

Bowel dysfunction in MS

**“It’s just horrible”: a qualitative study of patients’ and carers’ experiences of bowel dysfunction in Multiple Sclerosis**

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**Abstract**

**Background:** Around 50% of people with multiple sclerosis (MS) experience neurogenic bowel dysfunction (constipation and / or faecal incontinence), reducing quality of life and increasing carer burden. No previous qualitative studies have explored the experiences of bowel problems in people with MS, or the views of their family carers.

**Objective:** To understand 'what it is like' to live with bowel dysfunction and the impact this has on people with MS and carers.

**Methods:** Using exploratory qualitative methods, 47 semi-structured interviews were conducted with participants recruited from specialist hospital clinics and community sources using purposive and chain-referral sampling. Data were analysed using a pragmatic inductive-deductive method.

**Results:** Participants identified multiple psychological, physical and social impacts of bowel dysfunction. Health care professional support ranged from empathy and appropriate onward referral, to lack of interest or not referring to appropriate services. Participants want bowel issues to be discussed more openly, with clinicians instigating a discussion early after MS diagnosis and repeating enquiries regularly.

**Conclusions:** Bowel dysfunction impacts on the lives of people with MS and their carers; their experience with care services is often unsatisfactory. Understanding patient and carer preferences about management of bowel dysfunction can inform clinical care and referral pathways.

**Keywords:** bowel dysfunction; constipation; faecal incontinence; multiple sclerosis; qualitative research

### **Introduction**

Neurogenic bowel dysfunction (NBD) (faecal incontinence and / or constipation) is a recognised feature in multiple sclerosis (MS). In Western populations, 35 – 54% of people with MS (PwMS) experience constipation and 29 – 51% experience faecal incontinence (FI), compared with a general population prevalence of approximately 5% and 2% respectively [1]. With 126,700 PwMS in the UK [2] and up to 2 million worldwide, many thousands are likely to experience NBD, which results from a complex interplay between neurological effects of MS, mobility and toilet access issues; other influential factors include diet, fluid intake, medication and exercise [3].

Patients, carers and physicians report bladder or bowel problems as the third most troublesome symptom of MS across all disease severities, after fatigue and mobility [4]. NBD reduces quality of life for PwMS [5], and increases carer burden [4]. Help-seeking for FI is limited in other conditions where it occurs, including pelvic floor dysfunction [6], inflammatory bowel disease [7], and following gynaecological cancer treatment [8]. Passive acceptance, considering incontinence less troublesome than the original illness, and believing it is inevitable or will improve eventually without intervention, are factors which may deter patients from discussing these problems with clinicians. Taboo and embarrassment may also discourage help-seeking, so that PwMS endure NBD in private instead. Despite UK national recommendations for health care professionals (HCPs) to conduct “active case-finding” among people at high risk of bowel problems [9] this does not appear to happen [10;11]. Reluctance to instigate discussion may indicate lack of HCP expertise in bowel management, or pessimism about improvement.

NBD is difficult to manage with medications alone [1] which can easily tip the individual from constipation to incontinence, or vice versa. Containment difficulties and odour make FI almost impossible to conceal; flatus incontinence can also be very embarrassing. Constipation causes discomfort [e.g. bloating] and often means multiple unsuccessful toilet visits, and painful prolonged, difficult, or incomplete evacuation.

A single study has addressed experiences of living with MS-related constipation [12]. One quantitative study assessed bowel problems and coping strategies in PwMS [13], but no qualitative studies report the experience of FI for PwMS, or the impact on family carers. Understanding bowel dysfunction experiences of PwMS and their carers may inform appropriate support and care for those with these distressing symptoms.

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The research question was: ‘What is it like to live with faecal incontinence or constipation and MS, and how does this impact on the lives of PwMS and their family carers?’

### **Study design**

This exploratory qualitative study used standard qualitative techniques, including purposive sampling, semi-structured interviews and focus groups which enabled the participants’ voice to be heard, thematic analysis of textual data, and use of verbatim quotes when presenting findings [14]. Exploratory qualitative research has no specific philosophical basis in the manner of, for example, phenomenology and ethnography, but encompasses the principles of naturalistic research in seeking to reveal the meaning of experiences as described by study participants [15]. It is appropriate for first exploration of a topic [16].

### **Sampling**

Using purposive sampling to select people with a range of ages, both genders and a range of MS types and severity, forty-seven participants (41 PwMS, six carers) were recruited from National Health Service (NHS) MS clinics (n=31) and community sources (n=16), including the UK MS Society website, and via chain-referral sampling. Participants were included if they: a) were over 18 years of age; b) had a diagnosis of MS or were a carer; c) experienced MS-related constipation or FI, or were caring for someone with these symptoms. PwMS were excluded if they had co-existing bowel morbidities, such as inflammatory bowel disease or bowel cancer. Detailed MS and disability scores were not recorded as this qualitative study was seeking to reveal insight into the experience of NBD amongst PwMS, rather than perform any statistical or sub-group analysis.

### **Ethical considerations**

The study was approved by the North-West Research Ethics Committee (REC) (REF: 15/NW/0721), and the REC at King’s College London (REF: PNM/14/15-71). Informed consent was recorded immediately prior to data collection.

### **Data collection**

Data were collected via semi-structured face to face or telephone interviews, according to participant preference. All authors contributed to data collection. All authors are established qualitative researchers with experience of research interviewing. Participants with MS were

asked to ‘Tell me about the problems you have with your bowel,’ whilst family carers were asked ‘What is it like to care for someone with MS who has bowel dysfunction?’ Fidelity to the interview process by all authors was aided by use of topic guides, which were used to explore relevant related issues [Table 1]. In the absence of empirical evidence, topic guides were informed by the team’s clinical experience and comments of PwMS on the funder’s review panel. Interviews took 10 - 60 minutes, were digitally recorded, and transcribed professionally.

### **Analysis**

Thematic analysis was informed by an analytical hierarchy [17], enabling a progressively detailed exploration of data. All authors individually completed a preliminary analysis on a selection of transcripts to identify issues of interest before collaborating to synthesise findings and discuss and agree themes.

### **Results**

Demographic details of the 47 participants are given in Table 2. Six key themes emerged: 1) The physical experience of bowel dysfunction; 2) The psychological impact of bowel dysfunction; 3) The social impact of bowel dysfunction; 4) The impact on relationships and family; 5) Self-management strategies; and 6) Interactions with healthcare professionals. Issues were similar for PwMS and carers, unless specified. Verbatim quotes are followed by MS, or Carer, and a study ID number, eg. MS 1, Carer 6.

#### *1. The physical experience of bowel dysfunction*

Participants reported a range of physical consequences of bowel dysfunction, including difficulties with bowel evacuation (not knowing when or if the rectum was full, incomplete evacuation, and prolonged toileting):

*‘I can go seven to ten days without going at all. And then when I do go, it’s horrific. It hurts. It’s really stuck. I can sit there for a long time ... it makes me bleed and it makes me scream sometimes. It’s that painful.’ [MS 22]*

Faecal urgency, constipation with possible overflow diarrhoea or impaction, and faecal incontinence were reported, as well as loss of sensation:

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*'Sometimes, I don't even know ... I just want to go to wee. And I find my pants have got faeces in, which is really pretty ... pretty horrible really.'* [MS 42]

Symptoms, particularly constipation, could lead to abdominal pain, bloating, and loss of appetite resulting in weight loss. We did not detect a relationship between bowel symptoms and disease duration but did not gather quantitative scores to enable formal exploration. Constipation was reported by many, regardless of disease status or duration, and was often reported to have existed alongside symptoms prior to definitive MS diagnosis.

### *2. The psychological impact of bowel dysfunction*

Bowel dysfunction causes embarrassment, shame and humiliation:

*'It's just horrible. And it makes me cry even when they're cleaning me up ... it's so awful to have come to this.'* [MS 39]

as well as frustration and anger about the time wasted on the toilet. Anxiety and low mood were commonly reported as related to bowel dysfunction:

*'Having chronic constipation and the lifestyle that was giving me, created this depression. It affected the whole family'* [MS 29]

Even though participants tried to think positively, an under-current of anxiety related to bowel dysfunction remained:

*'You try and say to yourself, "No it's alright, you know where the loo is, you're going to be fine." But there's always that possibility of, "oh-I'm-not-sure" feeling'* [MS 41]

The impact of MS on mobility also contributes to anxiety over the risk of incontinence:

*'I really panic because I can't move fast. I can't run into the toilet the way anyone else can. I've got this walker and I'm like treacle getting from A to B.'*  
[MS 36]

### *3. The social impact of bowel dysfunction*

Participants acknowledged the social expectation for adults to control their bodily functions:

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*‘You can’t even hide (bowel incontinence), can you? There’s no way you can hide that sort of thing. So there is a degree of urgency which I’m aware [of] and I’m also aware that there’s a learnt external social pressure ... it makes you more anxious, which in its turn makes (incontinence) more likely to be a problem’ [MS 41]*

Risk and fear of faecal incontinence can lead to isolation and social withdrawal; because bowel dysfunction tends to develop over time, PwMS and their carers gradually adjust to changes, sometimes accepting restrictions as normal. Concerns about accessing toilets away from home, the risk of incontinence, or the need to use additional equipment and be in the toilet for longer, impacts negatively on PwMS:

*‘On holiday, if you’re on the beach during the day, [there is] only ever one toilet. And because it takes so long, quite often then I can’t go because people are always banging on the door.’ [MS 31]*

Reduced social activity by PwMS can also affect carers, who may find their own social engagement affected by the person’s bowel care needs:

*‘If I haven’t been to the toilet and it’s three days, and we’re due to go and do something the next day, I’m then saying to my husband, “Well I can’t really do that now because I’m supposed to be taking my laxatives now.” So then you’re having to change your plans again, you’re having to say, “Well we won’t go out and do that, we’ll stay in.”’ [MS 36]*

The need to know where toilets are away from home reduces spontaneity as every outing requires meticulous planning. Even knowing toilet locations cannot ease concerns about access in crowded venues such as theatres.

### *4. The impact on relationships and family*

People with MS worry about the burden of bowel care on partners. Many did not want their partner involved, although some appreciated this kept them independent of formal care services:

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*'I'm lucky [my 81 year old husband] is fit enough to do it or I couldn't be at home. Or you would have to organise carers four times a day.'* [MS 39]

There may also be a cost to relationships:

*'At times I feel far more carer than husband.'* [C 1]

Family carers could find providing practical bowel care to another adult challenging:

*'It's something that you never ever thought you would have to do for your partner. You do it for your child, when they're [young] but you don't expect to be doing it for another adult.'* [C 2]

and sometimes felt they had no choice but to accept and to help:

*'I don't like it, I don't like it. But I have to ... that's the only way I can describe it, I have to.'* [C 2]

Carers also wanted to avoid distress for their family member who relied on them for bowel care:

*'It was very difficult for us both, but I just wanted to manage it so that he didn't feel bad about it. I wanted to be the one who, you know, it's alright with me ... never mind, this is what we have to do and it's okay. So I kept as calm and as okay, at the time, as possible. ... So any distress I felt about it, I tried not to show.'* [C 6]

The need for bowel care to be managed within the family could cause mixed emotions including frustration, blame and guilt for everyone involved:

*'It just makes everyone cross and angry and grumpy, to be honest.'* [C 3]

as well as embarrassment and shame due to bowel incontinence:

*The embarrassment that comes with, with ... when you soil yourself. Even everything within the family, was getting embarrassing, even though [my wife] didn't mean anything by it, it embarrassed her.* [MS 1]

Bowel care or dysfunction also affected shared social activities. Loss of appetite could disrupt

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normal family interaction and mealtimes. Although many PwMS reported receiving huge support from partners and family, others felt that their bowel problems were a source of embarrassment for their close relatives.

### *5. Self management strategies*

PwMS adopted various strategies for managing their bowel, from dietary and fluid adjustments, exercise, appropriate toilet posture and emptying bowels before leaving home, to rectal stimulants, manual evacuation, digital rectal stimulation, and using licensed or home-made trans-anal irrigation products. One couple had engineered their own bowel irrigation system, unaware that licensed products are available, and sought reassurances over its safety:

*‘We were concerned about sticking the hose with water up there ... and [the nurses] said, well their attitude was ... if it helps, carry on.’ [C 5]*

Self-management strategies were often developed without input from HCPs:

*‘I do a bit of a clear-out myself sometimes when I can feel it’s all loaded down.... With my fingers. The MS nurse was horrified, but I just thought, well if that means that I feel that I can go out afterwards’ [MS 40]*

### *6. Interactions with healthcare professionals*

PwMS and carers reported varied experiences when seeking help for bowel problems from HCPs. Some had experienced positive encounters. The MS specialist nurse was the most valuable source of support, helping them feel they were not alone with the problem. Ongoing access to support as dysfunction altered over time, and a positive ‘can do’ attitude from some specialist HCPs, were greatly valued. Others appreciated being referred to specialist continence services although for some, referral was slow and restricted to a single appointment without follow-up. Licensed bowel irrigation systems had changed the lives of some PwMS for the better:

*‘Since I’ve been using this [irrigation system] – I just get on with it three times a week. I’m so lucky ... I may have had to take the odd glass of Movicol [polyethylene*

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*glycol] myself to soften things occasionally along the way. But I've not seen a continence advisor now for about three years. [MS 29]*

For others, experiences with HCPs had been less helpful. Some PwMS had been told that nothing could be done about bowel dysfunction and they should 'just live with it.' Even HCPs with specialist continence knowledge knew far less about bowel dysfunction than about bladder problems. The reluctance of HCPs to discuss bowels added to feelings that bowel problems are unmentionable, and under-recognised:

*'Talk about it more, because they (HCPs) don't always mention bowels. So unless you've done your research very, very well ...everyone knows about bladder in MS. But they don't know about bowels ... so you don't always think it's to do with the MS, you think it's another problem.'* [MS 3]

Community services to support those needing bowel care are variable in the UK, and can still require carers to be readily available:

*'I work literally five, six minutes from here. I can be home within ten.....it just makes more sense [for me to clean him up after FI] because what had annoyed me a bit about them was they had come and cleaned him up, but left [faeces] all lying on the toilet floor. So he was going to fall over all that.'* [C 3]

Although many PwMS had received basic advice about diet, fluids and exercise, knowledge about what to do if this was unsuccessful was limited. Participants were often unaware of alternative bowel management options available to them, and one who wanted to explore the potential for a stoma to improve her bowel management and quality of life could not persuade any HCP to discuss this with her.

Poor support and inflexible use of anti-spasmodics, anti-motility and laxative drugs significantly impacts on the ability of PwMS and their carers to manage bowel dysfunction effectively. PwMS were prescribed laxatives for constipation, but could easily become incontinent if specific instructions about tailoring ongoing use to optimise effectiveness was not also provided.

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Use of containment products (pads, continence pants) were not seen as a solution. These fail to address the underlying problem, and infantilise the individual:

*‘Nothing where I’m [faecally incontinent] in the public arena is an answer because you’re so self-aware ... We’re in nappies, that’s what you feel like, you’re in nappies in public. It’s not good.’ [MS 14]*

Participants wanted HCPs to inform them about potential bowel problems and solutions, and to open the discussion about bowels:

*‘I really would like to see healthcare professionals have a list of at least six things that they ask, and I’d just love to see bowels up there.’ [MS 29]*

Recognition of and discussion about MS-related bowel difficulties could help reduce the sense of taboo around the topic:

*‘Maybe make it not such a taboo subject. I don’t know how. But people don’t talk about it.’ [MS 3].*

Participants stressed the need for knowledge and education about all aspects of MS, including NBD:

*‘It’s just knowing and being able to get the best quality of life and try not to let the illness take over you ... being able to deal with it and people can understand why things are happening with you and ... just feeling normal.’ [MS 1]*

Although some PwMS would be reluctant to receive bowel care from anyone other than their trusted partner, there was recognition that carers might also need emotional support from HCPs.

## Discussion

These findings add to the small body of evidence which demonstrates the social, emotional, physical and psychological impact that NBD has on PwMS [12] and carers. As in other illnesses or neurogenic conditions where bowel function is likely to be compromised, such as

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Parkinson's disease [18], spinal cord injury [19], stroke [20] and spina bifida [21;22], the topic is stigmatising and difficult [12], probably due to the socially-prevalent attitudes towards stool as taboo [23]. People with MS and their families cannot secure support if embarrassment prevents discussion of the problem.

While evidence for neurogenic bowel management remains scanty [24,25], expert opinion recommends thorough history-taking and investigation, and offers guidance on management strategies [25-28] – but there is little to prompt MS clinicians to instigate discussion with PwMS about NBD [12]. UK national guidelines recommend active case-finding for FI in any condition where it may occur [9] but evidence demonstrates that this rarely happens [10]. Urge incontinence (the inability to reach the toilet in time) may be more likely in those with impaired mobility due to MS. As this was a qualitative study, we did not look for patterns between MS subtype or duration of disease, but some severe bowel problems were reported by people with apparently mild disease. This suggests that clinicians should not assume that newly-diagnosed patients have no NBD, or that only those with lengthy disease duration or more aggressive sub-types will have NBD. Reports that constipation was a problem for many participants prior to formal diagnosis of MS indicates that many patients may need screening and some level of intervention at a very early stage in their disease trajectory.

When clinicians begin conversations about bowel dysfunction with patients, they signal that the topic is acceptable and expected, opening the door to dialogue. Without honest regular discussion about bowel function, the needs of PwMS and carers are unlikely to be adequately addressed. However, social stigma associated with bowel dysfunction is such that anonymous methods of case-finding - questionnaires completed in private in advance of the clinic appointment, for example - may be more effective than face-to-face discussion in MS populations [29].

For some PwMS, NBD assistance is provided by a carer who themselves needs emotional or practical support from HCPs [30]. Our findings suggest that carers are often reluctant assistants who would prefer not to manage bowel dysfunction, but recognise that the person with MS would prefer not to be assisted by strangers. Although research has focused on carers' needs when managing cognitive and psychological consequences of MS, no previous study has addressed the impact on carers of delivering bowel care [30] despite 'increasing acknowledgment of the need to assist and support family carers' [31].

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These findings also indicate that in many cases, NBD experiences for PwMS are improved or worsened by the quality of interaction with HCPs - for example, some PwMS have benefitted from bowel management methods that have not even been mentioned to others. Without advice, PwMS may continue to struggle with constipation, impaction, and faecal incontinence. Newly-introduced therapies or medications need regular monitoring and follow-up to avoid unintended consequences such as tipping from constipation to incontinence, but this level of contact seems incompatible with current service delivery models.

### **Study strengths and limitations**

The self-selected participants may have had different experiences from those who did not take part. Participants' experiences may or may not be representative of the wider MS population. Although it was a large group for a qualitative study, recruited from both community and hospital sources, participants with MS had different durations and subtypes of MS, and varying degrees of mobility. The qualitative design precluded any sub-group analysis. Follow-up quantitative research might confirm whether or not there is any meaningful association between disease severity, duration, disability score, sub-type of MS, and NBD.

### **Conclusion**

Neurogenic bowel dysfunction causes concern, anxiety and distress for PwMS and carers who often feel that help is unavailable, or that bowel care is neglected in comparison with other MS symptoms such as mobility and urinary incontinence. NBD has a negative impact on social wellbeing and quality of life for many PwMS, with repercussions for carers and other family members. Understanding patient and carer preferences about management of bowel dysfunction can inform clinical care and referral pathways. Further research may clarify the significance of constipation as an early presenting symptom in MS.

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## **Declaration of Conflicting Interests**

The authors declare that there are no conflicts of interest.

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