

ORIGINAL ARTICLE

The impact of stoma for bowel management after spinal cord injury

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Study design: Multi-centre, retrospective self-report postal survey.

Objectives: To characterise spinal cord injured (SCI) individuals with a stoma, their stoma management and outcomes, to identify sources of information and support for decision making and to explore the impact of a stoma on life satisfaction.

Setting: Five UK spinal cord injury centres.

Methods: A study-specific questionnaire accompanied by self-concept, life satisfaction and mood measures, and three simple rating scales for satisfaction, impact and restriction on life were sent to all known ostomates at five participating centres.

Results: Respondents were 92 individuals, mean age 56 years, mean duration of injury 26 years, 91% with colostomy. Multiple sources of information were utilised in deciding on surgery; discussion with other SCI ostomates was important. Duration of bowel care, faecal incontinence, bowel-related autonomic dysreflexia, dietary manipulation and laxative use were all significantly reduced following surgery. Rectal mucous discharge was the most common and bothersome post-stoma problem. Satisfaction with stoma was high; provision of sufficient information preoperatively was important, those with ileostomy were more dependent and less satisfied. Life satisfaction and physical self-concept were both lower in this sample than in previously reported samples of SCI individuals without reported bowel difficulties or stoma.

Conclusion: The findings of this study of self-selected respondents with a stoma for bowel management after SCI emphasised the benefits of stoma in selected individuals and the importance of timely intervention, the complexity of the associated decision-making and of preoperative counselling. The impact of bowel dysfunction on physical self-concept warrants investigation.

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Keywords: stoma; colostomy; ileostomy; neurogenic bowel dysfunction; spinal cord injury

INTRODUCTION

Neurogenic bowel dysfunction and its management are increasingly recognised as a major constraint on quality of life after spinal cord injury (SCI).^{1,2} Bowel management difficulties include prolonged duration, constipation, abdominal pain, bloating, faecal incontinence and autonomic dysreflexia.^{2,3} Ageing and increasing duration of injury may contribute to increased difficulty.⁴ Where conservative management is ineffective, choice is limited to a small range of options including antegrade continence enema and nerve stimulation techniques of limited availability; the benefits of transanal irrigation are increasingly well established.⁵

Stoma has a place in chronic neurogenic bowel management where other interventions have failed. A number of studies have supported its effectiveness in relieving difficulties and improving quality of life.^{6,7} Few SCI individuals undergo colostomy for this reason, just 2.4% in the UK,² and little is known regarding decision making before surgery and ongoing management afterwards.

The aims of this study were to characterise SCI individuals with a stoma, their stoma management and outcomes, to identify sources of information and support available preoperatively and to explore the impact of stoma on life satisfaction.

MATERIALS AND METHODS

A multi-centre, retrospective self-report survey included SCI individuals with a stoma identified through electronic patient records and databases in five UK spinal centres. A questionnaire developed specifically for the study was accompanied by self-concept (Tennessee Self-Concept Scale (TSCS)),⁸ life satisfaction (Satisfaction with Life Scale (SWLS))⁹ and mood measures (Hospital Anxiety and Depression Scale (HADS)),¹⁰ and by three simple rating scales for satisfaction (0 indicated 'very dissatisfied'; 10 'very satisfied'), ability to live with bowel dysfunction (0 indicated 'terrible, worst possible', 10 indicated 'perfect, no problem at all') and how much bowel care restricts life (1 = not at all, 2 = a little, 3 = quite a lot, 4 = a great deal). All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Analysis

Quantitative data was managed and analysed using SPSS (SPSS Inc., Chicago, IL, USA, version 17). Chi-square (χ^2), Fisher's exact and Mann–Whitney *U*-tests were used to analyse categorical and ordinal data. Student's *t*-tests were used to analyse continuous data between groups (age and duration of injury) following confirmation of normal distribution using the Kolmogorov–Smirnov test. Spearman's rho was used to assess associations in non-parametric data. Level of significance was set at $P = 0.05$.

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RESULTS

Questionnaires were sent to 149 individuals and 104 responded (70%). Twelve reported having a stoma for malignancy or related to their initial SCI and were not analysed. Responses from 92 individuals reporting stoma specifically to resolve bowel management problems were analysed; 91% reported colostomy, 9% ileostomy. Demographic and injury information is shown in Table 1. Reasons reported for stoma formation are shown in Table 2.

When considering stoma surgery, most individuals reported using up to four sources of information, including stoma nurses (60%), SCI doctors (43%) and their surgeon (38%). More than half (54%) discussed the option with other SCI ostomates, which 84% reported was helpful. Stoma nurses had significant input, preoperatively (78%), postoperatively (88%) and post discharge (78%). Community healthcare professionals (HCPs) contributed little to the decision (general practitioners 8%); however, most individuals (86%) felt they had sufficient information for an informed decision. A SCI doctor initially suggested stoma to 39% of individuals but it was individuals themselves who first suggested surgery in 40% of cases. Individuals reported experiencing bowel difficulties for a mean of 10 years (range 0.5–40 years, s.d. 10) before surgery. For 53%, stoma formation was not undertaken at the right time: 11% of these would have preferred surgery a year earlier, 28% up to 5 years earlier, 30% up to 10 years earlier and 32% earlier still; none suggested stoma formation was too early.

Surgery was mostly conducted in SCI centres (63%) but locations included local district hospitals (17%) and gastroenterology units (4%); there was no association between location and any reported outcomes. Mean length of hospitalisation was 20 days (range 3–67). Peri-operative complications were reported by 32% including infection (8%), further surgery (8%), prolonged ileus (5%), retraction of stoma (4%) and respiratory problems (3%). For more than 70% the experience of undergoing the operation was as, or better than, expected but for 22% it was worse than anticipated.

Problems reported since stoma formation and at the time of the study are shown in Table 3. Rectal mucous discharge was reported by

45.7% (42) of respondents who managed it by using pads (26%), rectal washouts (26%), digital rectal stimulation (25%), suppositories (9.5%), enemas (5%), digital evacuation (5%) and hydrocortisone

Table 2 Reasons reported for stoma formation (*n* = 92)

Reason for stoma	Frequency	%
Prolonged bowel care	61	68
Faecal incontinence	47	53
Constipation	26	29
Autonomic dysreflexia	19	21
Pain	19	21
Carer difficulties	13	15
Recurrent peri-anal abscess	11	12

Table 3 Reported problems with the stoma

Problems with the stoma	Since stoma		At the time of study	
	n	%	n	%
Hernia	12	13	8	9
Retraction of stoma	8	9	5	5
Prolapse	5	5	2	2
Stenosis of the stoma	2	2	1	1
Rectal mucous discharge			42	46
Ballooning of stoma bag	65	71	61	66
Faecal leakage around flange	49	43	20	22
'Pancaking'	51	55	37	40
Soreness of peri-stomal skin	43	47	22	24
Odour	37	55	27	29
Problems with bag adhesion	26	28	15	16

Table 1 Sample characteristics

	n	Minimum years	Maximum years	Mean years	s.d. (years)
Age	92	24	86	56	9
Age at injury	92	6	64	30	13
Duration of injury	92	2	63	26	13
Age at stoma	92	20	77	51	13
SCI to start of bowel difficulties	87	5 months	40	10	11
SCI to stoma formation	92	5 months	55	19	13
Time since stoma formation	92	8 months	28	6	6
Gender, n (%)					
Male	64 (70%)				
Female	28 (30%)				
Level of injury					
	Complete	Incomplete	Unknown	Total	
Cervical	15 (58%)	10 (38%)	1 (4%)	26 (100%)	
Thoracic	49 (80%)	10 (16%)	2 (3%)	61 (99%)	
Lumbar	0	3 (75%)	1 (25%)	4 (100%)	
Missing	0	0	1	1	
Total	64	23	5	92	

Abbreviation: SCI, spinal cord injury.

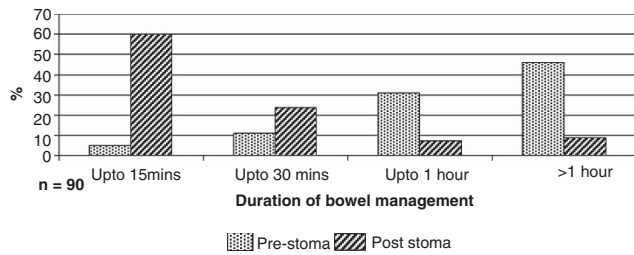


Figure 1 Duration of bowel management pre- and post-stoma.

enema (2%). Of the whole sample, 25% reported further stoma-related surgery, most frequently hernia repair (9%) and excision of the rectum (9%). There was no difference in demographic characteristics between those who required re-operation and those who did not. Autonomic dysreflexia associated with bowel management was reported by 50% fewer respondents following stoma surgery (37% before, 18% after stoma formation, $P=0.001$), reported duration of bowel care (Figure 1) and dependency, defined as needing no, some or total assistance with bowel care, were also reported to be significantly reduced ($P=0.007$ and 0.001 , respectively). Individuals reporting an ileostomy were more likely to need assistance than those with a colostomy ($P=0.005$) though there was no significant difference in levels of injury or pre-stoma dependency between respondents with either type of stoma.

Reported use of laxatives reduced from 58 to 31% ($P=0.005$) and dietary manipulation to assist bowel care was reduced significantly ($P=0.001$). Stoma irrigation was reported by 7% of respondents; none reported the use of enemas or suppositories in the stoma. Closed, disposable bags were used by 82%; 47% changed the bag daily, 39% on alternate days. Spontaneous passage of flatus was an embarrassment to 45%, while 36% were concerned about odour. Support continued to be provided by stoma nurses to 46% and 54% felt they had adequate community support. Just 13% belonged to an ostomy organisation.

Impact on body image was explored in four questions; 83 (70%) reported they felt very positive about their stoma, whereas 2 individuals felt others avoided them due to the stoma. A change in personal appearance post surgery was identified by 33%, mostly related to changes in shape of the abdomen and wearing different clothing to 'hide' the stoma or bag. For 23% there was impact on personal relationships; of the explanations provided nine were positive (improved personal relationship), six negative and three neutral. On the rating scales described above, median reported satisfaction with bowel management was 2 before stoma and 9 post stoma (χ^2 , $P<0.001$), median reported ability to live with bowel dysfunction was 3 preoperatively and 9 with a stoma (χ^2 , $P<0.001$), median reported impact of bowel dysfunction was 4 before and 1 after stoma formation (χ^2 , $P<0.001$).

Results for HADS, SWLS and TSCS are shown in Table 4. Greater satisfaction with stoma was positively correlated with lower HADS anxiety scores ($P=0.05$), lower HADS depression scores ($P=0.01$) and higher SWLS scores ($P=0.01$). An association between greater length of time since stoma formation and higher SWLS scores approached significance ($P=0.059$). The number of current problems with the stoma was significantly associated with higher HADS anxiety score ($P=0.01$), reduced SWLS ($P=0.05$) and reduced satisfaction with stoma ($P=0.01$). The number of problems reported since stoma formation negatively correlated with satisfaction ($P=0.01$).

Table 4 Scores for SWLS, HADS, TSCS short form *t* scores and physical scale raw score (*t* scores are not available for the physical subscale of the TSCS)

	n	Median	Minimum	Maximum
SWLS	80	17.58	3	33
HADS anxiety score	90	5	0	17
HADS depression score	91	3	0	14
TSCS short form <i>t</i> scores	71	93	83	100
TSCS physical scale	71	36.7	26	48

Abbreviation: HADS, Hospital Anxiety and Depression Scale; SWLS, Satisfaction with Life Scale; TSCS, Tennessee Self-Concept Scale.

Table 5 Decision to have a stoma

	Have stoma surgery again?		Recommend to a friend?		Have stoma closed?	
	n	%	n	%	n	%
Definitely yes	66	71.7	67	73	10	9.8
Probably yes	16	17.4	17	18.5	5	5.4
Probably not	0	0	1	1.1	4	4.3
Definitely not	2	2.2	0	0	68	73.9
Don't know	7	7.6	7	7.6	3	3.3
<i>n</i>	91		92		89	

To further explore satisfaction with their stoma, respondents were asked if they would have stoma surgery again with their current knowledge and experience, whether they would recommend it to a friend with similar bowel management difficulties and whether they would prefer to have their stoma closed (see Table 5). Individuals reporting they would close the stoma if they could, were significantly more likely to report insufficient preoperative information ($P=0.03$) and to have an ileostomy ($P=0.01$); there was a significant negative correlations between the wish to reverse the stoma and TSCS 'physical self' scores ($n=72$, -0.239 , $P=0.05$). Those who reported more restriction before surgery were more likely to report willingness to undergo surgery again ($n=84$, $P=0.01$ two tailed), while those who reported changed appearance or anxiety about odour were less likely to report willingness to repeat surgery ($n=90$, $P=0.006$ and $n=85$, $P=0.02$, respectively). There was a significant negative correlation between reporting that the stoma restricts life and the TSCS short form score ($n=72$, -0.287 , $P=0.05$).

DISCUSSION

Respondents were predominantly paraplegic with complete SCI who had experienced difficulties with managing neurogenic bowel dysfunction for a considerable time before stoma surgery. The decision to undergo stoma formation was complex, engaging multiple sources of information and influence; several motivating factors were reported by most respondents. As in other studies, duration of bowel management, faecal incontinence and constipation were the most common reasons for surgery. However stoma formation was also seen as an answer to care issues, underlining the problems many patients experience in receiving appropriate bowel care at home and is a finding that should concern all HCPs involved in transition of care to community settings for dependent patients.

Contact with other SCI ostomates appeared to have an important part in decision making and should be facilitated for all those considering stoma. Internet use provided a surprisingly small contribution, possibly reflecting its relatively recent development as an information source and a lack of high-quality resources. Stoma nurses provided much preoperative information along with specialist medical staff and there was very limited input from general practitioners and community nurses, possibly reflecting a lack of expertise among community HCPs. Most respondents felt able to make an informed choice regarding surgery but the association between reported lack of information and desire to close the stoma underlines the importance of effective informed consent. Nearly half of participants suggested stoma to their HCP rather than the reverse and many felt they had lived with severe bowel management difficulties for too long before surgery. It is unclear whether this delay relates to readiness in patients or reluctance amongst HCPs in proposing a stoma. While it is generally agreed that all other appropriate options should be explored before stoma formation, this should be undertaken in a timely way to avoid prolonging the impact of ineffective bowel management and consequent reduced quality of life for the individual.

The location for stoma surgery had no apparent impact on outcomes related directly to the stoma. Prolonged length of stay was common; with increasing use of laparoscopic surgery this will likely reduce in the future. Complications were common, but importantly not more than in the non-neurological stoma population.¹¹ In the longer term rectal mucous discharge was the most common and bothersome problem reported, though perhaps surprisingly it was not associated with a desire to close the stoma or unwillingness to undergo surgery again; consequent excision of the rectum was among the most common subsequent stoma-related surgery. More minor difficulties were reported less frequently with increasing experience with the stoma.

Improving outcomes of bowel care through surgery might be expected to maintain or increase life satisfaction, and the comparison between retrospective and current scores for the simple rating scales used in this study would support this. However, mean SWLS score for this sample was 17.58, substantially lower than the 19.498–20.8 mean score reported for a US sample of 230 individuals¹² and a Canadian sample of 781 individuals with SCI.¹³ This suggests that while a stoma improves bowel management issues, living with a stoma may result in a reduced quality of life in comparison to other SCI individuals without either a significant bowel management problems or a stoma.

Impaired self-concept has been reported in non-SCI patients undergoing stoma formation, where stoma surgery may represent a loss of control over bowel function and a new need for management of bowel function.^{14,15} Stoma formation for the present sample was a way of restoring control over a socially taboo bodily function and reducing the impact of management on daily life but still appears to impair physical self-concept. The mean TSCS 'physical self' score of 36.7 for this sample is considerably lower than the TSCS 'physical self' normative data mean of 71.78 (s.d. 7.67) and the mean of 65.92 (s.d. 8.24) for a sample of 71 individuals with SCI without recorded bowel management problems.¹⁶ The low scores may be related to the samples' long experience of bowel management difficulties. In contrast, responses to body image questions suggest only minor concerns, as reported elsewhere.¹⁷ However, concerns about change in appearance and odour were associated with reluctance to repeat surgery and should be addressed in counselling before surgery.

Although 23% of respondents reported altered personal relationships, the majority of changes were neutral or positive. These findings reflect very positive ratings of satisfaction with bowel function since

stoma, which increase with time since surgery, although when problems with the stoma were encountered anxiety was increased and satisfaction reduced, as is also reported in conservative bowel management.² Even so, 16% of the sample reported they would probably or definitely have their stoma closed if it were possible and 10% would definitely or probably not have the surgery again, associated with ileostomy and lack of preoperative information. The correlation between the degree of restriction and willingness to undergo surgery again supports the clinical perception that those with more severe bowel management difficulties are the most satisfied with stoma. Appropriate counselling and support of individuals considering surgery is essential and should include provision of a realistic picture of life with a stoma, especially in individuals considering an ileostomy. Similar findings were reported in a retrospective survey of 69 people without SCI with stoma formation for intractable faecal incontinence; respondents were generally very positive about the decision, despite numerous complications and poor overall quality of life.¹⁸

Stoma irrigation was reported by 7% of respondents, compared with 1–2% in the wider UK colostomy population.¹⁹ Irrigation can be time consuming but may provide a degree of continence, increasing quality of life further²⁰ and in addition can reduce costs of stoma equipment. This is not a direct concern for UK patients where healthcare costs are met by the National Health Service, which may help to explain low uptake. Further evaluation is warranted in this population.

As reported elsewhere, a stoma massively reduced duration of bowel care and the importance of this to quality of life should not be underestimated. It also eradicated faecal incontinence, another major outcome measure for effective bowel management. The significant reduction in reported autonomic dysreflexia may also contribute to increased wellbeing and satisfaction with bowel care. However, a stoma does not resolve constipation in all individuals; stoma for this reason requires careful consideration and counselling. Withdrawal of laxatives postoperatively should be undertaken cautiously.

This study reports on a self-selected cohort of patients who had chosen stoma for bowel management. We cannot be certain that these findings represent all the surveyed individuals, nor the wider SCI population, due to the response rate of 62%. A prospective study eliminating recall bias is needed to confirm these retrospective findings. We cannot draw any conclusions from our data on which patients will benefit most from stoma, nor on the best timing for surgery, although in the current group many felt they should have undergone stoma formation sooner.

CONCLUSION

The findings of this study lend further support to the benefits of a stoma in selected individuals with significant neurogenic bowel management problems. A stoma is associated with worthwhile reduction in the impact of bowel dysfunction, improvement in ability to cope and satisfaction, without impairing body image. However, the impact of severe bowel dysfunction on physical self-concept warrants investigation. These findings underline the importance of ongoing assessment of bowel dysfunction and timely, appropriate intervention. A proportion of respondents were dissatisfied with the stoma emphasising the importance of effective counselling and preparation, supported by the development and provision of information regarding stoma formation and its outcomes. This should be provided early after SCI to facilitate informed and timely decision-making. It is also important to ensure that the surgical approach aims to minimise post-operative complications.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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