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Title: There's more below the belt than first thought: A pilot screening project to identify bladder and bowel symptoms and quality of life in people with MS.

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Aims:

1. Develop a continence-screening tool that can easily be utilised by MS Nurses in Australia and New Zealand, in the first instance.
2. Identify the nature and prevalence of bladder and bowel symptoms, and quality of life in people with MS currently seen at the Eastern Health MS Service, Melbourne Australia.
3. Compare bladder and bowel symptoms and quality of life between patients referred to the Eastern Health Continence Nurse, with MS patients who were not referred.

Hypothesis: The continence-screening tool developed by the Eastern Health MS Service, will be sensitive to bladder and bowel symptoms in people with MS.

The continence-screening tool will identify a significant degree of bladder and bowel dysfunction and impact to quality of life.

The level of under reporting of bladder and bowel symptoms amongst people with MS is high.

Methods: 132 MS patients from the Eastern Health MS Service, Melbourne Australia were screened with a newly developed continence-screening tool. Patients who came for routine clinic appointments were invited to participate for continence screening and allocated to the *Non-Referred group*. Remaining patients included those who had been referred by the MS health professional team including Consultant Neurologists and MS Nurses to the Continence Nurse Consultant working in the Eastern Health MS Service, were allocated to the *Referred group*.

The screening process, taking between 5-10 minutes to complete, was administered by the Continence Nurse in a private consulting room. Patients in the *Non-Referred group* who were identified with bladder or bowel symptoms were subsequently offered further assessment and intervention by the Continence Nurse.

The screening tool comprises questions relating to:

- Voiding frequency, urgency, ability to defer, voiding dysfunction, history of UTI
- Bowel frequency, consistency, urgency, ability to defer, defaecation dysfunction
- Urinary and anal incontinence
- Quality of life: level of impact of bladder / bowel symptoms and degree of bother

Results: A total of 132 patients were screened including 38 (*Referred*) and 94 (*Non-Referred*). All *Referred* patients reported high levels of dysfunction. The *Non-Referred group* had higher than expected dysfunction, including incontinence, lower urinary tract symptoms, bowel symptoms including impact and burden. There was some discrepancy between the incidence of impact and burden associated with bladder and bowel symptoms. Patients were less inclined to be bothered by symptoms in the *Non-Referred group*, even though the impact of symptoms was high. The screening tool identified 92% had bladder/bowel dysfunction, a further 5% had bowel dysfunction only, and only 3% had no reported symptoms.

Interpretation of Results: The high incidence of bladder / bowel symptoms and reduced QoL in the *Referred group* of patients is not surprising. However the overall high prevalence of symptoms in the *Non-Referred group* was unforeseen. There are many reasons underlying patients' lack of disclosure, including embarrassment, unwillingness or fear to seek help and

perception that little can be done to ameliorate symptoms. The issue of adherence to therapy is a recognised challenge in people with chronic illness, including MS. The discrepancy between the degree of bother and level of impact provides an insight to the issue of adherence.

Concluding message: This pilot study has highlighted a critical need to provide a systematic, cost effective and comprehensive method of addressing the unexpected high levels of bladder and bowel dysfunction. The development of a simple screening tool is seen as an important first step in providing appropriate first line assessment by primary care practitioners, and a useful avenue to maintain open dialogue about this sensitive issue, so that long-term continence monitoring can occur over the course of the disease.

The high incidence of patients who do not disclose raises very important questions about continence screening, and challenges previously held understandings of symptom prevalence, impact and degree of bother, which have wide-reaching implications on clinical practice.

Ethical approval: This author has now received ethics approval for the following research project:

1. Refinement of screening tool for use in the first instance by MS Nurses across Australia and New Zealand.
2. Prevalence study to determine nature and incidence of bladder / bowel symptoms in MS patients across Australia and New Zealand.
3. RCT to determine whether nurse initiated intervention improves bladder and bowel symptoms in people with MS over a period of time