RESEARCH ARTICLE

Tablet-based screening improves continence management in multiple sclerosis

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Abstract

Objective: To investigate whether electronic continence questionnaires aid early identification and optimizes management of sphincter dysfunction in a multiple sclerosis clinic. Methods: A custom designed, tablet-based cross-platform software tool was designed to capture validated multiple sclerosis (MS) patientreported outcomes. An unselected cohort of MS patients from a tertiary referral clinic completed electronic tablet-based versions of the Bladder Control Scale (BLCS) and the Bowel Control Scale in the waiting room. Data were captured wirelessly "on-the-fly" and stored in a deidentified, secure database; and individual questionnaire results were immediately available to the treating neurologist in the electronic medical record. Scores of ≥ 2 on either questionnaire generated an automated electronic referral to the clinic MS continence nurse (MS CN). Results: One hundred and fifty-seven MS patients completed a total of 184 electronic continence test sets and on two occasions only the BLCS was completed. An automatic electronic referral for formal continence review was generated 128 times in 108 patients. Fifty-seven formal continence assessments were undertaken by the MS CN following automated referral. All reviews resulted in at least one clinical intervention being made. Interpretation: Tablet-based data capture and automated continence referral using this software tool is an efficient, sensitive, and feasible method of screening MS patients for bladder and bowel dysfunction. Concordance with the results of formal continence assessment in this pilot study validates the use of this technology as a screening tool.

Introduction

Multiple sclerosis (MS) manifests with a variety of cognitive and physical complaints including sphincter disturbance,¹ and is best managed in a multidisciplinary setting.^{2,3} Almost all MS patients experience sphincter dysfunction at some point during their disease course,^{4,5} however, social and personal factors may inhibit open discussion of continence issues,⁶⁻¹⁰ which means they may be overlooked or remain untreated.^{4,11–13} MS-related urinary tract disorders and urosepsis are thought to be significant factors in premature MS-related mortality,¹⁴ and disease-related bladder and bowel disturbance have a major impact on patient morbidity. To this end, untreated or poorly managed sphincter dysfunction can have devastating consequences. Time-effective methods that sensitively screen for continence problems and provide a pathway to effective management are important.¹²

Most existing continence screening tools focus on bladder function. The use of these questionnaires in clinical practice, including multidisciplinary MS clinics, is partly limited by time constraints and staff workload. Subsequently, our objectives were to (1) develop an electronic tablet-based platform to administer electronic versions of previously validated bladder and bowel self-report questionnaires to MS patients in the waiting room prior to their outpatient appointment; and to (2) validate this methodology with formal continence assessment in those patients with bladder and/or bowel dysfunction scores beyond a predetermined threshold.

We hypothesized that time-efficient, self-administered electronic questionnaires would improve the management of continence issues in a large, university-based MS clinic.

Methods

A custom-designed browser-based cross-platform software tool (TaDiMuS: Tablet-based Data capture in Multiple Sclerosis) was developed to capture previously validated MS Patient-Reported Outcomes (PRO) using an Apple iPad[®] (Apple Inc., Cupertino, California, United States of America). This included patient self-report questionnaires on sphincter function. A literature review (Pubmed search terms: "continence," "incontinence," "sphincter dysfunction" plus "questionnaire," "scale," "tool," or "screening" both with and without "multiple sclerosis") of continence questionnaires/scales used in the assessment of MS patients was undertaken and their adaptability to an electronic tablet-based version determined. Literature review of the use of electronic devices in administering "waiting room questionnaires" was also performed (Pubmed search terms: "iPad," "tablet," "internet," "electronic" plus "questionnaire," or "screening" with and without "multiple sclerosis").

The study was approved by the Human Research Ethics Committee (HREC) of the University of Sydney, and electronic written consent obtained from all patients directly through the TaDiMuS system. One hundred and fifty-seven consecutive MS patients meeting inclusion and exclusion criteria (Table 1) completed TaDiMuS versions of the Bladder Control Scale (BLCS)¹⁵ and the Bowel Control Scale (BWCS)¹⁵ in the waiting room prior to their clinical appointments. The time taken to complete each test was calculated automatically by the system.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria

- Patients diagnosed with MS according to McDonald 2010 criteria⁴⁵
- Age ≥18 years
- Electronic written consent for their data to be used in research Exclusion criteria
- Severe cognitive impairment
- Severe bilateral visual impairment
- Severe upper limb function impairment
- Individuals not willing or able to use a tablet (iPad[®])

MS, multiple sclerosis.

The BLCS consists of four questions and the BWCS contains five questions. Questions 1–3 of the BLCS and questions 1–4 of the BWCS receive a score of 0–4 according to the response. The final question of each scale receives a score of 0–10. The total score of the BLCS and BWCS is calculated by simply adding together the individual scores from each question in the respective questionnaires. The BLCS total scores range from 0–22, and the BWCS from 0–26. The higher the score, the worse the bladder or bowel control, respectively.¹⁵

A score of ≥ 2 on either questionnaire generated an immediate, automated electronic referral (Fig. 1) to the MS Continence Nurse (MS CN) that contained test scores and a patient-specific hyperlink to a secure web-based form (Fig. 2) for recording formal continence assessment and management outcomes. The predetermined threshold scores used to generate automated referral for formal continence assessment were selected by a group of expert neurologists (H. N. B., M. H. B.) and MS CNs (K. E. K., A. O.) to capture patients with mild (or worse) sphincter dysfunction.

Individual patient (continence) data were integrated with the patient's existing electronic medical record (eMR) as a PDF document and made available to the treating physician at the time of consultation. Deidentified, aggregated patient questionnaire data were captured in real time in a secure research database. The outcomes of all automated MS CN referrals and reviews were recorded. The data were analyzed using Microsoft Excel, and mean values and percentages were calculated. Figure 3 summarizes the data flow diagrammatically.

Results

Over a 13-month period, tablet-based electronic versions of the BLCS and BWCS were self-administered by 157 MS patients meeting inclusion and exclusion criteria in the clinic waiting room (two of these patients only completed the BLCS). All patients who were invited to participate in the study were consented and normal clinic workflow was not disrupted. The mean time taken to complete the BLCS and BWCS was 56.6 sec (range 14– 283 sec) and 39.3 sec (range 8–156 sec), respectively. A total of 184 continence test sets (BLCS and BWCS) were completed and on a further two occasions, the BLCS alone was completed. Twenty-five patients completed the continence test set more than once over the observation period of 13 months: 21 twice and four thrice.

An electronic referral for formal continence review was automatically generated 128 times (68.8%) in 108 patients (68.8%), when scores ≥ 2 in the BLCS and/or BWCS were achieved. Fifty-seven (57) formal reviews, including seven via telephone, were carried out by the MS CN following

05/05/2014

Dear MS Continence Nurse,

RE: Test DUMMY 1/01/1975

Thank you for seeing Mr Test DUMMY for assessment of sphincter function. Please note that this is an automated referral based on the following TADIMUS data:

Completed Date: 05-05-2014 11:59:54

Bladder Control Scale (BLCS)

Total Score: 11/22

Questions and actual scores:

1.) Lost control of your bladder or had an accident? 2/4

- 2.) Almost lost control of your bladder or had an accident? 2/4
- 3.) Altered your activities because of bladder problems? 2/4
- 4.) During the past 4 weeks, how much have bladder problems restricted your overall lifestyle? 5/10

Bowel Control Scale (BWCS)

Total Score: 2/26

Questions and actual scores:

- 1.) Been constipated? 1/4
- 2.) Lost control of your bowels or had an accident? 0/4
- 3.) Almost lost control of your bowels or almost had an accident? 0/4
- 4.) Altered your activities because of bowel control problems? 0/4
- 5.) During the past 4 weeks, how much have bowel problems restricted your overall lifestyle? 1/10

Please complete Web-based feedback here.

Thank you,

TaDiMuS

Figure 1. Automated electronic referral received by the multiple sclerosis continence nurse.

automated electronic TaDiMuS referral in 55 patients. The outcomes of formal continence reviews are summarized in Table 2. Review by the MS CN was declined following 66 (51.6%) electronically generated referrals for the reasons listed in Table 3. Of 57 MS CN reviews, patients were unaware that bladder (10.5%) and bowel (14.0%) problems could be caused by MS on six and eight occasions, respectively (Table 4). In 24 cases (42.1%), patients would not have mentioned their sphincter problems had they not completed the electronic questionnaires. In 46 of 57 reviews (80.7%), prior professional advice had been sought for continence problems. Table 5 summarizes the sources of prior management advice.

Discussion

In our single-center cohort, bladder and/or bowel dysfunction was identified in 68.8% of MS patients

TaDiMuS

CONTINENCE NURSE REFERRAL – web-based Data Collection Sheet

- (1) NAME: Mr Test DUMMY 1/01/1975
- (2) TADIMUS generated referral? Yes
- (3) Did the patient perform the questionnaire(s) on TADIMUS prior to the consultation with the doctor? Yes
- (4) Date Questionnaire Completed/Referral Generated: 05/05/2014
- (5) Date of MS Continence Nurse Review: 05/05/2014
- (6a) Patient agreeable to MS Continence Nurse Review? Yes
- (6b) If NO, why not? Select one option below:
- (6c) If YES, would the patient have mentioned their bladder &/or bowel problems in the following consultation unless they had performed the bladder and bowel questionnaires on the iPAD? **No**
- (7a) Has the patient already been reviewed or given professional advice regarding their bladder &/or bowel problem/s? **Yes**
- (7b) If YES, who by? Select from the list below: Nurse MS / continence nurse
- (8) Before performing the questionnaires on the iPAD, was the patient aware that MS could cause bladder problems? Yes
- (9) Before performing the questionnaires on the iPAD, was the patient aware that MS could cause bowel problems? **Yes**
- (10a) As part of the MS Continence Nurse Review were any interventions recommended or required? Yes
- (10b) If YES, please indicate on the list below which intervention(s) were made: **Bladder ultrasound performed** [MS nurse], Urology referral

The bladder/bowel dysfunction was unrelated to Multiple Sclerosis No

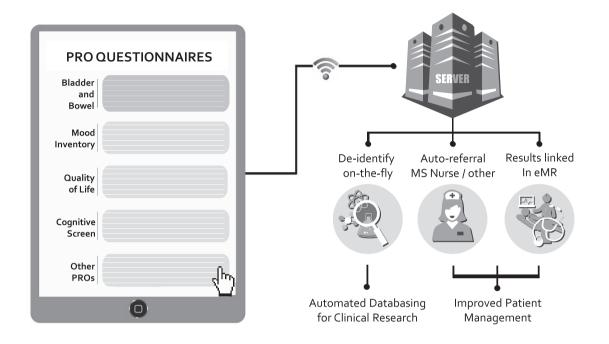
Save

Figure 2. Web-based form completed by the multiple sclerosis continence nurse.

completing tablet-based questionnaires, comparable with previous estimates of the frequency of bladder^{16–18} and bowel^{6,16,18,19} problems in MS populations.

Sphincter dysfunction significantly impacts the quality of life (QOL) in MS patients,^{4,5,12,20–23} but is often overlooked and/or undertreated.^{12,13,23,24} Patients may not

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TaDiMuS – Tablet-based Data capture in Multiple Sclerosis

Figure 3. Patients with MS complete electronic questionnaires on the iPad[®] and the information is automatically captured in real time on a secure server. Deidentified data are stored on-the-fly in an aggregated research database. Individual results are linked in the patient's electronic medical record. If patients reach threshold scores on continence questionnaires, an automated referral to the MS CN is generated. Questionnaire results and information from formal continence assessment are used to guide individual patient management. MS, multiple sclerosis; CN, continence nurse.

seek help for their continence problems,^{6,10,25,26} which may in part relate to social stigma attached to incontinence and sphincter dysfunction,⁷ or a belief that incontinence is an inevitable, untreatable aspect of MS.^{7,27} Patients with MS may feel that medical staff ignore and/ or do not properly assess the cause of their bladder and bowel problems,²⁵ and are often unaware of the range of management options available to address sphincter dysfunction.^{9,25} Finally, there may be limited access to resources to manage and treat continence problems.¹¹

Effective, early treatment of bladder^{5,23} and bowel⁵ symptoms complicating MS, and the provision of appropriate education,^{6,25} significantly enhances patient QOL. A lack of specialist continence advice and/or delayed referral to a urologist for bladder dysfunction may result in problems being more difficult to treat and more serious once they are finally identified.^{12,25}

Reliable, sensitive, and specific screening tools for sphincter dysfunction in the MS patient population¹² are

paramount. Although questionnaires that assess bladder and bowel symptoms as well as their impact on patient QOL exist, few have been specifically developed for use in patients with MS. The BLCS and BWCS are components of the MS Quality of Life Inventory (MSQLI)^{15,28} and were specifically developed for use in MS patients. The BLCS and BWCS are brief, self-administered, previously validated and adaptable to a tablet-based platform; for these reasons, we chose to implement them in this pilot study. Threshold scores for prompting further intervention (in the present study, automated continence referral) have not been previously defined or validated for the BLCS and BWCS or the majority of other questionnaires in routine use. While the MSQLI was designed as a comprehensive patient outcomes' assessment battery,15 the BLCS and BWCS components can be completed separately, are validated and have been shown to have good reliability.^{15,28,29}

The Actionable Bladder Symptom Screening Tool (ABSST) has been recently developed specifically for

Table 2. Outcomes of MS CN reviews following automated TaDiMuS referrals

Type of intervention	Number of times intervention took place as part of MS CN review (%)
Conservative management/practical advice ¹ Conservative management/practical advice only Medication recommendation(s) ³ Postvoid bladder ultrasound ⁴ Urology referral Catheter training	55 ² (96.5) 24 ² (42.1) 23 (40.4) 21 (36.8) 5 (8.8) 1 (1.8)
Total number of reviews Total number of reviews in which ≥1 intervention made	57 57 (100)

Some reviews resulted in more than one type of intervention. MS CN, multiple sclerosis continence nurse.

¹Fluid and caffeine intake, planned toileting, pelvic floor exercises etc. ²Two patients reviewed had non-MS-related sphincter problems. They were given conservative management/practical advice only. ³New medication and/or change of medication dose.

⁴Performed by MS CN.

Table 3. Reasons why MS CN review declined following automated TaDiMuS referrals.

Reason MS CN review declined	Number of declines (%)
Already reviewed in the last 12 months by	27 ¹ (40.9)
a specialist or continence nurse and/or	
their sphincter problem(s) were optimally managed ¹	11 (16.7)
Sphincter problems were not related to their MS	
Did not think they had sphincter problems that needed addressing	14 (21.2)
Referred directly to a urologist by their treating neurologist	2 (3.0)
Previously reviewed for sphincter problems and it was not useful/helpful	1 (1.5)
Unable to wait/not convenient to rebook a time	5 (7.6)
Did not want to learn intermittent self-catheterization	1 (1.5)
No reason given	2 (3.0)
Unknown/unable to contact ²	3 (4.5)
Total number of declines	66

¹On seven occasions, review declined because a MS CN review had already occurred following prior TaDiMuS automated referral (two occasions in the same patient). MS CN, multiple sclerosis continence nurse.

²Unsuccessful contact despite three attempts (by telephone).

patients with MS.12 While this instrument was found to have high sensitivity and specificity for bladder dysfunction, the questionnaire is longer than the BLCS and BWCS combined, and does not address bowel symptoms. A shortened version of the ABSST where a cutoff score of Table 4. Screening and educational data from the MS CN reviews.

Question	Yes	No
Had the patient been professionally reviewed or advised regarding their sphincter problems before?	46 (80.7%)	11 (19.3%)
Would the sphincter problems have been mentioned by the patient if they had not completed the electronic questionnaires?	33 (57.9%)	24 (42.1%)
Was the patient already aware that MS could cause bladder problems?	51 (89.5%)	6 (10.5%)
Was the patient already aware that MS could cause bowel problems?	49 (86.0%)	8 (14.0%)
Total number of reviews	57	

MS CN, multiple sclerosis continence nurse.

Table 5. Sources of prior management advice of sphincter problems.

	N (%)
MS nurse/continence nurse	32 (69.6)
Neurologist	9 (19.6)
Urologist	16 (34.8)
Other specialist	2 (4.3)
GP	2 (4.3)
Total number of reviews	46

In some cases, prior management advice had been sought from more than one source. MS, multiple sclerosis; GP, General Practitioner.

 ≥ 6 , rather than ≥ 8 , was deemed suitable for urology referral has been developed.³⁰ Our study approach differed from the ABSST approach, in that (1) the BLCS and BWCS threshold scores were used to prompt MS CN review, and (2) threshold score calculation and MS CN referral was fully automated and immediate. The abbreviated ABSST could feasibly be incorporated into the TaDi-MuS system and trialled in a real-world clinical setting.

Computer, tablet, and Internet-based patient data collection is now commonplace and is generally considered to be valid compared with paper-based surveys.^{31,32} While there are numerous examples of electronic patient questionnaires or tools being utilized in a variety of medical conditions,³¹⁻³⁴ published work in MS populations has predominantly focused on electronic cognitive screening and assessment.34-38 In the United Kingdom, an MS patient register has been developed in which PROs are entered via a web portal,³⁹ and tablet-based patient data capture systems similar to TaDiMuS have been previously used and validated in non-MS populations.^{40,41} The use of electronic bladder and bowel questionnaires to automatically generate CN referrals in both MS and non-MS populations is, to our knowledge, unprecedented.

TaDiMuS improved efficiency in our multidisciplinary MS clinic. Without interruption to clinic workflow, MS patients with potential sphincter dysfunction were automatically identified and, where appropriate, referred to the MS CN. This allowed a greater number of patients to access continence advice, education, and management from the MS CN. As this screening system did not rely on the neurologist making an MS CN referral, or the patient requesting MS CN review, it is unlikely that any patient with significant sphincter dysfunction was "missed." All patients in whom an automated referral was generated were followed up in person (immediately after completion of the questionnaires when logistically feasible) or contacted by telephone, and formal continence assessment undertaken following 62 out of 128 (48.4%) referrals. Of the 57 MS CN reviews performed, at least one clinical intervention was made in every case (Table 2), validating the specificity and clinical utility of the screening tool. Of the electronically generated MS CN reviews, 55 (96.5%) resulted in conservative advice (42.1% were given conservative advice alone), 21 (36.8%) had a postvoid bladder ultrasound performed by the MS CN, 23 (40.4%) were recommended pharmacological intervention, and 5 (8.8%) received specialist urological referral.

As threshold scores were set to maximize sensitivity, our system is likely to identify continence problems at an early, mildly symptomatic stage, potentially at the expense of generating a larger volume of patients requiring formal MS CN assessment. In 11 of the 57 TaDiMuS-generated reviews (19.3%), the patient had never received previous advice regarding their sphincter dysfunction. Patients were unaware that bladder or bowel dysfunction could be MS-related in 6 (10.5%) and 8 (14.0%) of the 57 reviews, respectively. The TaDiMuS system, therefore, effectively identified patients with early sphincter dysfunction, who are more likely to be therapeutically responsive.^{5,23} While TaDiMuS clearly facilitated continence education in this patient group, awareness of MS-related bladder and bowel dysfunction was likely enhanced in all patients, simply by completing electronic continence questionnaires.

In 24 (42.1%) of the TaDiMuS-generated reviews, patients reported that they would not have mentioned their bladder and/or bowel complaints had they not completed the electronic (BLCS and BWCS) questionnaires. MS patients are reluctant to discuss and/or seek professional assistance for sphincter dysfunction, especially if they have incontinence.^{8,9,20,42} The method used to collect information regarding continence in MS patients can markedly effect results.⁹ Prior research also indicates that patients may be more candid when interacting with a non-human interface.³¹ Electronic continence self-report questionnaires, as utilized in the TaDiMuS system, are therefore likely to effectively and reliably identify MS patients with sphincter dysfunction, compared with rou-

tine consultation alone, in part by facilitating appropriate discussion with the treating physician or continence advisor.

Despite the advantages of this automated screening system, TaDiMuS-generated referral for formal continence assessment was declined in 66 out of 128 instances. The reasons given by patients for declining formal continence assessment are listed in Table 3, and are not dissimilar to those indicated by previous studies.^{6,43} Over a third (n = 27) who declined formal continence assessment in our cohort did so because they had already been reviewed by a specialist within the last 12 months and/or their sphincter problems were already optimally managed.

While tablet-based data collection relies on the willingness of patients to use this technology, none of the patients approached in our clinic expressed any concern in this regard. However, we excluded MS patients with severe cognitive impairment, severe bilateral visual disturbance, and/or severe upper limb dysfunction from this pilot study on the basis that they would be unable to operate an iPad[®]. Similarly, severely disabled patients are also unlikely to be able to complete paper-based self-report questionnaires. As patients with significant disability are more likely to have continence problems, we plan to develop and validate carer-informed electronic questionnaires.

Conclusion

Tablet-based data capture and automated continence referral using the TaDiMuS system is an efficient, sensitive, and feasible method of screening MS patients for bladder and bowel dysfunction in the clinic setting. Concordance with the results of formal continence assessment in this small pilot study validates the use of this technology as a screening tool. The TaDiMuS system streamlines clinical workflow, provides a portal for patient education, and has the potential to improve patient outcomes through early detection and management of sphincter dysfunction in MS.

The TaDiMuS platform has been developed to capture a spectrum of MS PROs. We are currently exploring the utility of routine electronic screening for cognitive dysfunction, another underrecognized aspect of MS,⁴⁴ with automated threshold-based referral for formal neuropsychological testing. TaDiMuS has also been implemented in postmarketing surveillance studies at our center; and cloud-based server technology is being exploited to facilitate multisite TaDiMuS-based clinical studies.

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Author Contributions

M. Barnett codesigned and conceptualized the study, interpreted the data, and revised the manuscript. H. Beadnall codesigned the study, collected, analyzed and interpreted the data, and drafted and revised the manuscript. K. Kuppanda and A. O'Connell collected the data and revised the manuscript. T. Hardy and S. Reddel interpreted the data and revised the manuscript.

Conflict of Interest

None declared.

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