 NARCOMS questionnaire by registry participants were included in this analysis, except those by patients with prior bladder augmentation or urinary diversion were excluded.

Data analysis used descriptive statistics, χ^2 tests, Student's *t*-tests, and multivariable logistic and linear regression. Utilization of any form of urinary catheterization (i.e. ISC, SC, and TFC) was examined. Associations between frequency of OAB symptoms and catheter use were analyzed using a χ^2 test. Mean OAB symptom severity, disability status (PDDS), and QoL (SF-12 scores) were compared between catheter users and non-catheter users by the use of Student's *t*-test. Non-parametric tests using the Mann–Whitney test were also conducted and results were similar in nature.

Multivariable logistic regression was performed to determine associations between dependent variables of medication usage, evaluation by urology (yes versus no), and catheter use (any versus none) and independent variables of demographic information, disease duration, disability, employment status (yes/no), and OAB symptom score. Odds ratios (OR) and 95% confidence intervals (CI) were constructed for each independent variables. Multivariable linear regression was used to examine the relationship between QoL scores (SF-12 physical or mental composite score) and catheter use, disease duration, employment, disability status (PDDS), OAB symptom score, and age. PDDS, OAB symptom score, disease duration, and age were included as continuous variables in the model. All statistical tests were two-sided with significance set at $P < 0.01$ to account for multiple comparisons. Data analysis used SAS version 9.1 (SAS Institute Inc., Cary, NC, USA).

Results

During the Fall of 2005, the 16 858 active participants in the NARCOMS registry were asked to complete the semi-annual questionnaire. Of the 9702 (57.5%)

questionnaires completed, respondents with prior major bladder surgery (urinary diversion or bladder augmentation) were excluded, resulting in 9676 respondents analyzed for this study (24.6% males and 75.4% females). The demographic characteristics of these patients were described previously,⁹ but briefly, most were white (92.9%), women (75.3%), with an average age at MS onset of 30.2 (SD 10.0) years. No difference between responders and non-responders with regard to sex or income was noted. Non-responders were more likely to be African-American, less educated, live in the Midwest or Southern United States, to be less disabled, and to have earlier ages of symptom onset and age at diagnosis.

Of the 9676 respondents examined, 2514 (26.0%) reported utilizing some form of urinary catheterization. When divided temporally, 1091 (11.3%) of all respondents reported current catheter use, while 1423 (14.7%) respondents reported past use only. When analyzed by gender, males were more likely to report a history of past or current catheter use than females (31.5 versus 24.2%, $P < 0.001$).

Among respondents reporting past or current catheter use, ISC was the most common (81.2%), followed by TFC (42.8%) and SPC (7.7%, Table 1). Respondents were not limited to choosing only one form of catheter, but documented any history of use. Males utilized indwelling catheterization methods, including SPC and TFC, more frequently than females. The use of ISC did not differ between males and females.

OAB symptoms, including frequency, urgency, urine leakage, and nocturia were more severe among patients who reported ever catheterized than among those who had never catheterized (all $P < 0.001$, Table 2). Despite using some form of urinary catheterization, 264 (24.2%) reported moderate-to-severe urine leakage symptoms. Degree of bother from urine leakage symptoms reflected type of catheter used, with respondents using ISC more likely to be greatly bothered by difficulty emptying (54.0%), while only 18.8% of TFC and 8.5% of SPC utilizing patient reported similar complaints.

The use of antibiotic prophylaxis among patients utilizing urinary catheterization was mixed. Among patients performing TFC, 74 (35.6%) routinely utilized a prophylactic antibiotic, while rates were 33.1% in ISC and 26.3% in SPC patients ($P = 0.220$).

When compared to non-catheterizing patients, those who catheterized were more likely to have been evaluated by a urologist and to be treated with an anticholinergic medication at some point in time (Table 2). Among all respondents who reported ever using a catheter, urologic evaluation and treatment rates were

moderate, with 76.2% evaluated by urology, 41.4% undergoing urodynamic testing, 51.2% having a post-void residual checked, and 55.0% treated with an anticholinergic medication. Compared to non-catheterizing patients, respondents who had used a catheter were more likely to have undergone urodynamic testing and assessment for post-void residual (all $P < 0.001$).

Among all respondents treated with an anticholinergic medication, generic oxybutynin and tolterodine were most commonly used, with trospium, solifenacin, and darifenacin use also reported. Most patients were treated with oxybutynin (43.2% catheterizing versus 19.9% non-catheterizing, $P < 0.001$) and tolterodine (27.7% catheterizing versus 16.7% non-catheterizing, $P < 0.001$). Among all respondents with OAB symptoms ($n = 6263$), very few patients had undergone sacral neuromodulation (0.3%) or intra-detrusor botulinum A toxin injection (0.9%), although both treatments were readily available in 2005.

On univariate analysis, catheter use was associated with less education and unemployed status ($P < 0.001$, Table 3). Similar to our previous findings regarding OAB symptoms in MS patients (9), catheter use was associated with increasing disease duration and severity. These findings remained consistent on multivariable analysis, with increasing disability (PDDS score) [OR 1.28, 95% CI: 1.25–1.32], disease duration [OR 1.04, 95% CI: 1.03–1.04], and OAB symptom score [OR 1.04, 95% CI: 1.03–1.06] associated with catheter use. In contrast, increasing age [OR 0.99; 95% CI: 0.98–1.00] and being employed [OR 0.66, 95% CI: 0.58–0.75] were associated with decreased catheter use. Gender was not significant after controlling for all the above variables [OR 0.99, 95% CI: 0.88, 1.12].

Female gender and longer disease duration were associated with the use of anticholinergic medications. Female gender [OR 1.77, 95% CI: 1.57, 1.99], increasing PDDS score [OR 1.31, 95% CI: 1.27–1.34], OAB symptom score [OR 1.23, 95% CI: 1.21–1.25], and disease duration [OR 1.02, 95% CI: 1.01–1.02] were associated with increased medication use while increased age [OR 0.98, 95% CI: 0.97–0.99] was associated with decreased medication use. While statistically significant due to our large sample size, the size of the age effect would not be considered clinically significant.

Males with longer disease duration were more likely to have been evaluated by a urologist. Longer disease duration [OR 1.02, 95% CI: 1.01–1.03], OAB symptom score [OR 1.14, 95% CI: 1.12–1.15], PDDS [OR 1.16, 95% CI: 1.13–1.19], and age [OR 1.01, 95% CI: 1.00–1.01] were associated with evaluation by a urologist whereas employment [OR 0.79, 95% CI: 0.71–0.88]

Table 1 Catheter use in the NARCOMS population based on gender and type of catheter

Catheter type	Overall (n = 9676)	Male (n = 2386)	Female (n = 7290)	P value
Catheter use (any)	2514 (26.0%)	751 (31.5%)	1763 (24.2%)	<0.001
Current	1091 (11.2%)	382 (50.9%)	709 (40.2%)	
Past use only	1423 (14.7%)	369 (49.1%)	1054 (59.8%)	

and female gender [OR 0.71, 95% CI: 0.64, 0.78] were associated with decreased odds of being evaluated.

Catheter use of any kind was associated with reduced QoL in general, regardless of MS diagnosis or OAB symptoms. Patients who catheterized reported consistently lower QoL scores in all domains when compared to those who did not catheterize (all $P < 0.001$, Table 4). On multivariable linear regression analysis, catheter use (beta = -1.37 , $P < 0.001$ for mental and beta = -0.657 , $P = 0.002$ for Physical Composite Score) was associated with decreased QoL scores when controlling for disease duration, disability status (PDDS), employment status, OAB symptom score, gender, and age. Given the established associations between longer disease duration and increased physical disability, the negative effect on QoL of catheter use appears to be irrespective of the disability level.

Comment

Approximately 80% of patients with MS report urinary symptoms at the time of MS diagnosis.¹² Within 10 years of onset, up to 96% of patients with MS report urinary dysfunction.¹³ Urinary symptoms may range from frequency and urgency to urge incontinence or urinary retention. Among patients with neurogenic bladder, 62–65% have been diagnosed with OAB symptoms, 20% urinary retention, and 25% detrusor sphincter dyssynergia.¹² Although intermittent catheterization is perceived as the treatment of choice for urinary retention, supra-pubic catheters and chronic indwelling Foley catheters are also utilized.

In our large sample population, 26% of patients with MS have utilized any form of urinary catheterization and 11% report current catheter use. This rate was

higher than expected. Although catheter use is known to be common among patients with MS, quantification of rates of use has been unavailable until now. On the basis of our results, patients with MS have an approximately 1 in 4 chance of requiring urinary catheterization at some point in their disease course. Furthermore, among patients with moderate-to-significant urinary symptoms, the risk of requiring some form of urinary catheterization goes up to 1 in 3.³

Just as urinary symptom severity increases with disease duration and physical disability, rates of catheter use also increase among patients with MS. This association is not surprising, since more severely disabled patients tend to have higher rates of urinary dysfunction and more often require urinary catheterization. However, the predominant use of ISC among patients with MS was an unexpected finding in our study. The degree of manual dexterity required to perform ISC by a committed patient or caregiver is not small. Unfortunately, we lacked the data to distinguish between self- and assistant-performed intermittent catheterization.

The strong gender-based differences in the types of catheter use revealed by our study were unexpected. Higher rates of catheterization in men with MS have not previously been described. Our study may suggest greater bother among males, possibly resulting in increased acceptance of catheter use as a method of coping with urinary symptoms. Although both males and females were more likely to use ISC over other methods, the greater preference among males for indwelling catheters was surprising. No clear explanation for this difference could be found in our data analysis.

Using multivariable linear regression analysis, our data demonstrated that catheter use is associated with

Table 2 Types of catheters used by NARCOMS participants

Catheter type	Male and female (n = 2514)	Male (n = 751)	Female (n = 1763)	P value
Intermittent self-catheter	2042 (81.2%)	623 (82.9%)	1419 (80.5%)	0.147
Current	765 (37.5%)	252 (40.4%)	513 (36.2%)	
Past	1277 (62.5%)	371 (59.5%)	906 (63.8%)	
Foley catheter	1076 (42.8%)	355 (47.3%)	721 (40.9%)	0.003
Current	208 (19.3%)	74 (20.8%)	134 (18.6%)	
Past	868 (80.7%)	281 (79.2%)	587 (81.4%)	
Supra-pubic catheter	195 (7.7%)	87 (11.6%)	108 (6.1%)	<0.001
Current	118 (60.5%)	56 (64.4%)	62 (57.4%)	
Past	77 (39.5%)	31 (35.6%)	46 (42.6%)	

Table 3 Association of ever using a catheter with the presence of bladder symptoms*

Symptoms**	Catheter use: yes (n = 2514)	Catheter use: no (n = 7162)
Frequency	1831 (72.8%)	5133 (71.7%)
Urgency	1729 (68.8%)	4746 (66.3%)
Activity with leakage	1243 (49.4%)	3361 (46.9%)
Small leakage	1465 (58.3%)	3791 (52.9%)
Emptying	1721 (68.4%)	3768 (52.6%)
Abdominal pain	886 (35.2%)	1703 (23.8%)
Nocturia	1826 (72.6%)	5430 (75.8%)

*All $P < 0.001$; **score > 1 (mild) on UDI-6.

Table 4 Urologic evaluation and treatment trends based on catheter use

Urologic treatment	Catheter use: yes	Catheter use: no	P value
Evaluation by a urologist	1915 (76.2%)	2436 (34.0%)	<0.001
Urodynamic testing	1042 (41.4%)	983 (13.7%)	<0.001
Postvoid residual	1288 (51.2%)	1221 (17.1%)	<0.001
Sacral neuromodulation	16 (0.60%)	11 (0.2%)	<0.001
Intra-detrusor botulinum A toxin injection	48 (1.9%)	34 (0.5%)	<0.001
Any anticholinergic medication	1383 (55.0%)	2159 (30.2%)	<0.001

decreased QoL, regardless of disease duration, employment, OAB symptom score, and age (Table 5). However, it is unclear if catheter use itself results in reduced QoL or whether this reflects unmeasured confounders which have not been previously recognized. A qualitative study reported multiple negative responses to self-catheterization, some of which did not diminish over time. We lacked longitudinal data to determine whether improved control of urinary symptoms following catheterization can improve some aspects of QOL (Table 6).

Our study's strengths include our large number of socio-demographically diverse participants, and the focus on an under-explored area in this patient population. Because this was as an ancillary analysis of a previous dataset, we were unable to alter individual questions or explore areas of interest in more detail. NARCOMS participants are volunteers, and non-responders differed

somewhat from responders, but the NARCOMS population is similar to other MS populations.¹⁴ We plan to continue our research on the significance of pelvic floor disorders among patients with MS by re-surveying the NARCOMS population with additional questionnaires. While lengthier questionnaires are available to assess OAB, the UDI-6 is well-validated and has been used in the MS population previously.^{10,11} Further, the brevity of the questionnaire minimizes response burden, which is important for maintaining response rates.

Finally, we are aware that the data utilized in this study are from the Fall 2005 NARCOMS questionnaire. In the six years, since these data were acquired, intra-detrusor onabotulinum A toxin injection for neurogenic detrusor overactivity has become more widely available and even more recently, Food and Drug Administration (FDA) approved (October 2011).¹⁵ Furthermore, sacral

Table 5 Association of catheter use with demographic information, disease duration, and disease severity

Patient characteristics	Catheter use: yes	Catheter use: no	P value
Age (years), mean (SD)	54.4 (10.6)	50.8 (10.4)	<0.001
Race			
Caucasian	2326 (92.5%)	6628 (92.5%)	0.999
Non-Caucasian	188 (7.5%)	534 (7.5%)	
Education, n (%)			<0.001
< High School	78 (3.1%)	150 (2.1%)	
High school	988 (39.3%)	2398 (33.5%)	
Technical or associate degree	439 (17.5%)	1162 (16.2%)	
Bachelor's degree	580 (23.1%)	1945 (27.2%)	
Post-graduate degree	406 (16.1%)	1463 (20.4%)	
Employed, yes, n (%)	491 (19.5%)	3077 (43.0%)	<0.001
Disease duration (years), mean (SD)	17.1 (10.2)	12.1 (8.8)	<0.001
PDDS Score, median (interquartile range)	5.0 (4.0)	3.0 (4.0)	<0.001

Table 6 Comparison of SF-12 QoL measures between patients who used any type of catheter compared to those who did not catheterize

SF-12 measure	Any catheter use: yes (n = 2514)	Any catheter use: no (n = 7162)	Mean difference no versus yes [95% CI]	P value
Physical composite score	31.7 (9.8)	38.6 (11.9)	6.9 [6.4, 7.5]	<0.001
Mental composite score	44.1 (12.1)	45.9 (11.9)	1.8 [1.3, 2.4]	<0.001
BP (bodily pain)	39.5 (13.1)	43.7 (12.3)	4.2 [3.7, 4.8]	<0.001
GH (general health)	39.1 (11.5)	44.0 (11.2)	4.9 [4.4, 5.4]	<0.001
MH (mental health)	45.0 (10.7)	46.3 (10.6)	1.2 [0.8, 1.7]	<0.001
PF (physical functioning)	28.9 (10.1)	36.2 (12.8)	7.3 [6.7, 7.9]	<0.001
RE (role-emotional)	36.7 (14.4)	41.4 (13.2)	4.6 [4.0, 5.2]	<0.001
RP (role-physical)	30.7 (9.8)	37.4 (11.6)	6.7 [6.1, 7.2]	<0.001
SF (social functioning)	36.0 (12.7)	41.4 (12.1)	5.3 [4.8, 5.9]	<0.001
VT (vitality)	39.3 (10.0)	42.6 (10.5)	3.4 [2.9, 3.8]	<0.001

neuromodulation has also become more widely utilized for the treatment of refractory OAB. At the time of the Fall 2005 questionnaire both treatments were relatively new and only sacral neuromodulation was FDA approved, while onabotulinum A toxin was off-label, partially accounting for the limited use of these therapies. We previously noted under-treatment and low rates of use of newer oral medications for OAB in this population even when approved, thus we anticipate that although the frequency of use of neuromodulation and onabotulinum toxin A may have increased in this population, they likely remain underutilized; a clinically relevant finding. Recognizing treatment advances with time, our study remains unique and important as the first documentation of substantial rates of urinary catheterization among community-dwelling patients with MS. Previously, patients with MS could only be counseled that they may someday develop incomplete bladder emptying and require urinary catheterization. Now, patients can be counseled that they have a 1 in 4 risk of needing urinary catheterization in the future, increasing to 1 in 3 if they have moderate-to-severe OAB symptoms. This information is important for all providers caring for patients with MS.

Conclusion

This study is the first of its kind to demonstrate the significant 1 in 4 rate of urinary catheterization in patients with MS. Among patients with moderate-to-severe OAB symptoms, rates of urinary catheter use increase to 1 in 3. No information regarding the true rates urinary catheter for incomplete bladder emptying in patients with MS have previously been available. Although commonly used, urinary catheterization is associated with reduced QoL, increased physical disability, and longer disease duration among catheter-dependent patients with MS.

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