The management of neurogenic bowel dysfunction is increasingly recognized as a major constraint on quality of life following spinal cord injury (SCI). The development of bowel management difficulties such as prolonged evacuation times related to constipation, abdominal pain and incontinence among chronically injured individuals have been highlighted in a number of studies. Where conservative management is ineffective the management choices for the individual are very limited. The antegrade continence enema and percutaneous endoscopic colostomy procedures have not been effectively evaluated in this population and their use is not wide spread; transanal irrigation is a promising recent introduction in this population. Colostomy as an option for bowel management has received growing attention, with a number of studies published in recent years. The studies all report positive outcomes for the majority of individuals undergoing the procedure, and suggest that colostomy should not be considered only in response to complications but should be considered far earlier in the individuals post injury life. However, further studies are required to substantiate these positive results, and to provide a better understanding of preparation for colostomy, outcomes and ongoing management.

The aims of this study were to:

1. Characterize SCI individuals with colostomy, their bowel management and outcomes
2. Explore how effective colostomy is in meeting specific bowel management problems
3. Explore the impact of colostomy on quality of life in this population
4. Identify sources of information and support available to individuals considering colostomy
5. Identify factors that predict successful outcomes following colostomy formation

Methodology

A multi-centre, retrospective, cross sectional, descriptive survey was undertaken. Postal questionnaires were sent to 150 SCI individuals managed at five UK spinal centres known to have had a stoma formed. A questionnaire was developed specifically for the study and was accompanied by quality of life (Satisfaction with Life Scale (SWLS)) and mood measures (Hospital Anxiety and Depression Scale (HADS)).

Results

A total of 104 responses were received; only responses from those having colostomy to resolve bowel management problems (92) were included in the analysis (62% response). Those undergoing colostomy due to cancer or other reasons were excluded. Of the 104 included respondents 91% reported colostomy and 9% ileostomy. The mean age of the sample was 56 years (SD 14 years), mean duration of injury at the time of the study was 26 years (SD 13 years). Respondents reported cervical (28%), thoracic (66%) and lumbar (4%) lesions; 71% had ASIA A (complete) injuries. The mean years from injury to stoma formation was 19 (SD 13 years), and the mean time from onset of difficulties with bowel management to stoma formation was 10 years (SD 12 years). Time since stoma formation to study ranged from 1 month to 27 years. Reasons for colostomy were reported as constipation (26%), autonomic dysreflexia (21%), pain (21%), time spent on bowel care (65%), faecal incontinence (50%) and difficulties with carers (13%). Multiple responses were possible.

Around a third of respondents reported peri-operative complications. Problems with stoma management such as peri-stomal skin problems, non-adherence of the bag, faecal leakage, and ballooning of the bag were common (29%-71%) but herniation (5%) or herniation (13%) of the stoma much less. However, mucus leakage from the rectum was reported by 46% of respondents and subsequent further resection of the rectum accounted for 33% of further surgery. Use of laxatives was significantly reduced after colostomy (p=.01) but they were still taken regularly or occasionally by 40% of respondents. Irrigation of the stoma was reported by 7%. Use of dietary restriction for bowel control was significantly reduced (p=.001). Less time was spent on bowel management (p<.001) and less help was needed compared to pre stoma management (p=.01).

There was a significant improvement in satisfaction and ability to cope with bowel dysfunction following colostomy (both p<.001). Satisfaction with the stoma was correlated with lower HADS anxiety (p=.05) and depression (p=.01) scores and higher SWLS scores (p=.01). The length of time since stoma formation was non-significantly associated with better scores on the SWLS (p=.059) but not with satisfaction with the stoma. The association between SWLS and time since stoma formation may be confounded by an association between increasing age and SWLS scores. The number of current problems was significantly positively correlated with the HADS anxiety score (p=.01) and negatively correlated with the SWLS score (p=.05) and satisfaction with the stoma (p=.01). The number of problems reported since stoma formation was also negatively correlated with satisfaction (p=.01). More than half the respondents felt colostomy was not conducted at the optimal time; 68% of these would have preferred stoma formation 10 or more years earlier.

Respondents had discussed colostomy with an average of 4 individuals prior to surgery; half had discussed it with an SCI ostomist and this was useful to more than 90%. The most common sources of information were stoma nurses (74%), SCI doctors (46%) and nurses (19%); only 7% of respondents reported discussing colostomy with their GP.

Lower satisfaction with reported with pre-stoma bowel management was correlated with greater reported satisfaction with the stoma (p=.04) and those who reported that the stoma should have been done sooner were also more satisfied. There was no association between individual reasons for colostomy and satisfaction or SWLS score; 27% gave one reason and 31% two reasons for having the surgery (mean 2.5, SD 1.5). There was no association between duration of the problems prior to surgery or any other pre-operative clinical variable and satisfaction with the stoma. Reporting having enough information about colostomy pre-operatively was positively associated with satisfaction (p=.029).
Interpretation of results

SCI individuals who undergo stoma formation have usually been injured for many years and have struggled with bowel management for much and sometimes all of that time. It was not possible to determine how well stoma surgery alleviated specific problems as most respondents gave multiple reasons for choosing a stoma; however the continued use of laxatives suggests that issues around constipation are not entirely eradicated. While this surgery is mainly associated with the pathophysiology of neurogenic bowel, the finding that some individuals undertake it due to difficulties in obtaining bowel care is of concern. Colostomy is associated with reduced burden in terms of time spent and dependence in bowel care resulting in improved quality of life but problems are not uncommon; as with conservative bowel care these problems impact on satisfaction with the stoma, mood and life satisfaction. When determining the surgical approach, consideration should be given to minimising post operative management issues, such as mucous discharge. Stoma nurses provide much of the preoperative information for these individuals, along with spinal unit medical staff. The limited input of GPs and community nurses may reflect a lack of expertise in neurogenic bowel management amongst community healthcare professionals. The findings suggest that those whose bowel management problems are the most significant feel most satisfied with their stoma but a significant number also felt that they would have benefited from much earlier surgery. These findings should inform the assessment of individuals’ bowel management problems as well as specific discussion of a stoma with patients. Facilitating a well informed decision making process is essential to satisfaction with a stoma for bowel care; the process should include contact with a SCI individual with a stoma.

Concluding message

A stoma improves quality of life for individuals with SCI who have significant bowel management difficulties; information regarding stoma formation and its outcomes in SCI individuals should be provided early after injury to facilitate informed decision making. Choice of surgical procedure should minimise the risk of post operative difficulties.

References