

ORIGINAL ARTICLE

Management of neurogenic bowel dysfunction in the community after spinal cord injury: a postal survey in the United Kingdom

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Study design: Postal survey.

Objectives: To describe bowel management in community-dwelling spinal cord-injured (SCI) individuals and to explore associations between age, injury, dependency, problems, interventions and satisfaction.

Setting: Outpatients of a single SCI unit, in the United Kingdom.

Methods: Postal questionnaire to all outpatients with SCI for at least 1 year, of any level or density, aged 18 years or more.

Results: Response rate was 48.6% ($n = 1334$). Median age was 52 years, median duration of injury 18 years. The most common intervention was digital evacuation (56%). Up to 30 min was spent on each bowel care episode by 58% of respondents; 31–60 min by 22%; 14% spent over 60 min. Reported problems included constipation (39%), haemorrhoids (36%) and abdominal distension (31%). Reduced satisfaction with bowel function was associated with longer duration of each bowel care episode, faecal incontinence, greater number of interventions used and more problems reported (all $P \leq 0.001$); 130 (9.7%) had undergone any type of surgical bowel intervention. Impact of bowel dysfunction on the respondent's life was rated as significantly greater than other aspects of SCI ($P \leq 0.001$).

Conclusions: Managing SCI bowel function in the community is complex, time consuming and remains conservative. Despite potential for bias from a low response, for this large group of responders, bowel dysfunction impacted most on life compared with other SCI-related impairments. The study findings demand further exploration of bowel management to reduce impact, minimize side effects and increase the choice of management strategies available.

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Keywords: neurogenic bowel; bowel management; community setting; spinal cord injury

Introduction

Bowel dysfunction is a significant consequence of spinal cord injury (SCI) resulting in faecal incontinence and severe constipation.^{1,2} These dysfunctions necessitate regular, frequent and often demanding programmes of management. Bowel management and associated problems have been increasingly recognized as important factors in post-injury community reintegration and quality of life.^{3–5}

The purpose of this study was to describe bowel management in community-dwelling individuals with an SCI in the United Kingdom and to explore associations between age, injury characteristics, dependency, problems, interventions and satisfaction.

Materials and methods

A questionnaire was developed following interviews with a convenience sample of 24 SCI individuals. These interviews explored what methods of bowel management were used and what issues were of importance. Themes were analysed and a questionnaire was devised and piloted with 12 patients to ensure comprehension, with amendments made to compose the final questionnaire (Appendix 1). All outpatients of the study centre (a specialist tertiary SCI centre) with SCI following trauma or acute onset disease, injured more than 1 year and over 18 years of age, were surveyed ($n = 2960$). This was a postal questionnaire, sent with a patient information sheet and an invitation to participate, whether or not bowel problems were being experienced, to the patient's home address, with a covering explanatory letter and a stamped addressed return envelope. Those who did not respond within 4 weeks were sent a single reminder. Data were stored and analysed using the Statistics Package for the Social Sciences (SPSS Inc., Chicago, IL, USA).

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Categorical data were examined using the Pearson χ^2 test and odds ratios were calculated where appropriate. Correlations were conducted using Spearman's ρ . Friedman's test was used to look for differences between scores given for impact on aspects of daily life. The Wilcoxon test was used to explore the significance of these differences; due to the number of comparisons, a Bonferroni correction was applied and significance was set at $P=0.002$ for these tests. We certify that all applicable institutional and governmental regulations concerning the ethical involvement of human volunteers were followed during the course of this research.

Results

The response rate was 48.6% ($n=1334$). Non-responders were significantly younger than responders. Responders were more likely to have thoracic rather than other levels of injury compared with non-responders. There was no difference in gender between responders and non-responders. Demographic details are shown in Table 1. Men accounted for 73.4% of respondents. Injury characteristics are shown in Table 2. 'Complete' or 'incomplete' injury was as reported by the patient on the questionnaire and was not verified in any other way. Data from individuals with sacral and lumbar injuries are combined throughout because of the very few individuals with sacral lesions.

Reported bowel management

Most respondents (72%) had been conducting their reported method of bowel care for more than 5 years. Interventions reported are shown in Figure 1. Many responders reported that more than one intervention was used.

Stimulant laxatives were used by 36% of the sample, osmotics 15%, bulk formers 6% and stool softeners 3%.

Table 1 Age and injury duration of respondents

	n	Minimum	Maximum	Median
Age at study in years	1334	19	91	51.5
Duration of injury in years	1326	1	65	17.6
Age at injury in years	1326	<1	85	27.4

Table 2 Reported completeness of injury (% of each level of injury^a)

	Complete	%	Incomplete	%	Unknown	%	Total
Cervical	218	40.7	289	53.9	34	5.4	541 100
Thoracic	399	61.4	207	31.8	63	6.8	669 100
Lumbar	23	21.5	70	65.4	19	13	112 100
Sacral	0	0	1	25.0	3	75	4 100
Missing					8		8 0.6
Total	640		567		127		1334

^aThe percentage given is that of the total injuries at that level; therefore, the rows summate to 100%, but not the columns.

Rectal stimulants were used by 59.6%, often in combination with digital stimulation or manual evacuation (Table 3). Management was conducted daily (41%) or on alternate days (33%), completed in 15 min by 36% of the sample, 16–30 min by 22.4% and 31–60 min by 22%, more than 60 min by 14% (6% unknown). The median number of different interventions used was 3 (range 0–11). The most common was digital evacuation (56%); of those who used digital stimulation, 76% also used digital evacuation.

Few respondents had undergone any type of bowel surgery (9.7% in total, 6.8% excluding haemorrhoid-related procedures). Seven individuals reported a sacral anterior root stimulator. One individual reported an antegrade continence enema. Colostomy was reported by 2.4% of respondents (excluded from remainder of analysis).

Problems associated with bowel care

Reported problems are shown in Table 4. Only 1.5% of respondents reported no bowel problems (median 2 problems, range 0–9). People reporting more bowel problems were likely to report a longer duration of bowel care ($P<0.001$) and greater number of interventions used ($P<0.001$). More than one-third reported haemorrhoids. The concept of flexibility in the bowel programme emerged during questionnaire development interviews. Many respondents (35%) felt that they were 'not very flexible' ('I do not usually change my routine unless it is unavoidable') or 'not flexible at all' ('I will not go to activities if they clash with my bowel management time').

To assess the impact of bowel dysfunction on daily life, respondents scored statements as shown in Table 5. Aspects of SCI were rated according to impact on daily life (impact scores 0–10, where 10 = most impact) (see Table 6). Scores allocated to the different aspects varied significantly ($P=0.001$). Impact scores for bowel function were significantly greater ($P<0.001$) than those for all other rated aspects. Low or no flexibility was associated with greater impact of bowel management.

Twenty per cent of respondents were dissatisfied or very dissatisfied with bowel management. Low satisfaction was associated with longer duration of care ($P<0.001$), more frequent incontinence ($P<0.001$), more frequent management ($P=0.008$), more problems ($P<0.001$) and more interventions used ($P<0.001$). Higher satisfaction was associated with greater flexibility ($P<0.001$). Digital evacuation, anorectal stimulation, abdominal distension, pain, constipation and haemorrhoids were all associated ($P<0.001$) with dissatisfaction with management.

Interventions and outcomes

Relationships between interventions and outcomes are summarized in Table 7. Constipation, abdominal pain, abdominal distension and haemorrhoids were each associated with greater use of interventions, increased frequency of autonomic dysreflexia and increased duration of bowel care (all $P<0.001$).

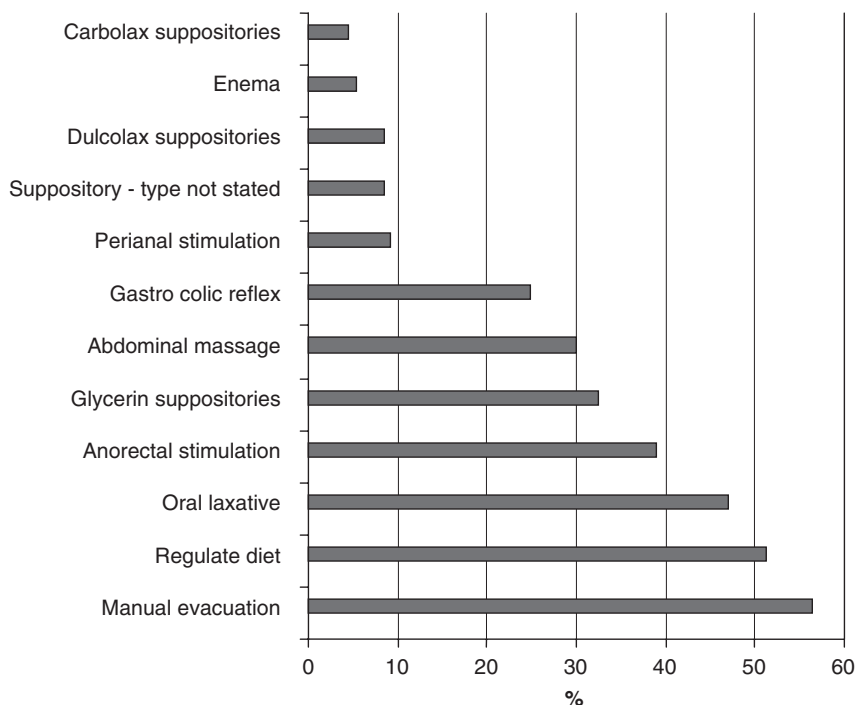


Figure 1 Interventions used for bowel care (multiple responses possible).

Table 3 Combined use of suppositories and digital interventions (*n* = 1334)^a

Rectal stimulant type	Suppository use	Suppository with digital stimulation	Suppository with manual evacuation
	n	n	n
Glycerin	434	222	270
Dulcolax	114	62	67
Carbolax	61	37	37
Type not known	114	55	68
Enema	73	35	45
Total	796 (59.6%)	411 (51.6%)	487 (61.1%)

^aPercentages are proportion of those using each combination who used the specific product named.

Table 4 Reported problems with bowel care (*n* = 1334)

	Frequency	% of respondents
Constipation	522	39.1
Haemorrhoids	485	36.4
Abdominal distension	409	30.7
Abdominal pain	268	20.1
Duration of bowel care >60 min	185	13.9
Surgery to bowel	130	9.8
Incontinence at least monthly	112	8.4
AD often/always	108	8.1
AD often/always—lesions above T7 only	93	9.5
AD occasionally—lesions above T7 only	348	35.6
No flexibility in routine	101	7.6
Anal fissure	96	7.2
Rectal prolapse	55	4.1
Other	58	4.3
Total	2529	

Abbreviation: AD, autonomic dysreflexia.

Dependency

Some help with bowel care was needed by 11.8% of respondents, whereas a complete assistance was required by 22.8%. Unsurprisingly, individuals with complete cervical injuries were more likely to require complete assistance than any other group ($P < 0.001$). Care was provided by nurses (23.8%), personal carers (30%) or partners (32%).

Those needing assistance used more interventions ($P < 0.001$), spent more time and had more problems ($P < 0.001$); complete care was associated with less satisfaction ($P = 0.02$). Assistance with bowel care was associated with fitting life around bowel management, bowel management interfering with working, greater impact on relationships, staying away from home, social life, feeling that bowel management was a problem and with increased ratings of how much bowel care affected life (all $P < 0.001$).

Table 5 Reported effect of bowel management on life activities

	Fit life around bowel care		Stops me working		Interferes with relationships		Prevents staying away from home		Its a problem		Affects social life	
	n	%	n	%	n	%	n	%	n	%	n	%
Not at all	501	37.6	865	64.8	821	61.5	714	53.5	528	39.6	704	52.8
A little	488	36.6	198	14.8	279	20.9	295	22.1	507	38.0	399	29.9
A lot	277	20.8	105	7.9	102	7.7	222	16.6	212	15.9	133	10.0
Total	1266	94.9	1168	87.6	1583	90.1	1231	92.3	1247	93.5	1236	92.7

Table 6 Mean impact scores (0–10 where 10 is the greatest impact)

Assessed aspect of spinal cord injury	Mean scores
Bowel function	4.72
Sexual function	4.70
Bladder function	4.19
Wheelchair use	3.99
Pain	3.74
Spasticity	3.42
Skin care	3.24

Individual and injury characteristics

Associations between respondents' characteristics and bowel management outcomes are summarized in Table 8.

Level of injury. Respondents with cervical injuries reported greater use of dietary manipulation ($P=0.02$), gastrocolic reflex, glycerin suppositories, all laxatives and stimulant laxatives (all $P<0.001$). Those with thoracic injuries reported significantly greater use of digital evacuation ($P=0.001$) and abdominal massage ($P=0.003$). A higher level of injury was associated with using more interventions ($P<0.001$), longer duration of bowel care ($P\leq 0.001$), less frequent care ($P\leq 0.001$) and less flexibility ($P<0.001$). Individuals with higher lesions were more likely to report abdominal pain ($P=0.02$), distension ($P<0.001$) and constipation ($P<0.03$). Haemorrhoids were reported more frequently by individuals with lumbar/sacral and thoracic lesions than by individuals with cervical injuries ($P<0.001$). Those with lumbar/sacral lesions were most likely to report daily or weekly incontinence ($P<0.001$).

Density of injury. Individuals with incomplete injuries used fewer interventions, less time, were more likely to conduct bowel management less than twice a week, adopt an upright posture and report flexibility in their routine than those with complete lesions (all $P<0.001$).

Gender. Men used more dietary manipulation ($P=0.004$), anorectal stimulation ($P=0.04$) and suppositories ($P=0.009$) than women. Women reported more problems than men ($P=0.002$), including abdominal pain ($P=0.001$), distension ($P<0.001$), constipation ($P<0.001$) and were more likely to use pads ($P<0.001$). Women were less likely to receive care from a partner and more likely to receive care from a nurse than men ($P=0.004$).

Duration of injury and age. Increasing duration of injury was associated with greater use of digital evacuation ($P<0.001$), bisacodyl suppositories ($P=0.001$), sodium acid phosphate and sodium bicarbonate suppositories ($P=0.05$) and reduced use of glycerin suppositories ($P<0.001$). Laxative use was increased ($P\leq 0.02$) but stimulant laxatives specifically were not increased.

Greater age was associated with increased use of digital evacuation ($P\leq 0.001$), laxatives ($P\leq 0.001$), stimulant laxatives specifically ($P\leq 0.02$), reduced use of glycerin suppositories ($P=0.001$), using fewer interventions ($P=0.007$), reduced flexibility ($P\leq 0.001$) and more abdominal pain ($P=0.01$). There may be a degree of confounding between the two variables of age and duration of injury.

Discussion

This study reports a large sample of community-dwelling SCI individuals with stable bowel management. The sample was not recruited from a health-care setting, giving the possibility of a more balanced representation of bowel care in the community than in a sample recruited from hospital attendees. However, we recognize that there is a major possibility of response bias, especially as the response rate was below 50%. It seems likely that responders would tend to have more bowel problems than non-responders and our reported results should be read with this in mind.

Although the acceptability of digital evacuation has been questioned by some authors,⁶ it was the most frequently reported intervention and was clearly associated with better outcomes in independent individuals with thoracic lesions, as suggested elsewhere.⁷ However, causation cannot be ascribed to this association from our data. Less reported use of digital evacuation and associated increased duration of bowel care among individuals with cervical lesions may be due to the reluctance of carers, who may see digital evacuation as a last resort. Anorectal stimulation was reported to be used by fewer than half of the individuals who had reflex bowel function; it did not eradicate the need for digital evacuation and was associated with a longer duration of care. Earlier authors⁸ have suggested that anorectal stimulation could replace the use of suppositories once bowel care was well established; the findings of this study suggest that this technique should be thoroughly evaluated in each individual. Rectal stimulants alone were frequently insufficient to achieve complete evacuation and additional digital interventions were usually required.

Table 7 Associations between interventions and outcomes (only significant associations are shown)

	<i>Haemorrhoids</i>	<i>Faecal incontinence</i>	<i>Rectal prolapse</i>	<i>Abdominal pain</i>	<i>Abdominal distension</i>	<i>Constipation</i>	<i>Duration</i>	<i>Autonomic dysreflexia</i>	<i>Anal fissure</i>
Manual evacuation	L/S $P=0.02$, OR 2.6 T $P=0.05$, OR 1.3			C $P=0.006$, OR 1.78 T $P=0.03$, OR 1.6	C $P\leq 0.001$, OR 2 T $P=0.055$ OR 1.5	C <0.01 OR 1.6	C Longer $P\leq 0.001$ T Shorter $P\leq 0.001$	C $P\leq 0.001$	$P\leq 0.001$ OR 2.4
Anorectal stimulation	C $P\leq 0.001$, OR 2 T $P\leq 0.001$, OR 1.7			$P=0.002$, OR 1.5	C <0.001 , OR 2.1 T $P=0.002$, OR 1.7		C and T Longer $P\leq 0.001$ LS $P=0.009$	Less dysreflexia $P\leq 0.001$	C $P=0.006$ OR 2
Laxatives	T $P=0.02$, OR 1.4	Stimulant C $P\leq 0.001$ T $P=0.01$	Stool bulking agent $P=0.01$	All laxatives—C $P=0.01$, OR 1.75 T $P=0.008$, OR 1.7, SL $P=0.008$, OR 3 Stimulant C $P=0.004$, OR 1.9 T $P=0.05$, OR 1.6, L/S $P=0.02$, OR 3.2	All laxatives—C and T $P\leq 0.001$, OR 2, Stimulant C $P=0.001$, OR 1.9 T $P\leq 0.001$, OR 3.2 stool bulking agents C $P=0.01$, OR 2.5, Softeners C $P=0.05$, OR 3	All—C $P=0.002$ OR 1.8 T $P\leq 0.001$ OR 2.5 Stimulant C $P=0.02$ OR 1.5 T $P\leq 0.001$ OR 2.2 L/S $P=0.001$ OR 5.1	Any laxative Longer C and T $P\leq 0.001$ Stimulant Longer C and T $P\leq 0.001$	Stimulant $P\leq 0.005$	
Chemical rectal stimulants	T Glycerin $P\leq 0.001$, OR 1.5, C Dulcolax $P=0.02$, OR 1.7	Dulcolax $P=0.01$ Enema $P=0.01$	Enema $P=0.01$	Dulcolax $P=0.002$ Enema $P=0.01$, OR 2		Enema C $P=0.003$ OR 2.8	All Longer $P\leq 0.001$	Dulcolax $P\leq 0.001$ Enema 0.002 Carbolax $P=0.008$	
Abdominal massage	C $P=0.03$, OR 1.5, T $P=0.01$, OR 1.5			C $P=0.002$, OR 1.8 T $P=0.001$, OR 2	C $P\leq 0.001$, OR 2.6 T $P\leq 0.001$, OR 2.2 L/S $P=0.04$ OR 2.9	T $P\leq 0.001$, OR 1.9	C&T Longer $P\leq 0.001$ $P=0.02$	Less dysreflexia C $P\leq 0.001$ T $P=0.01$ C $P=0.05$	T $P=0.007$ OR 2.3
Gastrocolic reflex	T $P=0.001$, OR 1.8			C $P\leq 0.001$, OR 0.4—pain reduced	C $P=0.001$, OR 1.5	C $P<0.001$ OR 2 T $P=0.03$ OR 1.5	C $P=0.02$ T $P=0.01$		
Sitting up for bowel care	$P=0.001$						Shorter C $P\leq 0.001$ T $P=0.06$		$P\leq 0.001$

Abbreviations: C, cervical; L/S=lumbar/sacral; OR, odds ratio; T=thoracic.
All associations are positive except where indicated.

Table 8 Associations between respondent characteristics and bowel management outcomes (significant results only)^a

		Increasing age at study	Increasing duration of injury	Gender (women reported more in all cases)	Greater density of lesion	Higher level of injury
Total problems reported	<i>P</i> =			0.002	0.001	
Duration of bowel care	<i>P</i> =	0.03 reduced	<0.001		<0.001	<0.001
Rectal prolapse	<i>P</i> =		0.04		0.02	
Constipation	<i>P</i> =			<0.001	<0.001	0.03
Haemorrhoids	<i>P</i> =	0.004	<0.001		<0.001	<0.001
Surgery	<i>P</i> =	<0.001 less	<0.001 less			
Reduced flexibility	<i>P</i> =	<0.001			<0.001	<0.001
Abdominal distension	<i>P</i> =	0.03 less		<0.001		<0.001
Incontinence	<i>P</i> =				<0.001	<0.001
Abdominal pain	<i>P</i> =	0.004		0.001		0.02
Frequency of bowel care	<i>P</i> =	<0.001 reduced	0.001 reduced		0.001	<0.001

^aAll associations are positive except where stated.

The efficacy of rectal stimulants also requires further exploration. The contribution of diet remains unclear; a strong association with abdominal distension (see Table 8) suggests that the dietary interventions used may contribute to this problem.

Laxative use among SCI individuals is widespread, though they may be ineffective.⁹ More than half of laxative users reported constipation. It is not clear whether this is because the laxatives were ineffective or were successful, but individuals still regarded themselves as constipated because they continued to need laxatives.

In clinical practice, the importance of regular, frequent bowel management is often emphasized; an association between decreasing frequency of management or lack of a regular routine and reported constipation supports this. However, a rigid routine may reduce quality of life, and very frequent care is associated with dissatisfaction. Frequency should be determined by individual needs and response to bowel care and allow as much flexibility as possible.

A relatively low incidence of faecal incontinence emphasizes the general success of care in achieving managed continence, but may obscure the real cost of achieving continence. The impact of time spent on bowel care was significant, as reported in earlier studies,^{4,5} both greater frequency and duration were significantly associated with dissatisfaction and greater effect on daily life. Time spent on bowel care may be an important outcome measure of the success of bowel management from the patient's perspective in both rehabilitation and chronic settings.

Bowel management has been identified as a stimulus for autonomic dysreflexia¹⁰ but was a frequent complication of bowel care for very few respondents; 9.5% of those with injuries above T7. Fifteen individuals with SCI below this level also reported dysreflexic symptoms.

Although haemorrhoids were frequently reported, only 3% reported banding or injection; haemorrhoids in this population seldom give rise to major complications. Surgical management interventions were notably rare. Only seven individuals reported a sacral anterior root stimulator despite its availability for several decades and positive impact on bowel management.¹¹ One individual reported an antegrade continence enema; these are common in spina bifida

children and have been performed successfully in SCI adults.¹² Colostomy for bowel management after SCI has been found to be effective,¹³ but was reported by only 2.4% of respondents (excluded from analysis). The low level of surgical intervention merits exploration as it is possible that some potentially helpful operations are currently under used.

Significant associations were identified between some interventions and problems, some of which may be explained through the mediation of constipation; stimulation of the autonomic nervous system during digital interventions may also play a part. It seems likely that problems with bowel management are to some extent the product of the interventions used; however, until new improved interventions are developed these side effects remain significantly preferable to non-management. Lack of association with duration of injury supports earlier suggestions that individuals with problems could be identified early, allowing swifter access to non-conservative methods of treatment.¹⁴

One-third of respondents needed assistance with bowel management, similar to levels in Denmark,¹ Australia⁵ and somewhat less than that in America (53%).¹⁵ Involvement of partners in bowel care is generally discouraged. The fact that 30% of assistance in this study was given by partners may reflect inadequacy in community health-care provision. Needing assistance significantly increased the impact of bowel dysfunction; those receiving complete care were less satisfied than those receiving partial care perhaps due to the very personal nature of the care and the implicit breaking of social taboos. Bowel care has considerable implications for all involved; 50% of individuals who require assistance spend more than 30 min on bowel management, 70% of those assisted by personal carers. This has a negative impact on life activities for the SCI individual, but also has implications for carers and community nursing services.

As reported elsewhere,⁴ individuals with cervical lesions experienced the greatest burden with bowel management. Physically, this may be related to loss of sympathetic input to the colon, greatly increased transit times and loss of control of abdominal musculature.^{16,17} However, differences in management and outcomes may also reflect attitudes among

carers who are often reluctant to use 'invasive' interventions, for example digital evacuation, despite approval of professional organizations.¹⁸ This reluctance may necessitate greater use of rectal stimulants and oral laxatives, resulting in longer management time. Limited availability of carers may explain the reduced frequency and flexibility seen in dependent individuals.

Interesting gender differences emerged, as in the general population, women reported more constipation, abdominal pain and distension than men. Incontinence was no higher among women, but their greater tendency to wear pads and higher rating of impact on life suggest that they may be more anxious regarding bowel dysfunction than men.

Earlier studies have suggested a relationship between increasing age and duration of injury and changes in bowel function.¹⁴ Here they were associated with greater laxative use, stronger rectal stimulants and an increased use of digital evacuation, suggesting that reflex bowel function does deteriorate over time. However, greater duration of injury was not associated with more problems, surgery was more likely earlier than later post-injury, faecal incontinence reduced over time and the use of stimulant laxatives did not increase. Greater age, however, was associated with increased use of stimulant and other laxatives, suggesting that deterioration in bowel function over time may be associated with age-related changes in the bowel and diminishing mobility rather than the effects of prolonged stimulant laxative use or increasing duration of SCI alone. Changes in bowel management and function with age after SCI have been reported,¹⁶ but are also reported in the non-SCI population.¹⁹ Changes in function may be more significant after SCI due to other disability-related factors.

The impact of bowel dysfunction has been ranked as significant in this and earlier studies,^{4,16} but surprisingly few respondents reported dissatisfaction. Very low expectations of bowel management and lack of awareness of the admittedly limited choices available, such as transanal irrigation,²⁰ may provide some explanation. This may be compounded by the lack of clinical services with specialist staff dedicated to optimizing bowel management, thereby denying SCI individuals a pathway through which to seek assistance with this aspect of care. Satisfaction may not be a useful outcome measure for bowel care after SCI.

The results of this study may not generalize to the entire chronic SCI population as they are from just less 50% of patients at a single centre. However, given this caveat, it seems likely that they apply to substantial numbers of people with SCI.

Conclusions

Managing bowel function in the community after SCI involves multiple interventions and considerable time and impacted on life most compared with other SCI-related impairments in these chronically injured individuals. This and the associations between interventions and problems demand further exploration of bowel management to reduce the impact on quality of life, minimize side effects and

increase the choice of management strategies available. The aim of professionals engaged in this area should be to develop, with the patient, an individualized programme reflecting the complex interplay of SCI, dependency and individual characteristics of each patient, using minimum interventions and time to deliver effective care.

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Appendix 1**About you**

Date of birth
<input type="checkbox"/> Male <input type="checkbox"/> Female
Date of injury or onset of spinal cord damage
Level of your spinal cord injury or damage
Is your spinal injury
<input type="checkbox"/> Complete <input type="checkbox"/> Incomplete <input type="checkbox"/> Don't know

If you would like more information about the rest of this research project please complete the section below:

NAME.....

Address.....

.....

.....

.....

.....

Telephone.....

Received	
Info date	
Data entered	
Tel con	

About your Bowel Care

<p>1. Are you satisfied with your bowel management routine? Please tick one box</p> <p>1. <input type="checkbox"/> Yes, very satisfied. 2. <input type="checkbox"/> Yes, satisfied. If you ticked box 1 or 2 please go to Question 3</p> <p>3. <input type="checkbox"/> No, I'm dissatisfied 4. <input type="checkbox"/> No, I'm very dissatisfied If you ticked box 3 or 4 please continue with Question 2</p>								
<p>2. If you ticked NO (box 3 or 4) in Question 1 please explain why and then continue with the remaining questions.</p>								
<p>3. Do you regulate your diet to help with bowel management?</p> <p>2 <input type="checkbox"/> No 1 <input type="checkbox"/> Yes- please explain</p>								
<p>4. How much do you usually drink each day?</p> <p>1 <input type="checkbox"/> About ½ a litre 2 <input type="checkbox"/> 1 litre 3 <input type="checkbox"/> 1-2 litres 4 <input type="checkbox"/> More than 2 litres</p>								
<p>5. What steps do you usually use to empty your bowel? Tick all that you use</p> <table><tr><td><input type="checkbox"/> Drink/food before bowel management</td><td><input type="checkbox"/> Massaging or rubbing your tummy</td></tr><tr><td><input type="checkbox"/> Touching the skin around the anus</td><td><input type="checkbox"/> Stimulation – putting a finger inside the anus and circling</td></tr><tr><td><input type="checkbox"/> Manual evacuation – using a finger to remove stool from the bowel</td><td><input type="checkbox"/> Suppositories – what kind and how many?</td></tr><tr><td><input type="checkbox"/> Laxatives – what kind and how much?</td><td><input type="checkbox"/> Enemas – what kind?</td></tr></table> <p><input type="checkbox"/> Other steps. Please explain.</p>	<input type="checkbox"/> Drink/food before bowel management	<input type="checkbox"/> Massaging or rubbing your tummy	<input type="checkbox"/> Touching the skin around the anus	<input type="checkbox"/> Stimulation – putting a finger inside the anus and circling	<input type="checkbox"/> Manual evacuation – using a finger to remove stool from the bowel	<input type="checkbox"/> Suppositories – what kind and how many?	<input type="checkbox"/> Laxatives – what kind and how much?	<input type="checkbox"/> Enemas – what kind?
<input type="checkbox"/> Drink/food before bowel management	<input type="checkbox"/> Massaging or rubbing your tummy							
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<input type="checkbox"/> Manual evacuation – using a finger to remove stool from the bowel	<input type="checkbox"/> Suppositories – what kind and how many?							
<input type="checkbox"/> Laxatives – what kind and how much?	<input type="checkbox"/> Enemas – what kind?							
<p>6. How long have you been managing your bowel this way?</p> <p>1 <input type="checkbox"/> Less than 6 months 2 <input type="checkbox"/> Less than 1 year 3 <input type="checkbox"/> Upto 5 years 4 <input type="checkbox"/> Longer</p>								

7. How long do you usually spend on your bowel management? 1 <input type="checkbox"/> Up to 15 minutes 2 <input type="checkbox"/> Up to 30 minutes 3 <input type="checkbox"/> Up to 1 hour 4 <input type="checkbox"/> More than 1 hour – how long?.....
8. How often do you manage your bowels? 1 <input type="checkbox"/> Daily 3 <input type="checkbox"/> Three times a week 2 <input type="checkbox"/> Alternate days 4 <input type="checkbox"/> Other. Please say how often.....
9. What is your posture during bowel management? 1 <input type="checkbox"/> Sitting up right 2 <input type="checkbox"/> Laying down 3 <input type="checkbox"/> Other
10. At what time do you usually do your bowel care? 1 <input type="checkbox"/> Morning 2 <input type="checkbox"/> Evening 3 <input type="checkbox"/> Other – please explain
11. Do you suffer from headache or sweating or both (Autonomic Dysreflexia) during your bowel management? 1 <input type="checkbox"/> Never 2 <input type="checkbox"/> Occasionally 3 <input type="checkbox"/> Often 4 <input type="checkbox"/> Always
12. How often do you have a 'bowel accident'? Please tick one box 1 <input type="checkbox"/> Daily 2 <input type="checkbox"/> Weekly 3 <input type="checkbox"/> Monthly 4 <input type="checkbox"/> Occasionally 5 <input type="checkbox"/> Rarely 6 <input type="checkbox"/> Never
13. How often do you pass wind, apart from when you are managing your bowel? Please tick one box 1 <input type="checkbox"/> Daily 2 <input type="checkbox"/> Weekly 3 <input type="checkbox"/> Monthly 4 <input type="checkbox"/> Occasionally 5 <input type="checkbox"/> Rarely 6 <input type="checkbox"/> Never
14. Do you wear a pad for your bowels? 1 <input type="checkbox"/> Yes sometimes 2 <input type="checkbox"/> Yes always 3 <input type="checkbox"/> No
15. Do you suffer with any of the following problems: Please tick all that apply. 1 <input type="checkbox"/> Haemorrhoids (piles) 2 <input type="checkbox"/> Rectal prolapse 3 <input type="checkbox"/> Abdominal distention (bloating) 4 <input type="checkbox"/> Abdominal pain 5 <input type="checkbox"/> Constipation 6 <input type="checkbox"/> Anal fissure 7 <input type="checkbox"/> Other. Please explain:
16. Have you had any surgery to your bowel or back passage? 1 <input type="checkbox"/> No <input type="checkbox"/> Yes – please say what

17. How flexible is your bowel management routine? Please tick one box

1 Very flexible – I often change the time or frequency at which I manage my bowels 2 Quite flexible – I can delay management or alter the timing if I want to

3 Not very flexible – I don't usually change my routine unless its unavoidable 4 Not flexible at all – I will not go to activities if they clash with my bowel management time

18. Do you need assistance with your bowel management?

1 No help needed 2 I need some help 3 I do not do my own bowel care

19. If you need help with your bowel management, who usually helps you? Please tick one box.

2 Member of the Community or District Nursing team 3 Partner

4 Personal carer 5 Other family member

6 Other – please explain

20. How does bowel management fit into your life? Please tick one box beside each statement.

I fit my life around my bowel management	1 <input type="checkbox"/> Not at all	2 <input type="checkbox"/> A little	3 <input type="checkbox"/> A lot
Bowel management stops me working outside my home	<input type="checkbox"/> Not at all	<input type="checkbox"/> A little	<input type="checkbox"/> A lot
Managing my bowels interferes with personal relationships	<input type="checkbox"/> Not at all	<input type="checkbox"/> A little	<input type="checkbox"/> A lot
Bowel management stops me staying away from home	<input type="checkbox"/> Not at all	<input type="checkbox"/> A little	<input type="checkbox"/> A lot
My bowel management is a problem to me	<input type="checkbox"/> Not at all	<input type="checkbox"/> A little	<input type="checkbox"/> A lot
Bowel management interferes with my social life	<input type="checkbox"/> Not at all	<input type="checkbox"/> A little	<input type="checkbox"/> A lot

21. How much does bowel management affect your life compared to other aspects of Spinal Cord Injury?
Please give each of the following items a score between 1 and 10, where 10 is the worst effect and 1 is the least.
If you feel an item does not apply to you please put a cross in the box.

Managing my bladder	
Changes in my sexual function	
Using a wheelchair	
Taking care of my skin	
Managing my bowel	
Living with chronic pain	
Living with spasticity	

Thank you very much for completing this questionnaire. Your help is valuable.
If there is any thing else you would like to tell us about your experience with bowel management please do so here.