

MS neurogenic bladder and bowel: not such an 'invisible' symptom!

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Introduction

Neurogenic bladder and bowel are common features of multiple sclerosis (MS)¹. Described as 'invisible symptoms', they contribute to poor quality of life due to the physical and psychosocial consequences². Continence is an important component of health and well-being and when compromised can lead to isolation and loss of dignity. Incontinence costs the NHS £1.8 billion per annum³. The Urology Foundation found in a survey that 60% of people would be embarrassed to speak about urinary incontinence³. A recent study⁴ of people with MS (PwMS) showed that 50% have bladder & 39% bowel issues by year two of MS diagnosis; increasing to 75% having bladder and 60% bowel issues by year ten after MS diagnosis. Individuals with MS experience significantly lower well-being when having bladder problems, bowel problems, urinary tract infections and self-manage their bladder problems⁵.

Study objective

We initiated a research project in 2023 to gain more understanding into PwMS's experience of neurogenic bladder and bowel. Few studies have explored the patient perspective. Our insights highlight the unmet need for person-centred care within bladder and bowel.

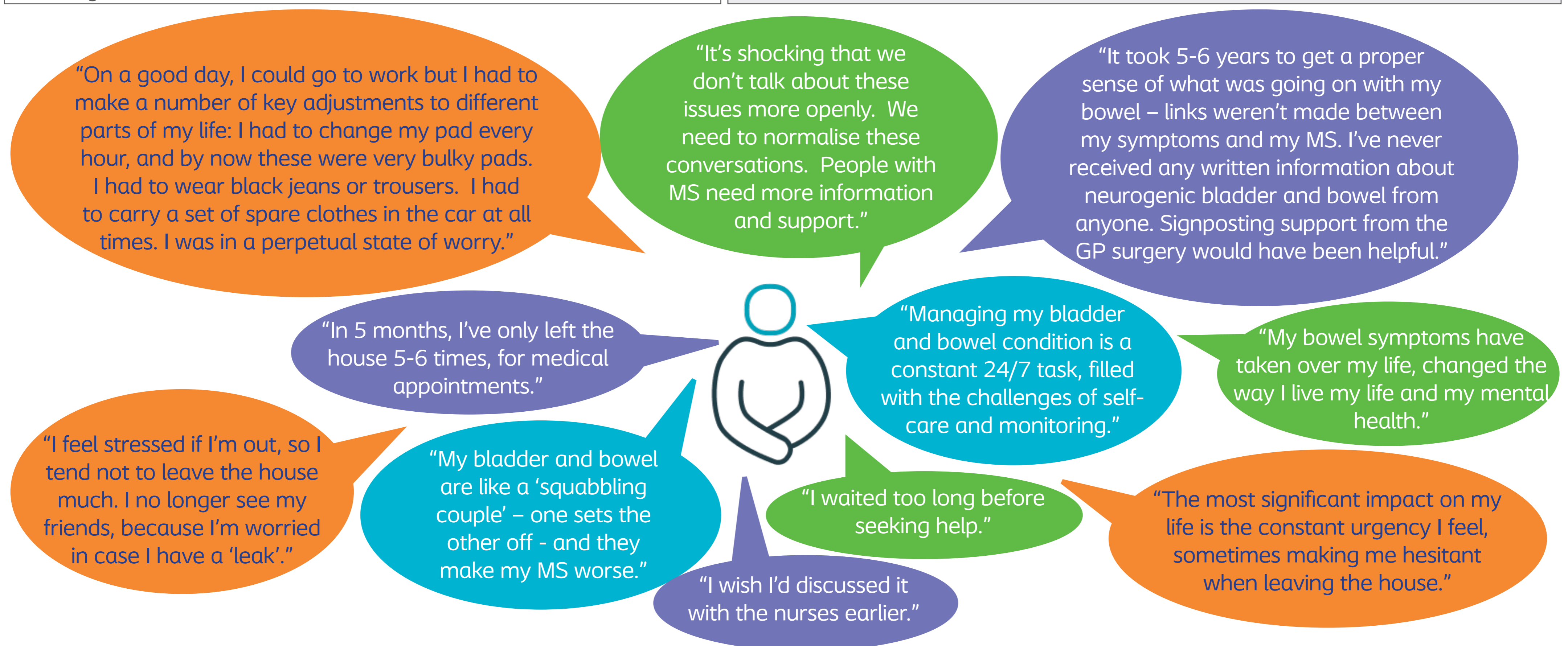
Design and method

Our study involved qualitative data collection. A discussion guide was developed in consultation with a panel of PwMS. The guide was used to facilitate 16 semi-structured interviews. Both the co-production panel and the interviewees were recruited through the MS Trust. Purposive sampling was used to include a diverse range of experience, including gender, age, and type of MS. Each semi-structured interview lasted 60-90 minutes, totalling around 24 hours of discussion. We explored whether or not bladder and bowel symptoms had been discussed around the time of diagnosis or in subsequent appointments; what information they had received; treatments and journey to receiving them.

Results

All 16 participants described the profound impact of their bladder and/or bowel symptoms on their mental health, self-esteem, work, relationships and activities of normal daily life. Participants expressed frustration, shame and embarrassment over their condition and management. All described on-going challenges with self-management, while many lamented not having being forewarned by a healthcare professional that these symptoms were linked with their MS. The quotes below illustrate examples of recurring themes from the interviews and demonstrate where PwMS are struggling the most. The emerging themes can be summarised as follows:

- Reluctance to seek help, leading to delayed diagnosis
- Impact on daily living and work and on MS symptoms
- A desire to normalise conversations about bladder and bowel issues



Discussion

The research demonstrates that PwMS experience significant issues in relation to their bladder and bowel, placing pressure on their mental health and limiting their daily life, social interactions and travel. Management of neurogenic bladder and bowel can require careful advanced planning. The research findings reveal the impact of suboptimal treatment of neurogenic bladder and bowel in MS, which can help inform our approach to improving this. It is important that PwMS receive the most appropriate treatment options for their symptoms and are moved timely and appropriately through the treatment trajectory. Their bladder and bowel should be regularly assessed and adjustments made briskly as required.

Conclusion

Following the 16 qualitative interviews, two key barriers become clear:

- 1.) 'Loo taboo' is real for many PwMS and we need to acknowledge that some find it difficult and embarrassing to bring up and openly discuss their bladder and bowel problems with their healthcare professionals. We need to break down the barriers, 'normalise' conversations about bladder and bowel and address the fact that PwMS would welcome earlier discussions.
- 2.) 'Every contact counts' for every member of the MDT in contact with PwMS. Clinicians must be confident to proactively ask questions about bladder and bowel dysfunction, thereby providing 'permission' for PwMS to raise any difficulties. We know that bladder and bowel dysfunction is treatable and too many people are self-managing suboptimally, and when left untreated has a significant impact on all aspects of daily living and mental health. PwMS need to be encouraged to speak-up, clinicians need to help improve pathways and to set in place a bespoke, tailored programme of treatment and support.

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