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ABSTRACT

Objectives: To gain more understanding of the real-world lived experience of neurogenic bladder and bowel among people with multiple sclerosis (PwMS). Few studies have explored this important perspective.

Methods: Qualitative and quantitative methods were applied for data collection. A total of 16 PwMS were recruited into the qualitative phase. The themes emerging from these interviews were used to develop a questionnaire. An online survey was hosted on the Analyzer platform with the link promoted by The MS Trust. In total, 1148 PwMS took part in the survey. **Results:** The authors identified key personal impacts of bladder and bowel symptoms, and varying levels of patient satisfaction with their care and the information they received. **Conclusions:** Two themes were identified as needing to continue to be explored in order to improve the care landscape for PwMS: 'breaking the loo taboo' – encouraging PwMS to talk about their bladder and bowel problems and 'making every contact count' – encouraging the multidisciplinary team to be proactive in asking questions. Neurogenic bladder and bowel should be prioritised and championed both at a national and local level in terms of policy and service delivery, to ensure that PwMS have timely access to person-centred pathways and treatments.

Keywords Multiple sclerosis, neurogenic bladder and bowel, people living with MS (PLWMS), 'loo taboo', 'make every contact count'

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to make personalised care 'business as usual' across the health and care system (NHS England, 2019). Personalised care means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths and needs. Continence is an important component of health and wellbeing. When compromised, it can lead to isolation and loss of dignity which, in turn, has a negative impact on quality of life. It also leads to increased NHS expenditure, costing the NHS £1.8 billion per annum (The Urology Foundation, 2024). Many individuals are embarrassed to seek help or to discuss continence problems. A survey by the Urology Foundation (2024) found that 60% of people would be embarrassed to speak about urinary incontinence. Described as 'invisible symptoms', neurogenic bladder and bowel are common features of multiple sclerosis (MS) (Lin et al, 2019) which contribute to poor quality of life due to the physical and psychosocial consequences (Lakin et al, 2021). Individuals with MS experience significantly lower physical and mental wellbeing when living with bladder and bowel problems (Nazari et al, 2020). These issues may be exacerbated in those newly diagnosed or those who have minimal support from health professionals.

A recent study of people living with MS (PwMS) showed that 50% had bladder issues within 2 years of their MS diagnosis, 22% of whom were found to have had bladder symptoms pre-diagnosis (Coloplast, 2023), and nearly all will have some bladder symptoms after living with the condition for 10 years (Panicker et al, 2015; Tornic et al, 2018). Neurogenic bowel problems can affect between 39–73% of PwMS (Emmanuel et al, 2018). In 2023, Coloplast initiated a research project to gain more understanding of the real-world lived experience of neurogenic bladder and bowel among PwMS. Few studies have explored this important patient perspective. These insights into the real-world lived experience of people with neurogenic bladder and bowel issues highlight the unmet need for holistic and person-centred care.

The NHS Constitution (NHS England, 2015) states that the patient will be at the heart of everything the NHS does, that it should support individuals to promote and manage their own health. Shared decision-making is part of the NHS Long Term Plan's commitment

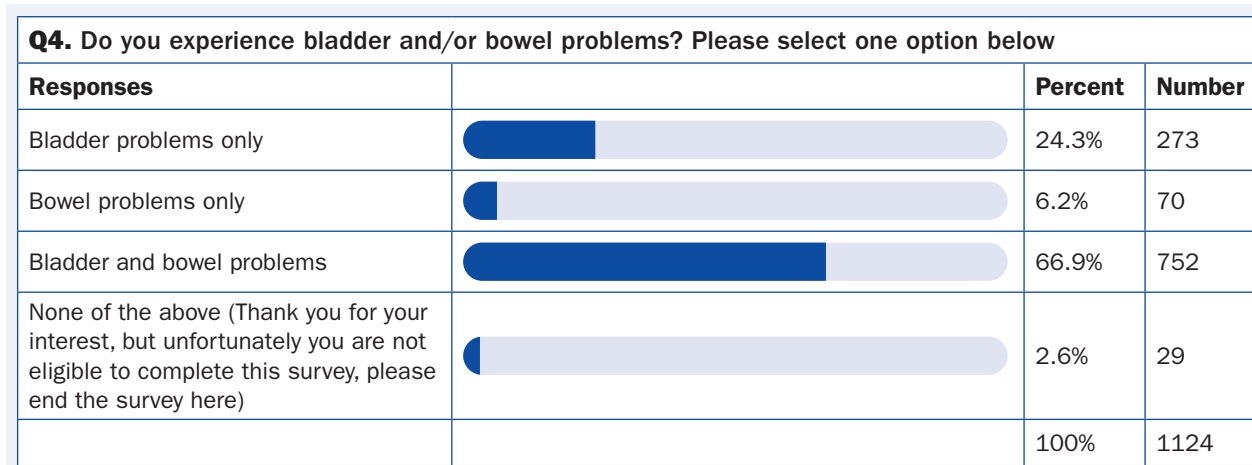


Figure 1. A total of 1124 individuals living with multiple sclerosis responded to the survey question

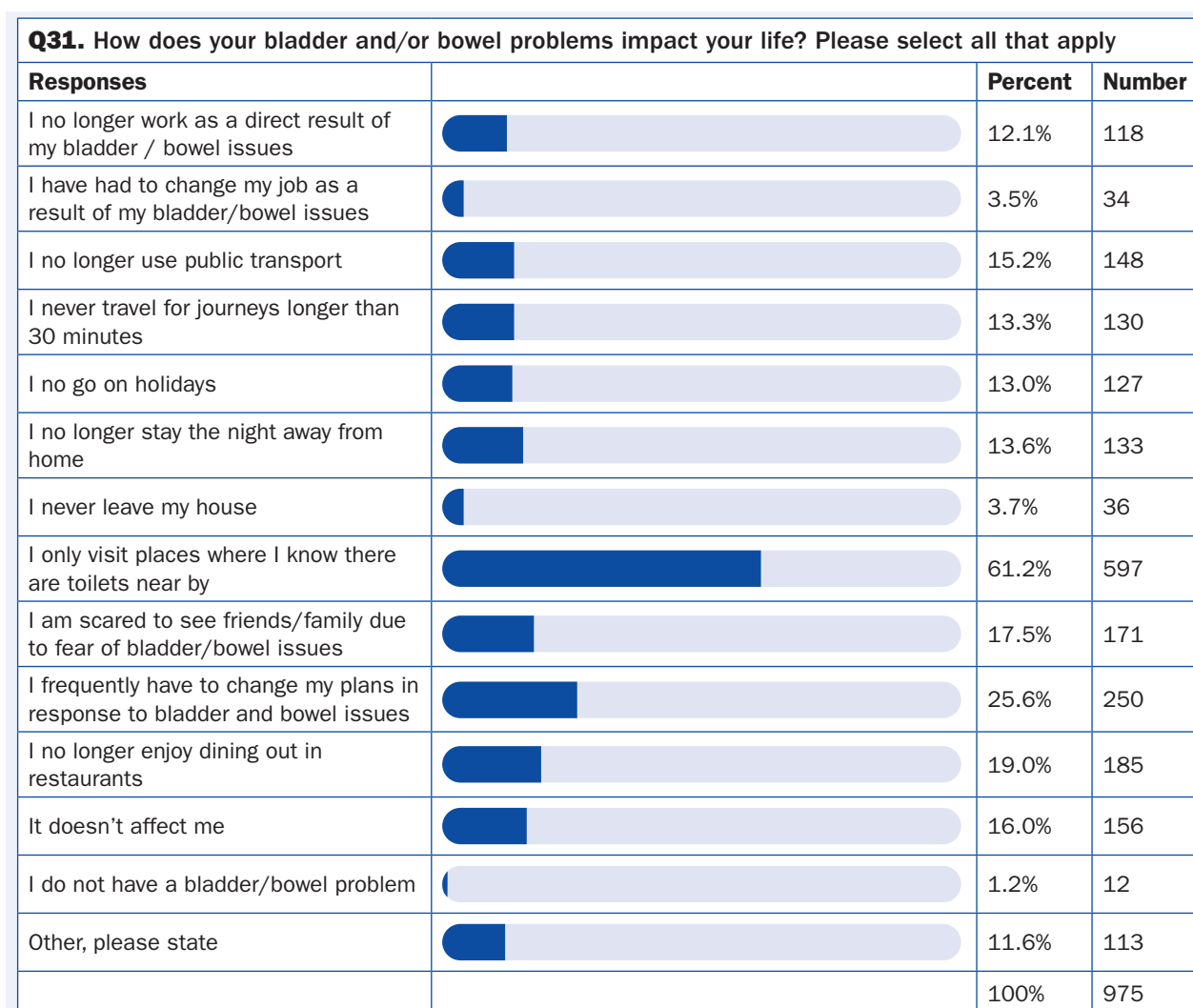


Figure 2. A total of 975 individuals living with multiple sclerosis responded to the survey question

Literature review

There is a wealth of data documenting the prevalence of neurogenic bladder and bowel in MS, but comparatively little on the lived experience of PwMS

copng with bladder and bowel symptoms. Previous research has concluded that bowel dysfunction impacts the lives of PwMS and their carers and that their experience with care services is often unsatisfactory

(Dibley et al, 2017). Understanding patient and carer preferences about the management of bowel dysfunction can inform clinical care and referral pathways (Dibley et al, 2017). In addition, it can highlight unmet needs. For example, despite bladder dysfunction being ranked third and bowel sixth in terms of impact by PwMS (Coloplast, 2023), gaps persist in awareness and management of these hidden symptoms. The 2022 National Institute for Health and Care Excellence (NICE) guideline, '*Multiple sclerosis in adults: management*' includes bladder and bowel symptoms on the list of topics to be covered in the annual review (NICE, 2022). Specific guidance addressing neurological-related bladder and bowel dysfunction can be found in the 2012 NICE clinical guidance, '*Urinary incontinence in neurological disease: assessment and management*' and in the 2007 guideline on '*Faecal incontinence in adults: management*' (NICE, 2007). Studies that suggest the existence of a prodromal phase in MS have begun to emerge in the past decade (Makhani and Tremett, 2021) and bladder and bowel symptoms could provide a clue or 'red flag' to the existence of MS. There is a significant increase in the risk of urinary tract infections (UTIs) in neurogenic bladder and bowel. Indeed, bladder problems are one of the leading causes of emergency hospital admission in conditions such as MS (Thomas et al, 2022a). Lower urinary tract symptoms affect around two-thirds of PwMS (Al Dandan et al, 2020). Hospital Episode Statistics data show that, in 2019/20, UTIs were the cause of emergency admission for 9.5% of PwMS' hospital stays, incurring an average cost of £2710 per emergency admission, with a total cost of £7.9 million (Thomas et al, 2022b).

In the MS Trust's '*MS Forward View*', the consensus acknowledged that to live well, every person with MS needs an individually tailored, flexible blend of symptom management, disease modification and neurorehabilitation (Bowen et al, 2016a). To meet this need, PwMS require good care coordination with access to a multidisciplinary team, bringing skills from both MS specialist neurology and neurorehabilitation (Bowen et al, 2016a). Furthermore, the report acknowledged the increasing demands on MS services: with a growing population of people with MS; a greater range of disease modification drug (DMD) options; and a move to earlier initiation of treatment and switching or escalating to achieve optimum treatment response. A further report, '*Improving the efficiency of disease modifying drug provision*' (Bowen et al, 2016b), showed that MS teams are becoming increasingly overwhelmed by the workload associated with DMD provision. This, in turn, will more broadly have an impact on symptom management.

Methodology

The current study used qualitative and quantitative data collection. The authors developed a discussion guide in consultation with a panel of PwMS. Once approved, this

guide was used for semi-structured interviews. Both the co-production panel and the interviewees were recruited through the MS Trust. The authors used purposive sampling to include a diverse range of experience, including gender, age, and type of MS. In all, 16 PwMS were recruited to participate. Participants were included if they:

- were over 18 years of age
- had a diagnosis of MS
- experienced MS-related bladder or bowel problems.

Detailed MS and disability scores were not recorded as the study sought to reveal insight into the experience of neurogenic bladder and bowel dysfunction among PwMS, rather than to perform any statistical or sub-group analysis. Each semi-structured interview lasted around an hour and was recorded with the participants' consent. The questions and probes used in the semi-structured interviews were open and explored the individuals' experiences of bladder and/or bowel dysfunction. The discussion elucidated whether or not bladder and bowel symptoms had been discussed with them around the time of diagnosis or in subsequent appointments, and if so, what information they had received. They were asked to explain the treatments they had used, and to describe their pathway to receiving treatment. The questionnaire was distributed by the MS Trust via its email newsletter and social media channels and was live between 20 October and 24 November 2023. In total, 1148 people responded to the questionnaire. The qualitative phase of the study was analysed by the authors using an inductive narrative analysis. Themes were drawn from the interviews, which were used to feed into the development of the questionnaire, for example: the impact of bladder and bowel issues on daily living/quality of life; strategies put in place to self-manage; level of satisfaction with the management of their bladder and bowel condition; information provided about bladder and bowel symptoms. For the quantitative phase, the online survey (a combination of 38 multiple choice and open-ended questions) was developed by the authors and hosted on the Enalyzer platform. The raw data was exported into Microsoft Excel for analysis by the authors and data visualisation was created by Enalyzer.

Results

Of the 1148 people who responded to the questionnaire, 1137 (99%) confirmed they had a diagnosis of MS and 752 (66.9%) of 1124 respondents said they had bladder and bowel problems (*Figure 1*).

The top three day-to-day impacts were listed as being 'confidence' (72.1%), 'the ability to go on a journey of an hour or more' (54.2%) and 'the ability to leave the house' (31.2%). Furthermore, 61.2% said

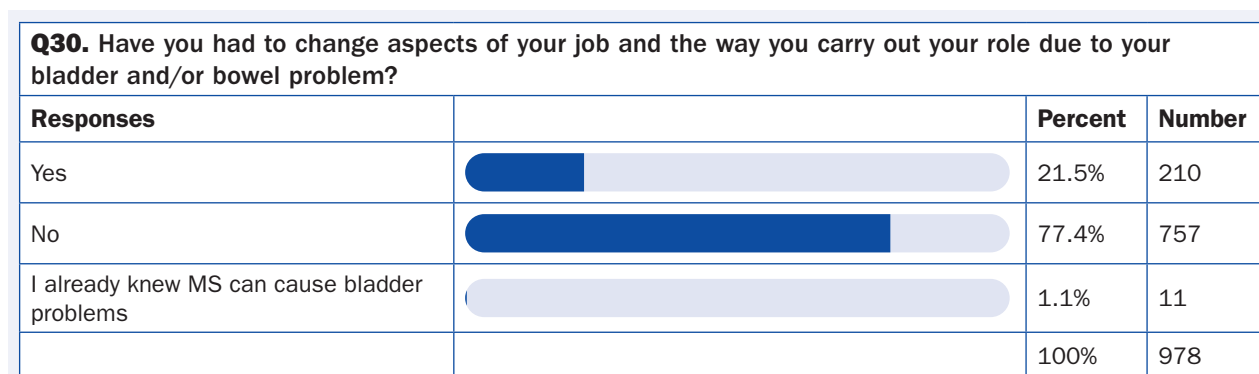


Figure 3. A total of 978 individuals living with MS responded to the survey question

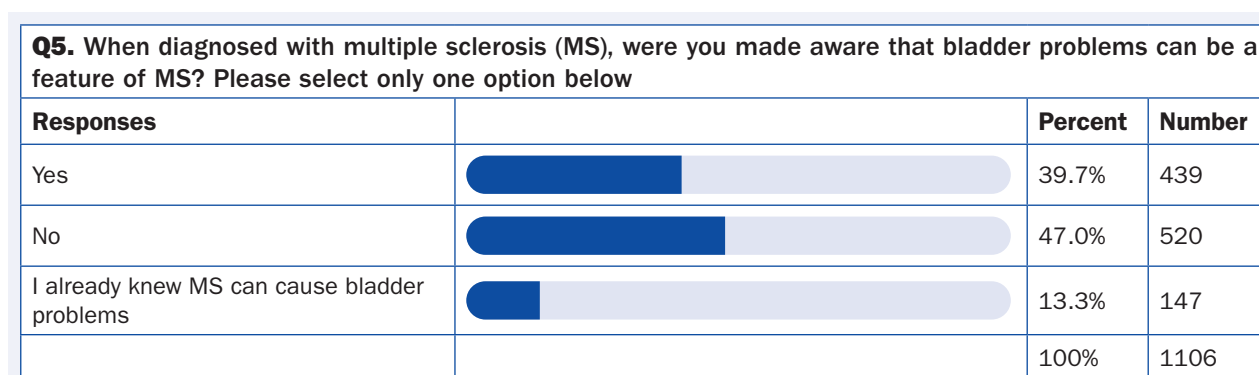


Figure 4. A total of 1106 individuals living with multiple sclerosis responded to the survey question

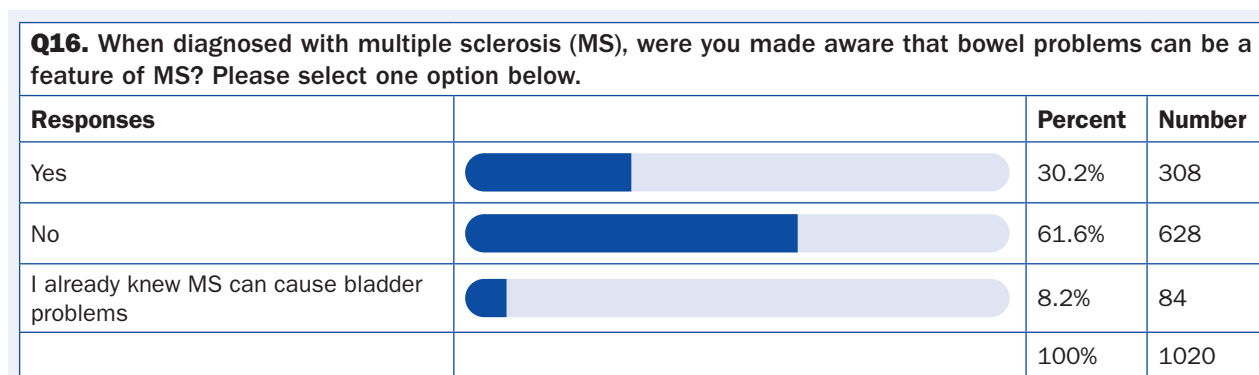


Figure 5. A total of 1020 individuals living with multiple sclerosis responded to the survey question

they only left the house if they knew there were toilets close by (*Figure 2*). This was also clearly articulated in many of the interviews, for example:

‘The most significant impact on my life is the constant urgency I feel, sometimes making me hesitant when leaving the house.’

and

‘My bowel symptoms have taken over my life,

changed the way I live my life and my mental health.’

A sense of the isolation and loneliness experienced by some PwMS was described by another interviewee:

‘In 5 months, I’ve only left the house 5-6 times, for medical appointments.’

‘I feel stressed if I’m out, so I tend not to leave the house much. I no longer see my friends, because I’m worried in case I have a ‘leak’.’

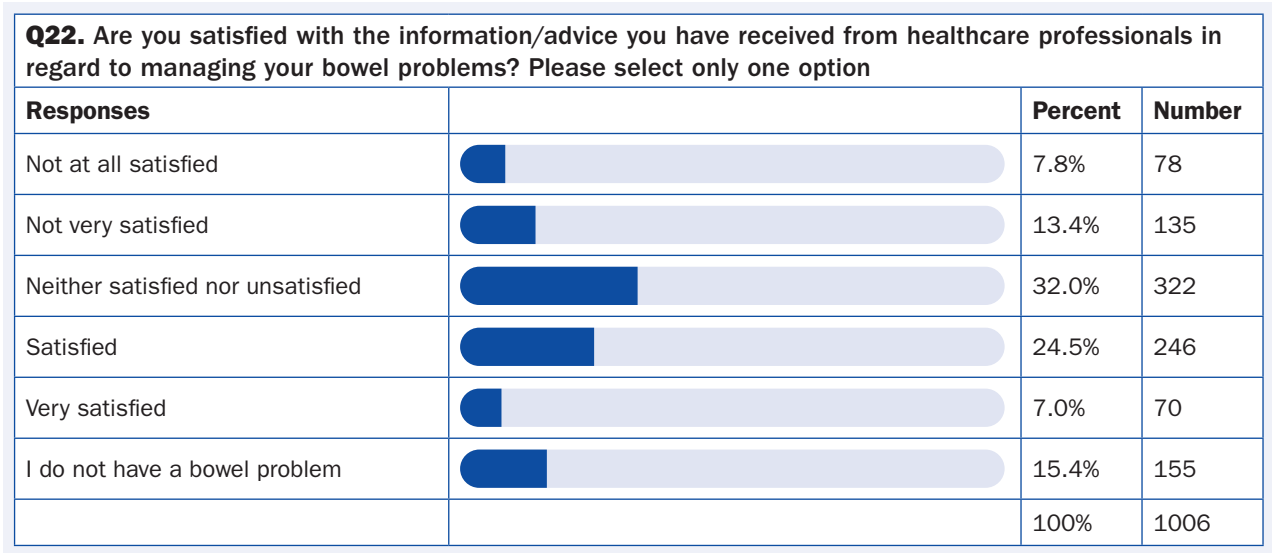


Figure 6. A total of 1006 individuals living with multiple sclerosis responded to the survey question

For 21.5% of people, bladder and bowel symptoms mean having to make changes at their place of work (Figure 3):

‘At work I have an office next to the toilet. People at work understand that sometimes I ‘just have to go’.’

Another said:

‘On a good day, I could go to work but I had to make a number of key adjustments to different parts of my life: I had to change my pad every hour, and by now these were very bulky pads. I had to wear black jeans or trousers. I had to carry a set of spare clothes in the car at all times. I was in a perpetual state of worry.’

Bladder and bowel problems take a significant amount of time to manage: 40% of respondents spend between 1–2 hours per day, and 15% between 3–5 hours per day:

‘Managing my bladder and bowel condition is a constant 24/7 task, filled with the challenges of self-care and monitoring.’

Another said:

‘My bladder and bowel are like a ‘squabbling couple’ – one sets the other off – and they make my MS worse.’

Despite this, some PwMS are positive about their situation:

‘With the right treatments and support, I feel that my bladder and bowel issues are appropriately managed.’

Of those diagnosed with a bladder problem, 47% had not been told this can be a feature of MS, while just under 40% had been informed and 13.3% knew already (Figure 4). Some 61.6% were unaware that bowel problems are a symptom of MS (Figure 5):

‘It took 5–6 years to get a proper sense of what was going on with my bowel – links weren’t made between my symptoms and my MS.’


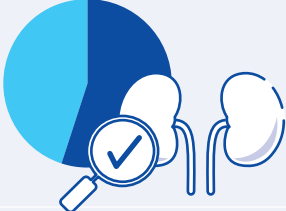






and

‘I’ve never received any written information about neurogenic bladder and bowel from anyone. Signposting support from the GP surgery would have been helpful.’

In terms of treatment for bladder problems, 45% of respondents said their bladder management focuses on the use of pads, while 64% said that they use lifestyle advice and medication (Table 1). The personal cost of buying products to help with bladder problems was highlighted – one person said they spend £80 per month on pads. Continence pads are a significant cost to the NHS: in the UK, the NHS spends around £80 million each year on pads, a figure that does not include individuals’ expenditure on pads to supplement the limited supply provided without charge by local NHS services (NHS England, 2018). Among those PwMS who experience bowel problems, 77% said their problem was being managed through lifestyle advice, while 27% said they had not been given any treatment (Table 1).

Unsurprisingly, the embarrassment of discussing issues relating to bladder and bowel symptoms with healthcare professionals was highlighted:

Table 1. Impact of neurogenic bladder v impact of neurogenic bowel

Findings of those experiencing bladder issues only	Findings of those experiencing bowel issues only
Nearly half (47%) of respondents were unaware that bladder problems can be a feature of multiple sclerosis (MS) 	61.6% of respondents were unaware that bowel problems can be a feature of MS 
More than half (55%) of respondents had their bladder problem diagnosed by a urology team, urology nurse, general practitioner (GP) or neurologist 	31% of respondents were diagnosed with a bowel problem by either their GP, Neurologist or MS Nurse; while 28% have yet to be diagnosed 
Majority of respondents (73%) all shared the symptom of feeling the urge to rush to the toilet to urinate (urgency) 	60% of respondents said that they experience constipation as one of their most prominent bowel symptoms 
45% of respondents say their bladder management focuses on the use of pads, while 64% say that they also manage via lifestyle advice and medication 	77% of respondents said their bowel is being managed via lifestyle advice, medication; while 27% said that they have not been given any treatment 
Nearly half of respondents (47%) are not satisfied with the information/advice they receive from healthcare professionals regarding their bladder problems 	53% of respondents are not satisfied with the information / advice they have received from healthcare professionals regarding managing their bowel problems 
34% of respondents say that they see a healthcare professional regarding their bladder problem either every six months or once a year, while 29% saying the last time they saw a healthcare professional was more than one year ago 	Nearly one-quarter (24%) of respondents said that the last time they saw a healthcare professional regarding their bowel condition was more than one year ago 
35% of respondents say that they do not consider their bladder problems to be well managed 	36% of respondents do not consider their bowel problems to be well managed 

Note: Table 1 compares key survey results from both the bladder and bowel sections of the survey, displaying the similarities and differences between living with a bladder and / or bowel problem

KEY POINTS

- The article highlights the significant impact of bladder and bowel problems on individuals with multiple sclerosis (MS), affecting 66.9% of respondents.
- People living with MS and neurogenic bladder and bowel dysfunction experience day-to-day challenges including lack of confidence, mobility, and social interactions.
- Research findings underscore the importance of timely and appropriate treatment for neurogenic bladder and bowel in MS to improve outcomes for people with MS (PwMS)
- It is crucial for PwMS to receive comprehensive treatment options tailored to their symptoms, empowering them and ensuring regular assessment and adjustments
- Barriers to effective care include the ‘loo taboo,’ where people living with MS find it difficult to discuss bladder and bowel problems openly with healthcare professionals, and the need for every member of the multi-disciplinary team to proactively inquire about these issues
- Early recognition of bladder and bowel symptoms could serve as a ‘red flag’ for MS diagnosis, highlighting the importance of encouraging conversations and improving pathways for treatment and support.

CPD REFLECTIVE QUESTIONS

- How do you think poor bladder and bowel management impacts a person with multiple sclerosis (MS)? Include the psychological, physical and social impacts in your answer.
- Individuals living with MS often ‘fall between the net’ of their specialist MS nurse/service and the continence services when it comes to the management of bladder and bowel, how might this be improved for people with MS (PwMS)? What solutions do you have to improve management?
- What is neurogenic bladder and bowel dysfunction and what are their anatomical and physiological underpinnings?
- Reflecting on your own experiences or observations, what barriers do you think exist that prevent PwMS from discussing their bladder and bowel problems?
- Thinking about the varying levels of patient satisfaction in regard to care and information on neurogenic bladder and bowel in MS, and the findings of this study; how might this influence policy both at government and hospital trust level. What changes might you make/lobby for?

‘I waited too long before seeking help.’

and

‘I wish I’d discussed it with the nurses earlier.’

Also, the embarrassment with family and friends:

‘It impacts everything: I don’t feel able to talk to my husband about it’,

and

‘the only person I can discuss it with is my mother.’

The research showed there is a level of satisfaction with care received for bladder and bowel issues; however, the questionnaire found that around half (47%) of respondents are not satisfied with the information they received about their bladder problems (Table 1), and 53% are not satisfied with the information they received about managing their bowel problems (Figure 6, Table 1). One of the interviewees said:

‘It’s shocking that we don’t talk about these issues more openly. We need to normalise these conversations. People with MS need more information and support.’

Discussion

This data showed that PwMS experience significant issues in relation to their bladder and bowel, placing pressure on and limiting their daily life, social interaction and travel, requiring careful advanced planning to manage. The research findings reveal the impact of slow and/or under-treatment of neurogenic bladder and bowel in MS and can help inform our approach to improving outcomes for PwMS. It is important that PwMS receive the most appropriate treatment options for their symptoms, feel empowered and are moved appropriately through the treatment pathway. Their needs should be regularly assessed and adjustments made as required. These should include options in addition to lifestyle advice and pads, such as: intermittent self-catheterisation, sacral nerve stimulation, transanal irrigation, percutaneous tibial nerve stimulation and intravesical botulinum toxin ‘botox’. Further research is needed to look in more detail at the factors preventing a more person-centred approach, and ways to optimise care, but this study highlights two clear barriers: firstly, the ‘loo taboo’ –the fact that we need to acknowledge that some PwMS find it difficult and embarrassing to bring up and openly discuss bladder and bowel problems with their healthcare professionals. Secondly, there is a need to ensure that ‘every contact counts’: every member of the multi-disciplinary team in contact with PwMS should be skilled in how to proactively ask questions about bladder and bowel dysfunction, thereby providing ‘permission’ for PwMS to raise any difficulties.

Healthcare professionals need to break down the barriers, ‘normalise’ conversations about bladder and

bowel and address the fact that PwMS would welcome earlier discussions. The AWARE study findings showed that 64% of PwMS with bladder and bowel issues would like to receive information prior to issues occurring, compared to 22% who would prefer information when symptoms present (Coloplast, 2023a). However, this does pose the question as to whether PwMS will know what to look for. A myriad of prodromal symptoms can precede MS diagnosis, including bladder and bowel issues. Studies that suggest understanding of a prodromal phase in MS have begun to emerge in the past decade and bladder and bowel symptoms could provide a clue or 'red flag' to the existence of MS. This is confirmed by AWARE, where 22% had bladder issues and 19% bowel issues, before their MS diagnosis (Coloplast, 2023a). More research is needed to highlight the best way to flag symptoms, how to encourage conversations and the best time to do so.

While bladder and bowel dysfunction is treatable, if left untreated, it has a significant impact on all aspects of daily living. PwMS need to be encouraged to speak-up, clinicians need to help improve pathways and set in place a bespoke, tailored programme of treatment and support. The authors acknowledge the considerable pressure right across the NHS and that the introduction of newer disease-modifying treatment options for MS has created added time pressures and complexity to the MS team workload. The authors encourage the whole of the multi-disciplinary team to make sure that 'every contact counts' for bladder and bowel and to talk openly about how to manage bladder and bowel dysfunction as a core part of the MS management plan.

Conclusion

This research has brought to light critical themes that shed light on the multifaceted challenges faced by PwMS with bladder and bowel issues. Below are two key themes that need to continue to be explored in order to improve the care landscape for PwMS:

Break the 'loo taboo'

Healthcare professionals need to tackle the 'loo taboo' by talking about bladder and bowel issues in MS more openly. Educating PwMS early about symptoms they may experience can empower them to recognise and address issues early and be proactive about seeking treatment. Disseminating educational materials and information, such as the bladder check tool (Flachenecker et al, 2024), as well as podcasts, films and material from the MS Trust through support groups and online platforms can contribute to building this crucial awareness. The current survey was conducted online, indicating that respondents have a level of comfort in accessing information online, and yet 47% were unaware of the link between MS and bladder symptoms (Figure 4). This emphasises the need to reach out across all channels, as the lack of awareness is potentially even

higher than this. In a recent study among MS nurses (Coloplast, 2023b), they expressed an interest in learning more about the assessment and management of bladder and bowl issues, expressing interest in further education on the topic.

Make every contact count

Optimising interactions between PwMS and the multi-disciplinary team has emerged as another key point. While the authors acknowledge the constraints on the time available during appointments with the MS team, their research findings underscore the necessity of finding ways to start conversations around bladder and bowel issues, ensuring that un-met needs are addressed. There is a huge opportunity for services to learn from each other, and to share many of the great examples already in use by MDTs around the country. Neurogenic bladder and bowel needs to be prioritised and championed both at a national and local level in terms of policy and service delivery, to ensure that PwMS have timely access to person-centred pathways and treatments. **BJNN**

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