

## ABDOMINAL MASSAGE FOR THE RELIEF OF CONSTIPATION SYMPTOMS IN PEOPLE WITH MULTIPLE SCLEROSIS – RESULTS OF A QUALITATIVE STUDY

### Hypothesis / aims of study

Multiple sclerosis (MS) is the commonest disabling neurological disease affecting younger adults. Neurogenic bowel dysfunction (NBD) occurs in 50-80% of these patients and is the term used to describe constipation and faecal incontinence which often coexist. A pragmatic randomised controlled trial aimed to determine the effectiveness of abdominal massage in the management of NBD. This qualitative process evaluation nested within the trial aimed to capture the experiences of those participating in the intervention.

### Study design, materials and methods

The main study was a parallel group multicentre randomised controlled trial. People with MS who had reported constipation symptoms as being bothersome and had no confounding 'red flags' e.g. rectal bleeding, were invited to take part. Following randomisation, a purposive sample of 20 participants from the intervention group were recruited to reflect a variety of characteristics; different types of multiple sclerosis and various stages of disease progression; a range of age groups, with different lifestyles (e.g. some employed, others retired or unemployed due to ill health); drawn from half of the twelve sites involved in the trial (see table 1).

**Table 1**

Age range	Gender	Employment Status	Geographical Location	Type of MS	Years with MS*	Serial semi-
<21 0	Male 1	Unemployed 2	W Scotland 3	Benign 0	<5 3	
21-30 0		Employed 3	NW England 10	Relapsing remitting 11	5-10 3	
31-40 1		Business owner 1	NE England 6	Secondary 3	11-20 6	
41-50 4	Female 19	Retired (on ill health basis) 12	SE England 1	Progressive 8	21-30 3	
51-60 7		Retired (reached retirement age) 2		Primary Progressive 1	>30 6	
>60 8						

structured telephone interviews were conducted at four weeks post-enrolment in the trial and again at the end of the trial (at twenty-four weeks). Interviews explored: expectations about the treatment; motivations for taking part in the trial; experiences of taking part in the trial, whether they felt the treatment worked for them and their post-trial intentions. Each interview was transcribed and thereafter analysed in QSR NVivo (v10) informed by the framework approach. Reliability and credibility was ensured by frequent discussion of emerging themes/coding between two of the authors (SD & FH) as well as further expertise being contributed by the wider AMBER team.

### Results

*'My whole life is ruled by my bowels – that's all I think about every day 24/7 (P1)*

Participants spoke of the impact that bowel dysfunction has on the quality of their lives. For those with more severe problems, it could lead to social isolation because potential faecal incontinence made them reluctant to leave home. For others, persistent constipation led to fatigue, bloating and in extreme cases required hospitalisation. Coping strategies included reducing food intake or limiting meals to only certain times of day in order to try to control symptoms and for many participants bowel problems were a constant source of anxiety. The most common motivator for taking part in the AMBER trial was thus the need to eradicate or reduce current bowel problems and to gain personal control over their lives.

Part of the appeal of the massage was that it did not involve additional medication and many participants were hopeful that abdominal massage might offer an alternative to the use of laxatives which could lead to unpredictable bowel movements and 'accidents'. However, there was also a degree of scepticism about the likely benefits of undertaking the abdominal massage and for these participants, the motivation to take part was altruistic, wanting to give something back to the NHS.

Three-quarters of the patients interviewed felt the treatment had some positive impact on their bowel problem and expressed intent to continue with it at the end of the trial. The main improvements reported by these patients were around visiting the toilet more frequently and with more ease and/or being able to stop other forms of treatment such as laxatives. On the other hand, four patients perceived a lack of impact with the treatment. In both of these groups there was a mixture of those who expected improvement at the outset and of those who were sceptical. Several who stopped doing the massage for personal reasons noticed a reversal in any improvements.

A number of the patients who had a reduction in constipation symptoms also reported additional benefits such as reduced anxiety, feeling less fatigued, and improved eating and sleep patterns. Another unanticipated benefit was shared intimacy where a partner assisted with the massage.

Although four patients did not perceive any direct benefit from the massage, nevertheless they remained in the trial and reported feeling some benefit from the additional support provided by the regular supportive telephone calls from the research nurses. No one reported disappointment in taking part in the study and those who experienced symptom improvement reported an intention to continue with the massage in future.

#### Interpretation of Results

Bowel dysfunction can have a detrimental effect on the quality of life of people with MS, to the extent that it may be a constant source of anxiety and may lead to social isolation. Self massage is one way that patients can gain back some control over their lives, whether this leads to active reduction of symptoms or not. This self-management strategy may offer a means to take personal control that does not involve medications that may have adverse side effects. While it may not benefit all participants, it does not cause harm.

#### References

1. Richie, J and Spencer, L (1994), 'Qualitative data analysis for applied policy research', in Bryman and Burgess, eds., *Analysing Qualitative Data*, London: Routledge, p173-194.

#### Disclosures

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