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A Qualitative Study of Health Care Professionals' Views on Bowel Care in Multiple Sclerosis: Whose Job Is It Anyway?

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Running title: HCP Views on Bowel Care in MS

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Practice Points

- Health care professionals assume that people with MS will tell them when they experience bowel dysfunction, but people with MS want to be asked explicitly. Active case finding is vital for all people with MS who may not volunteer these symptoms.
- Assessment processes, treatment options, and referral pathways vary, and evidence-based clinical guidelines and referral pathways are required.
- People with MS are often referred to specialist continence or bowel services at a crisis point, and earlier referral is called for.

Abstract

Background: Bowel dysfunction, including constipation and fecal incontinence, is prevalent in people with multiple sclerosis (MS), adversely affecting quality of life and increasing caregiver burden. How health care professionals (HCPs) identify, assess, and manage people with MS with bowel dysfunction is understudied. This study explored how HCPs think about, assess, and manage bowel dysfunction in people with MS.

Methods: Semistructured interviews were conducted with 18 HCPs from different professional disciplines and clinical specialities recruited from UK National Health Service primary, secondary, and tertiary care services using purposive and chain referral sampling through professional networks. One participant worked for a bladder and bowel charity. Data were analyzed using thematic analysis.

Results: Views differed regarding responsibilities for providing bowel care. Participants thought people with MS should notify HCPs of bowel symptoms and take responsibility for self-management where possible, with family caregivers required to help with bowel care. Although people with MS were often referred to bladder and bowel specialists when a crisis point was reached, earlier referral was called for by these HCPs. There were variations in assessment processes, treatment options offered, and service provision. Participants thought HCPs needed more education on bowel dysfunction, bowel care should take a high priority, and evidence-based clinical guidelines and referral pathways would improve service delivery.

Conclusions: The HCPs caring for people with MS see many with bowel dysfunction, and there is variation in care and service provision; HCPs require more education, evidence-based clinical guidelines, and referral pathways to improve case finding, assessment, and management of these symptoms for people with MS. *Int J MS Care.*

Introduction

Neurogenic bowel dysfunction (fecal incontinence and constipation) is prevalent in multiple sclerosis (MS). In Western populations, 35% to 54% of people with MS experience constipation, and fecal incontinence affects 29% to 51% of people with MS.¹ Bowel dysfunction is multifactorial, may be intrinsic to MS, and results from neurologic damage. Extrinsic factors include diet, medication, poor exercise, and injury during childbirth. Despite UK national guidelines recommending that health care professionals (HCPs) conduct active case finding among people with a high risk of bowel problems,² this does not seem to be happening, possibly due to clinicians and patients being reluctant to address the issue,^{3,4} lack of expertise in bowel management, or pessimism about the likelihood of symptom relief. There is a risk of “diagnostic overshadowing” wherein any problem in people with MS is assumed to be due to the MS and further investigations for other potential causes are not considered. In addition, people with MS may not seek help if they are unaware of available services, do not know whom to ask,⁵ have previously worked up the courage to ask but received no useful response, or believe that bowel problems are either expected with MS or unrelated to their MS.⁶

Most evidence on incontinence in MS relates to bladder dysfunction, with little to guide HCPs in management of bowel dysfunction.^{7,8} Bowel management advice that is provided is based on expert opinion rather than on empirical evidence. Although bladder management is addressed in a UK consensus paper,⁹ there is no equivalent for bowel dysfunction. In a recent Australian study,¹⁰ bladder or bowel problems were reported as the third most troublesome symptoms, after fatigue and mobility, by people with MS, caregivers, and physicians across all disease severities, affecting quality of life and increasing caregiver burden. Yet, few studies have

tested interventions to improve bowel function,¹¹ and there is no evidence reporting on what HCPs know, think, and do about bowel dysfunction in MS.

The perspectives and priorities of HCPs delivering specialist care to people with MS may be at odds with the perspectives of those with the disease.¹² The first phase of a larger project explored the experience of bowel dysfunction and care of people with MS and their caregivers, the findings of which have been reported elsewhere.⁶ Understanding the experiences and perceptions of HCPs regarding bowel dysfunction will help guide and promote more appropriate support and care for these distressing symptoms. As part of this larger project exploring bowel dysfunction in MS, this study aimed to explore how bladder and bowel, gastroenterology, and MS specialist HCPs think about and assess MS-related fecal incontinence and constipation and how they meet patient needs.

Methods

The study was approved by the North West Research Ethics Committee and the research ethics committee at King's College London. Informed consent was recorded immediately before data collection.

Study Design

This study used an exploratory qualitative approach,¹³ which is appropriate for exploring participant experience and useful when little is known about a topic and/or a specific philosophical approach is not essential.¹⁴ Rigor is achieved through robust design using qualitative techniques such as purposive sampling, face-to-face interviewing, appropriate

techniques for analyzing textual data, and representation of participants' experiences through verbatim data extracts.

Sampling

Using purposive and chain referral sampling¹⁵ through professional networks of nurses, physicians, and physiotherapists to select HCPs from a range of disciplines, 18 participants were recruited from UK National Health Service primary, secondary, and tertiary care services. This group included a variety of clinicians with experience in supporting people with MS who have bowel problems and their caregivers.

Data Collection

Data were collected via semistructured interviews conducted by two of us (S.W. and M.C.), both trained and experienced in these methods, either face-to-face at the HCP's place of work or via telephone using a preprepared topic guide (Box S1, which is published in the online version of this article at ijmsc.org). Participants were subsequently asked for their views on issues raised by people with MS and their caregivers who took part in the previous phase of this larger project,⁶ continuing with interviews until apparent data saturation was reached. The interviews lasted 30 to 45 minutes and were digitally audiorecorded and professionally transcribed verbatim before being anonymized.

Analysis

Data were analyzed thematically following the method described by Braun and Clarke,¹⁶ an inductive process in which data were read and reread before coding and emerging broader

themes from the coded data were identified (Figure S1). Two authors (S.W. and M.C.) performed preliminary analysis to identify themes, which were then discussed and agreed on with all authors.

Results

Interviews were conducted with eight bladder and bowel care specialist nurses (BBCSNs), four MS specialist nurses (MSSNs), one neurology clinical nurse specialist (CNS), one gastroenterologist, one physiotherapist, one representative of a bladder and bowel charity, one neurologist, and one rehabilitation medicine consultant (Table 1). Verbatim quotations are given to illustrate findings, with participant number and role in parentheses.

Three main themes emerged from the data: 1) whose job is it anyway?, 2) practicalities of bowel management, and 3) improving service delivery. Several subthemes were also revealed (Table 2).

Whose Job Is It Anyway?

Participants reported a range of experiences of involvement in bowel care and discussed who they believed should be responsible for identifying needs and providing this care, ranging from people with MS or their caregivers to a variety of general and specialist HCPs.

Responsibilities of People with MS

Participants reported that bowel problems were prevalent among people with MS, being cited as one of the “top three” symptoms encountered (001, MSSN), with constipation

predominating, and that people with MS may not realize that these symptoms could be related to MS. Where prevalence of bowel dysfunction was expressed as a percentage for the caseload, this ranged from 50% to 80%. HCPs thought that, where possible, people with MS should self-manage, particularly in the early stages of the disease, but believed that knowledge was essential for self-management. Overwhelmingly, HCPs identified that the main responsibility of people with MS was to report bowel problems after appropriate education and supported by patient guidelines. Participants thought that people with MS should titrate laxative doses, for example, or manage transanal irrigation on their own. Although the challenges of promoting self-management were acknowledged, so was the approach taken by HCPs in promoting “dependent management” (003, MSSN).

Caregiver Responsibilities

There were differences of opinion among professionals about family caregiver involvement. It was acknowledged that family caregivers were able to provide a bowel history, if the person with MS was unable to, and to provide bowel care in some cases. However, although some caregivers may be happy to be involved, others may not be, and it could have an adverse effect on relationships. Decisions regarding involvement of family caregivers were based on understanding their stories, which influenced whether HCPs felt that partners, for example, should be involved.

The strain on caregivers was also described as a “secret strain” (004, BBCSN) because it was not a topic one could discuss with friends. The role of family caregivers was discussed. Although it was considered appropriate for family members to make people with MS comfortable after an episode of fecal incontinence, it was less acceptable for them to deliver

interventions such as transanal irrigation, which should remain the domain of “community nursing” (005, BBCSN).

HCP Responsibilities

Both MSSNs and BBCSNs thought that district nurses should provide bowel care to people with MS, although the time and resource constraints that primary care services were working under were acknowledged and district nurse involvement was inconsistent. This may lead to non-nurse paid caregivers becoming involved in bowel management, although this was “hit and miss” (006, MSSN) and dependent on local policies and available resources rather than on patient need. It was unclear how this care should be delegated and who carried legal responsibility for delegated care. Paid (non-nurse) home caregivers were not allowed by their employers to give any rectal interventions, such as suppositories or transanal irrigation, although this seemed to be changing.

It was also acknowledged that “[bowel care] is not a very nice thing” and “puts a lot of people off” (002, MSSN). Good practice was highlighted, with joint assessments being undertaken by bowel specialist nurses and district nurses together, but this was rare. Some district nurses were perceived as “difficult” (002, MSSN) about giving transanal irrigation, but attitudes changed when treatment proved successful. In one case, lack of community care meant that one individual with MS had to stop using transanal irrigation, which had been helping her.

It was thought that bowel care should be provided by “whoever the patient feels comfortable with” (005, BBCSN), which could be compromised because of lack of continuity of care provided by care agencies.

Practicalities of Bowel Management

Practical aspects of providing bladder and bowel care to people with MS, including case finding, processes and challenges of assessment, and management options/treatment hierarchy, were raised.

Delayed Reporting

Participants identified delayed reporting of bowel problems by people with MS and that by the time they became aware that someone had symptoms it had “been a problem for some time” (006, MSSN) or had reached a “crisis point” (009, BBCSN). People with MS were thought to normalize bowel dysfunction and accept it as part of the disease, often increasing caregiver burden. It was thought that general practitioners (GPs) and neurologists should refer people with MS to specialist bladder and bowel services earlier, although people with MS were thought to be more likely to report bowel problems to a nurse than to a doctor. Bowel problems often became apparent only when referred to bladder and bowel services for bladder dysfunction.

Assessment

The impact of bowel dysfunction on other MS symptoms, such as spasticity, bladder dysfunction, and sexual dysfunction, was identified. All participants who were not bladder and bowel specialists reported asking people with MS about bowel problems but preferred to develop a rapport before discussing this topic, which was perceived to be sensitive or embarrassing. People with bowel dysfunction could also be missed, and when medical records of people with long-standing problems were reviewed there was “actually no mention of it” (010, gastroenterologist).

It was considered that HCPs may not ask questions about bowel function either because they do not know what to offer or because they are embarrassed discussing the subject themselves. There may also be insufficient appointment time to ask detailed questions about bowel problems, which may be “left off the list” (011, neurologist) and referred to MSSN colleagues for assessment. A consistent finding was the importance of all HCPs asking patients about bowel problems. The MSSNs were more likely to think that bringing this into early conversations was inappropriate both because other topics took priority and they did not want to overwhelm their patient with too much information after diagnosis or because they did not want to “make a big thing of it” (006, MSSN) and worry people who may never develop symptoms. The BBCSNs expressed a different opinion and thought that people with MS should be given information about potential bowel problems and “... they need a proper assessment” (013, BBCSN) should this occur.

Assessment processes varied from informal to structured, with BBCSNs and the gastroenterologist more likely to use a structured bowel assessment process. Bowel diaries were mentioned, but use of self-assessment scales in advance of appointments was not reported. Assessments by MSSNs, however, were more informal. The BBCSNs and the gastroenterologist used triage to prioritize bladder or bowel problems, with a systematic approach to assessment incorporating a structured history, supported by bowel diaries and locally developed assessment questionnaires, followed by physical examination and investigations such as colonic transit studies.

It was thought important to begin by identifying what was “bothersome” and not “go wading in” (014, BBCSN). Identification of red flags (such as rectal bleeding) possibly

indicating more serious bowel problems was also considered, and the potential for diagnostic overshadowing was acknowledged.

Management

The MSSN participants felt confident to discuss bowel problems, although more so the management of constipation than fecal urgency or incontinence. This normally included advice about diet, fluid intake, and possibly laxatives, but MSSNs soon felt that they had reached the limits of their competence and acknowledged that MSSNs were probably “not the best at attacking this issue” (003, MSSN).

There seemed to be a hierarchy of interventions offered, beginning with lifestyle and dietary advice, followed by laxative and suppository use, transanal irrigation, biofeedback, digital stimulation, and, ultimately, stoma formation. Digital rectal interventions and rectal medications were rarely mentioned, and stoma formation was seen as a “last resort” (006, MSSN), although one participant questioned this, identifying that a stoma should be “the right option at the right time, not the last resort” (007, BBCSN).

Different HCPs used different interventions, based on expertise/preferences, while also working within local constraints and “incredible resistance” from some GPs they encountered to prescribe transanal irrigation (016, neurology CNS). The hierarchy contained in the UK national neurogenic bowel guidelines that had been developed for people after spinal cord injury¹⁷ was followed, and trial and error was also used as a strategy. Patient preference was also considered important, and participants recognized their role in empowering choice.

Coupled with this was the need to provide continuing support when commencing a new intervention, for example, titrating laxative doses, to ensure that they achieved a “good result”

(014, BBCSN) and persist with it. Some professionals (including the gastroenterologist, MSSNs, and BBCSNs) provided people with MS with a telephone number to call between appointments, and others used e-mail. Follow-up and review of the outcomes of treatment was an important aspect of management; however, MSSNs reported that they had limited capacity for follow-up on bowel issues between scheduled 6-month reviews and so often the success of their suggestions was unknown.

Improving Service Delivery

The need to improve service delivery for people with MS with bowel dysfunction was a strong theme. The HCPs acknowledged that these symptoms warranted higher priority and called for improved professional education and training, evidence-based clinical guidelines, and referral pathways.

Education, Education, Education

A consistent view expressed was the need for improved education of HCPs in managing bowel dysfunction for people with MS. Participants reported developing skills from clinical experience, including jointly working with other professionals, or conference attendance, and no formal education was reported. The need to self-educate was acknowledged. The gastroenterologist and BBCSN participants also reported that other HCPs did not know enough about bowel management and believed that improving education would lead to improved service delivery through appropriate referral.

Education was also thought to improve primary care services because professionals would be aware of “stuff they [primary care providers] can do” before referring to a specialist service, which included asking questions about bowel problems.

Prioritizing Bowel Care

Bowel dysfunction was a “don’t ask, don’t tell” symptom that needed increased priority. Participants reported asking about bowels but not putting “the same weighting” on this as other symptoms (003, MSSN) or prioritizing disease-modifying treatments. Frustration was expressed that bowel care was not given the same priority as bladder care. There was a perception that district nurses and service commissioners did not “see [bowel care] as a priority” (008, BBCSN). It was widely acknowledged that education of all HCPs was essential to improve case finding and avoid normalization of bowel problems.

Referral Pathways

Referral pathways both into and onward from the services of participants were discussed. The need to develop relationships with likely referrers and to publicize services was highlighted. Referrals into continence or bowel services came from a GP, neurologist, or gastroenterologist or from MSSNs. Some BBCSN and MSSN services had an “open referral system” and were able to see patients in clinics or at home. This was thought to remove barriers and reduce the number of embarrassing conversations required, but services need to be promoted to people with MS, and there is a need for triage. There was a clear desire for a referral pathway.

Bladder and bowel nurses believed that they should be the ones to assess and manage people with neurogenic bowel dysfunction rather than MSSNs. There was a desire to see these

patients and avoid unwarranted hospital admissions for constipation and fecal impaction. Those working in specialist services in tertiary referral centers saw their role as working with people with MS with refractory problems.

The MSSNs seemed to adopt a consistent onward referral pattern, providing services were available in the local area. Onward referral to continence services from MSSNs was widely reported after initial screening, although continence services were not always perceived to be helpful by MSSNs or others, often perceived as “urology focused” (017, rehabilitation physician). Joint clinics between the MSSNs and BBCSNs had proved to be effective but difficult to sustain.

The BBCSNs would refer onward to other bowel specialists as necessary, such as a specialist neurogenic bowel service, gastroenterologists, and/or colorectal surgeons. They may also contact specialists in their own professional networks for advice. However, lack of opportunity to refer to a local specialist bowel service was a source of frustration.

Need for Guidelines

The lack of clinical guidelines for the management of neurogenic bowel dysfunction in MS was a consistent finding compared with other clinical conditions. Participants thought that guidelines for management of bowel problems in MS would be helpful and that “an algorithm would be great” (009, BBCSN). Some participants used generic guidelines for management of neurogenic bladder dysfunction and thought that patient care would benefit from having a clear pathway to follow. Participants thought that a guideline would improve both treatment consistency for people with MS and communication between professionals, ensuring that treatment was based on evidence rather than on individual opinion. It was thought that guidelines

should assist practitioners to “do the simple things properly” (010, gastroenterologist) and include details of when to escalate treatment or refer onward.

Discussion

This is the first study, to our knowledge, to explore the views of HCPs about provision of bowel care to people with MS. Three main themes were identified: Whose job is it anyways?; practicalities of bowel management; and improving service delivery.

There was a strong sense that people with MS should be supported by HCPs to self-manage bowel dysfunction. People with MS are increasingly expected to manage the impact and symptoms of their long-term condition on a day-to-day basis.¹⁸ However, there is little evidence of effectiveness of self-management interventions among people with MS generally and almost none for self-management of bowel dysfunction. Further research should develop and explore the effectiveness of a bowel self-management program for people with MS

Generally, HCPs value the input of family caregivers in assessment of bowel dysfunction. Although the prevailing attitude was that they should not be involved in direct bowel care, it was pragmatically recognized that much bowel care would not take place without the support of family caregivers. Toileting has previously been identified as a common activity performed by family caregivers of people with MS that increases with increasing disease impact, leading to poorer health status and quality of life among caregivers with increasing caregiver burden.¹⁹ Caregivers should not feel that they are obliged to be involved in bowel care, but the subtext is that with an increasing demand-capacity gap in district nursing services,²⁰ there is sometimes

little alternative than for family caregivers to take this on. Health professionals should be mindful of the potential impact that bowel care may have, particularly on spousal relationships.

The importance of maintaining a good relationship with district nursing teams was highlighted, although it was unclear who was responsible for providing bowel care outside of the hospital. If care was devolved to paid caregivers, it was unclear who would be responsible for their training and assessment of competence. This raises the question as to who would be accountable for the care provided by unqualified paid caregivers.

Bowel problems are prevalent among people with MS, and the reported prevalence in this study was consistent with that in the literature,¹ yet a crisis point is often reached before appropriate care is provided. Case finding by HCPs, GPs, neurologists, and MSSNs, in particular, needs to improve to avoid treatment delays and normalization of bowel problems. In line with current recommendations,² HCPs need to ask about bowel problems or people with MS may not think that these symptoms are important or may remain unaware of treatment options. Equally, people with MS may be embarrassed by their symptoms and find them difficult to discuss, wanting the HCP to take the lead.⁶ It has been acknowledged previously that bowel dysfunction can be a socially stigmatizing condition and, therefore, that HCPs should “actively yet sensitively enquire about symptoms in high-risk groups,”^{2, page 6} including those with MS, yet this does not always happen. Participants in this study reported asking people with MS about their bowels, yet some people with MS cared for by these same HCPs reported no recollection of being asked when interviewed.⁶ Discrepancies between patient and physician perceptions have been noted in previous surveys of people with MS, with only 23% of patients (n = 331) thinking that they had discussed their treatment with their health care team compared with 47% of physicians (n = 280).²¹ Although this finding may be accounted for in part by cognitive decline,

it could equally be that either the question was not asked or people with MS did not remember being asked in the midst of the consultation. It was noted that no participants reported using the Expanded Disability Status Scale,²² the most commonly used scale for assessing the impact of MS on functional ability in the United Kingdom, during consultations. This scale includes a bladder and bowel domain and could provide an opportunity to raise the question of bowel dysfunction with people with MS as a “jumping off” point, although it is acknowledged that some HCPs, for example, neurologists, will be more familiar with this scale than others.

The MSSNs were perceived to have a particularly important role in case finding by participants in the study and should have knowledge of bowel dysfunction and continence care, even if only to refer onward. The MSSNs could be the lynchpin in early detection and referral, although not every person with MS has access to this support.²³ Contact with an MSSN has the potential to provide a gateway to other specialist support services.²⁴ The MSSN has been identified as the preferred provider of bowel care by 83% of people with MS (n = 101) in a previous survey¹⁰ and echoed again more recently,⁶ although the MSSNs in this study did not feel that they had the competence or confidence to manage these symptoms. Similarly, 94% of HCP respondents thought that MSSNs were the most appropriate care providers for bowel dysfunction,¹⁰ in contrast to the findings of this study. This may reflect the changing role of the MSSN in the past decade, with the emphasis now much more on supporting people with MS undergoing treatment with disease-modifying treatments,²⁵ or lack of emphasis on bowel care in the MSSN role.²³

In this study, MSSNs were more cautious than others about when and how much information about possible bowel problems they give to people with MS, whereas BBCSNs were more enthusiastic about providing information early. Giving information early could ameliorate

risks, such as those associated with laxative use, and help patients understand that bowel dysfunction may be a feature of their MS and that there are treatments available.

Bladder and bowel services were seen as the most appropriate service for advice on all but the most basic bowel care by HCPs. There was a strong sense that it was important to make access to continence services as easy as possible, with self-referral one way to make the patient journey easier. Continence service specialists preferred earlier referrals rather than waiting until a crisis point was reached. A recent study demonstrated the effectiveness of screening for bladder and bowel dysfunction in people with MS using completion of validated outcome measures on a handheld computer tablet while waiting for a clinic appointment.²⁶ The use of technology could be explored to improve case finding and appropriate onward referral.

There was a request for clinical guidelines or a treatment algorithm from many participants, with some reporting that they referred to the Guidelines for Management of Neurogenic Bowel Dysfunction in Individuals with Central Neurological Conditions.¹⁷ Although these guidelines are based on the best available evidence, this is primarily from the spinal cord injury literature rather than MS, and either the suitability of these existing guidelines for the MS population needs exploring or specific guidelines for this population are required. A referral pathway was also considered highly desirable. The GPs were perceived as powerful and, although potentially lacking knowledge or interest in neurogenic bowel dysfunction, would be important in any pathway; GPs acted as gatekeepers and may block access to treatments, such as transanal irrigation, that they do not understand or perceive as expensive.

Strengths and Limitations

This study included participants from a wide range of health disciplines who may be involved in providing bowel care to people with MS. The sample was self-selecting and so may not be representative of all professional views, and no GPs were included, but it was representative of diverse services throughout the United Kingdom. Although this study did not seek to explore similarities and differences in opinions between different professional groups, the key messages seem to be the same from all participants.

Conclusions

Participants reported that bowel dysfunction is prevalent among HCP caseloads of people with MS, but there is variation in service provision depending on knowledge and attitudes of HCPs and configuration of local services, which makes identifying referral pathways challenging. There is a lack of evidence-based guidance for HCPs in managing bowel dysfunction in people with MS, whereas this exists for bladder dysfunction, leading to inconsistencies in treatments offered and calls for better education for HCPs. Development of guidelines and referral pathways should be prioritized to improve case finding, support self-management of bowel function by people with MS where possible, and improve service delivery across primary, secondary, and tertiary care.

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References

1. DasGupta R, Fowler CJ. Bladder, bowel and sexual dysfunction in multiple sclerosis: management strategies. *Drugs*. 2003;63:153-166.
2. National Institute for Health and Care Excellence. *Faecal Incontinence: The Management of Faecal Incontinence in Adults: Clinical Guideline 49*. London:National Institute for Health and Care Excellence; 2007.
3. Duncan J, Sebeos-Rogers G, Poole-Wilson O, et al. P243 Faecal incontinence in inflammatory bowel disease: we don't ask and they don't tell. *J Crohns Colitis*. 2013;7(suppl 1):S106-S107.
4. Bartlett L, Nowak M, Ho YH. Reasons for non-disclosure of faecal incontinence: a comparison between two survey methods. *Tech Coloproctol*. 2007;11:251-257.
5. Norton C, Dibley L. Help-seeking for fecal incontinence in people with inflammatory bowel disease. *J Wound Ostomy Continence Nurs*. 2013;40:631-638; quiz E1-E2.
6. Dibley L, Coggrave M, McClurg D, Woodward S, Norton C. "It's just horrible": a qualitative study of patients' and carers' experiences of bowel dysfunction in multiple sclerosis. *J Neurol*. 2017;264:1354-1361.

7. Khan F, Gray O. Disability management and rehabilitation for persons with multiple sclerosis. *Neural Regen Res.* 2010;5:301-309.
8. Williams D. Management of bladder dysfunction in patients with multiple sclerosis. *Nurs Stand.* 2012;26:39-46.
9. Fowler CJ, Panicker JN, Drake M, et al. A UK consensus on the management of the bladder in multiple sclerosis. *J Neurol Neurosurg Psychiatry.* 2009;80:470-477.
10. Khan F, McPhail T, Brand C, Turner-Stokes L, Kilpatrick T. Multiple sclerosis: disability profile and quality of life in an Australian community cohort. *Int J Rehabil Res.* 2006;29:87-96.
11. Coggrave M, Wiesel PH, Norton C. Management of faecal incontinence and constipation in adults with central neurological diseases. *Cochrane Database Syst Rev.* 2006;2:CD002115.
12. While A, Forbes A, Ullman R, Mathes L. The role of specialist and general nurses working with people with multiple sclerosis. *J Clin Nurs.* 2009;18:2635-2648.
13. Stebbins RA. *Exploratory Research in the Social Sciences.* Sage Publications Inc; 2001.
<https://methods.sagepub.com/book/exploratory-research-in-the-social-sciences>
14. Sandelowski M. What's in a name? qualitative description revisited. *Res Nurs Health.* 2010;33:77-84.
15. Valerio MA, Rodriguez N, Winkler P, et al. Comparing two sampling methods to engage hard-to-reach communities in research priority setting. *BMC Med Res Methodol.* 2016;16:146.
16. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3:77-101.

17. Coggrave M, Ash D, Adcock C. Guidelines for management of neurogenic bowel dysfunction in individuals with central neurological conditions. Published 2012.
<https://www.mascip.co.uk/wp-content/uploads/2015/02/CV653N-Neurogenic-Guidelines-Sept-2012.pdf>
18. Fraser R, Ehde D, Amtmann D, et al. Self-management for people with multiple sclerosis: report from the first international consensus conference, November 15, 2010. *Int J MS Care*. 2013;15:99-106.
19. Forbes A, While A, Mathes L. Informal carer activities, carer burden and health status in multiple sclerosis. *Clin Rehabil*. 2007;21:563-75.
20. Maybin J, Charles A, Honeyman M. *Understanding Quality in District Nursing Services: Learning from Patients, Carers and Staff*. The King's Fund; 2016.
21. Lugaresi A, Ziemssen T, Oreja-Guevara C, Thomas D, Verdun E. Improving patient-physician dialog: commentary on the results of the MS Choices survey. *Patient Prefer Adherence*. 2012;6:143-152.
22. Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an Expanded Disability Status Scale (EDSS). *Neurology*. 1983;33:1444-1452.
23. Mynors G, Perman S, Morse M. *Defining the Value of MS Specialist Nurses*. Multiple Sclerosis Trust; 2012.
24. Somerset M, Campbell R, Sharp DJ, Peters TJ. What do people with MS want and expect from health-care services? *Health Expect*. 2001;4:29-37.
25. Burke T, Dishon S, McEwan L, Smrtka J. The evolving role of the multiple sclerosis nurse: an international perspective. *Int J MS Care*. 2011;13:105-112.

26. Beadnall HN, Kuppanda KE, O'Connell A, Hardy TA, Reddel SW, Barnett MH. Tablet-based screening improves continence management in multiple sclerosis. *Ann Clin Transl Neurol.* 2015;2:679-687.

Table 1. Participant characteristics

| Participant No. | Sex | Occupation/role | Practice location | Setting | Experience, y |
|-----------------|-----|-------------------------------------|-------------------|-------------------------|---------------|
| 001 | F | MSSN | Rural | Primary care | ≥10 |
| 002 | F | MSSN | Suburban | Secondary/primary care | ≥35 |
| 003 | F | MSSN | Urban | Secondary care | ≥12 |
| 004 | F | BBCSN | Urban | Primary care | ≥10 |
| 005 | F | BBCSN | Rural | Primary care | ≥15 |
| 006 | F | MSSN | Suburban | Secondary care | ≥15 |
| 007 | F | BBCSN | Urban | Secondary/primary care | ≥22 |
| 008 | F | BBCSN | Urban | Tertiary care | ≥15 |
| 009 | F | BBCSN | Urban | Primary care | Unknown |
| 010 | M | Gastroenterologist | Urban | Tertiary care | ≥30 |
| 011 | F | Consultant neurologist | Urban | Tertiary care | ≥25 |
| 012 | F | Bladder and bowel charity employee | National | Telephone helpline | Unknown |
| 013 | F | BBCSN | Urban | Secondary/tertiary care | ≥5 |
| 014 | F | BBCSN | Urban | Secondary/tertiary care | ≥5 |
| 015 | F | Physiotherapist | Urban | Tertiary care | ≥10 |
| 016 | F | Neurology CNS | Suburban | Secondary care | ≥7 |
| 017 | M | Consultant rehabilitation physician | Suburban | Secondary care | ≥10 |
| 018 | F | BBCSN | Urban | Secondary care | ≥20 |

Abbreviations: BBCSN, bladder and bowel care specialist nurse; CNS, clinical nurse specialist; MSSN, multiple sclerosis specialist nurse.

Table 2. Themes and subthemes with illustrative quotations

| Theme | Subtheme | Exemplar quotation |
|------------------------------------|---------------------------------|---|
| Whose job is it anyway? | Person with MS responsibilities | “Maybe a bit more information ... there could be self-management areas ... speaking about bowels and, you know, if you do get into sort of particular problems ... discussing this with your GP or MS nurse.” (002, MSSN) |
| | Caregiver responsibilities | “Some people really don’t want to get involved at all, they want to keep that personal relationship going, and that’s just a step too far. Other people think if they’re caring for them and they can see the benefit of it, then they’re happy to do anything.” (004, BBCSN) |
| | HCP responsibilities | “I might give them some advice about diet or sort of things like laxatives or Movicol [polyethylene glycol], things like that, because some of them will be taking things or randomly taking things. So I might try and regiment some of that. But then I will tend to refer to the continence team.” (006, MSSN) |
| Practicalities of bowel management | Delayed reporting | “[There’s] ... a lot of acceptance before there’s a tipping point. And it’s normally the carer calls us first, because they can’t cope.” (006, MSSN) |
| | Assessment | “So I think people actually asking the question is really, really important” (012, bowel helpline) But “... we felt we weren’t tackling bowels very well, we felt we needed a proper assessment tool.” (005, BBCSN) |
| | Management | “I think with bowels, you can almost always get it right eventually. It’s trial and error isn’t it because everybody is so different.” (009, BBCSN) |
| Improving service delivery | Education, education, education | “The first I think is to educate health care professionals to know that there’s something they can do ... we see them early on because the referring teams ... know that something can be done.” (010, gastroenterologist) |
| | Prioritizing bowel care | “I just think it is my personal frustration with—we have quite a large MS caseload of patients with bladder and bowel dysfunction. And I would say there is [sic] more options with the bladder dysfunction.” (005, BBCSN) |
| | Referral pathways | “So if I looked at other things, I’d say ‘Oh this is the process, this is my red flag, I need to refer on here’ ... so I know I work by guidance for lots of things ... with MS, it’s slightly different.” (014, BBCSN) |
| | Need for guidelines | “It would be really fantastic if there was a pathway, you know, from a bowel care for an MS patient, because then that would be consistency ... because even though we’re based in the |

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| | | hospital, it would be nice for our colleagues in the community or for MS nurses to also follow the pathway, because that is what we really need.” (013, BBCSN) |
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Abbreviations: BBCSN, bladder and bowel care specialist nurse; CNS, clinical nurse specialist; GP, general practitioner; HCP, health care professional; MS, multiple sclerosis; MSSN, multiple sclerosis specialist nurse.