



## Original Article

# Does a colostomy alter quality of life in patients with spinal cord injury? A controlled study

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**Study Design:** Prospective controlled comparative analysis.

**Objective:** To determine whether a colostomy changes quality of life in patients with a spinal cord injury.

**Method:** A previously validated questionnaire designed to assess quality of life in spinal injured patients (Burwood Questionnaire) was sent to 26 spinal cord injured patients with colostomies and 26 spinal cord injured patients without colostomy. The two groups were matched for level of injury, completeness of injury, length of time since injury, age ( $\pm 5$  years) and gender.

**Results:** There was 100% completion of the questionnaire. There was no significant difference ( $P > 0.05$ ) in the two groups of patients in regard to their general well being, emotional, social, or work functioning.

**Conclusions:** Patients with colostomy following spinal injury are no worse off in regard to quality of life, than those without. The inference is that perhaps a colostomy should be considered earlier in patients with major bowel dysfunction following spinal cord injury.

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## Introduction

Improvement in rehabilitation and medical care has led to an increased life span in patients with spinal cord injuries (SCI).<sup>1</sup> This has meant that chronic problems are now emerging as a significant source of disability. Of these bowel and bladder care remain the most challenging concerns for many SCI patients and carers as it is this area that severely affects patient quality of life.<sup>2,3</sup> Bowel dysfunction is perceived by patients as one of the most important disabilities, and it is thought that it may correlate with greater anxiety and be a source of emotional upset.<sup>4</sup> It has been reported that a colostomy is a safe and effective way of managing bowel habit and the amount of time spent on bowel care is decreased dramatically from 99 to 18 min per day.<sup>5</sup> Furthermore it has been reported that a colostomy simplified bowel management in SCI patients. The only long term management problem reported was occasional appliance leakage and mucoid discharge per rectum. All patients involved in the study

found the stoma had impacted significantly on their lifestyle with increased feelings of independence, freedom and raised self-esteem.<sup>6</sup>

The effect of colostomy on bowel function in SCI patients is well understood.<sup>5</sup> However, the impact that colostomy has on an individual patient's quality of life is poorly documented. The aim was to compare quality of life in SCI patients with and without colostomy and thereby make inference about the impact of stoma formation. The focus was the individual's perception of lifestyle and not bowel function or frequency. It was expected that the information gathered would enable future patients to be more fully educated about the role that a colostomy may have in bowel management.

## Methods

### Patients

Spinal cord injured patients with colostomies were identified by reviewing the records of the two New

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Zealand spinal units located at Burwood, and in Auckland, and contacting all enterostomal therapists.

The inclusion criteria were:

1. Colostomy or ileostomy;
2. Minimum of 18 years of age;
3. At least 2 years post injury;
4. At least 6 months post stoma formation.

All patients were matched to an appropriate control using the Department of Surgery database of SCI patients. Each patient was matched according to the following: (1) age, (2) gender, (3) level of injury, (4) time since injury and (5) complete or incomplete injury.

### Procedure

The participants were contacted by mail over the period of November 1998 to February 1999. Each mailing involved a letter of introduction, and the questionnaire, with a reply paid envelope. The questionnaire (Burwood QoL Questionnaire) had been validated in a number of other studies,<sup>7,8</sup> and assessed quality of life in five areas; systemic symptoms, and emotional, social, work and bowel function (see Figure 1).

Participants were given 6 weeks to respond to the questionnaire, then addresses of non responders were checked before a second letter was mailed. If a reply was not received after a further 6 weeks, the patient was then contacted by telephone. Patients who were admitted to the Burwood Spinal Unit over the study period and were part of the study population were visited and asked to participate.

### Instruments

The questionnaire (Figure 1) was the primary instrument used to assess perceived quality of life. This questionnaire was made up to 29 questions grouped into five sub headings related to symptoms, level of function and bowel function. The aspects of function assessed were emotional, social and work function. The final section on bowel function included dimensions of stool frequency, assistance with and ability to delay toileting and incontinence.

The Flesch-Kinaid Grade Level readability score for the questionnaire was calculated to be Grade 6, with all questions phrased in a positive manner.

### Results

Twenty-nine spinal cord injured patients with stomas were identified. Thirteen patients were identified from the Burwood Spinal Unit, Christchurch, and six from the Auckland Spinal Unit and 10 through contact of enterostomal therapy nurses.

Twenty-six patients (90%) fitted the inclusion criteria, and the questionnaire was completed by all subjects and controls. Their age ranged from 22–87 years. Ten had cervical spinal cord injuries and 16

lumbar or lower thoracic spinal cord injuries. There were 11 female and 15 male patients. Time from injury to stoma formation ranged from 7 months to 20 years, with the majority having had their stomas formed within 5 years of initial spinal cord injury.

The matching of control and subject was analyzed first to detect any anomalies in the participant pairs. The two groups were matched for age, gender, time since injury, level of injury and completeness of injury ( $P>0.05$ ). Results of the questionnaire were then subjected to a paired non parametric multi variate analysis, with 95% confidence intervals, using the Statistix software programme. The results of this analysis are summarised in Table 1. The results show that for all QoL areas investigated in this study there was no difference between the two groups for any parameter.

### Discussion

Of all the medical problems experienced by patients with a spinal cord injury (SCI), many rate the loss or change in their bowel habit to be one of the most significant factors affecting their quality of life.<sup>4,9</sup> Previous studies have shown that spinal patients given colostomies reported subjective feelings of improved independence, freedom, and raised self esteem<sup>6</sup> and spent 75 min less per day on bowel maintenance.<sup>5</sup> However, colostomy following SCI is not routinely used, and is seen by many as failure of rehabilitation services. The aim of this project was to assess the effect that colostomy had on patient quality of life. It was expected that the information from this study would enable spinal patients to be more informed about the role of colostomy in bowel management.

The results of the study show that there were no differences between the two groups in any of the areas assessed by the questionnaire. This suggested that patient QoL was not impaired by the presence of a colostomy.

Colostomy has been considered by many medical professionals as a failure in the rehabilitation process, while urostomy or superpubic catheter have been used routinely with great success for many years. As a result there are few SCI patients with stomas, and although exhaustive methods were employed to find all eligible patients, the sample size was still small. Nevertheless no trends towards differences in QoL between cases and controls were detected and it is therefore unlikely that a larger study would produce substantially different conclusions.

The questionnaire has been validated and used in a number of previous studies assessing quality of life.<sup>7,8</sup> It specifically assesses aspects of the patient's life that is relevant to bowel function and QoL in spinal injured patients and it is not a coarse global assessment of QoL that is found in more commonly used questionnaires such as SF36.

SCI patients who receive an elective colostomy, have usually exhausted medical treatments available to

Please mark the questionnaire 1 to 5 to answer the questions, 1 being "never" and 5 being "often"

**Systemic Symptoms**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1. How often has the feeling of fatigue or of tiredness been troubled you?                                    | 1 | 2 | 3 | 4 | 5 |
| 2. How often have you felt strong and full of energy?   | 1 | 2 | 3 | 4 | 5 |
| 3. How often have you felt generally unwell?  | 1 | 2 | 3 | 4 | 5 |
| 4. How often have you had problems getting a good night sleep or been troubled by waking up during the night? | 1 | 2 | 3 | 4 | 5 |

**Emotional Function**

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 5. How often have you felt frustrated, impatient or restless?                            | 1 | 2 | 3 | 4 | 5 |
| 6. How often have you been troubled by fear of not finding a bathroom?                   | 1 | 2 | 3 | 4 | 5 |
| 7. How often have you felt embarrassed by your bowel function?                           | 1 | 2 | 3 | 4 | 5 |
| 8. How often how you felt tearful or upset?  | 1 | 2 | 3 | 4 | 5 |
| 9. How often have you felt irritable because of your bowel problems?                     | 1 | 2 | 3 | 4 | 5 |
| 10. How often have you felt lack of understanding about your bowel function from others? | 1 | 2 | 3 | 4 | 5 |
| 11. How often have you been satisfied, happy or pleased with your bowel function?        | 1 | 2 | 3 | 4 | 5 |

**Social Function**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 12. How often have you had to avoid attending events where there was no bathroom close at hand?           | 1 | 2 | 3 | 4 | 5 |
| 13. How often have you had difficulty doing leisure or sports activities that you would have liked to do? | 1 | 2 | 3 | 4 | 5 |
| 14. Have your bowel problems limited your sexual function?  | 1 | 2 | 3 | 4 | 5 |
| 15. How often have you had to delay or cancel a social engagement because of your bowel problems?         | 1 | 2 | 3 | 4 | 5 |

**Work Function**

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 16. How frequently are you unable to attend work because of your bowel problems?                                 | 1 | 2 | 3 | 4 | 5 |
| 17. How often do you feel your ability to work to your own standards are limited by your bowel function?         | 1 | 2 | 3 | 4 | 5 |
| 18. How often do you think that your work standards slip because of your bowel habits?                           | 1 | 2 | 3 | 4 | 5 |
| 19. How often do you think opportunities are not given to you because of others perceptions of your limitations? | 1 | 2 | 3 | 4 | 5 |
| 20. How often are you happy with your work ethic and your achievements?  | 1 | 2 | 3 | 4 | 5 |

**Bowel Habit**

21. Do you consider your bowel pattern normal ?  
Yes  
No

22. How many bowel motions do you have?  
On average over 24 hours? \_\_\_\_\_  
or, On average over a week? \_\_\_\_\_

23. What best describes your bowel control (continence)?  
Perfect control (continence)  
Leakage of gas (wind) at times  
Leakage of mucus or liquid motion occasionally  
Leakage of mucus or liquid motion frequently  
Leakage of solid motions occasionally  
Leakage of solid motions frequently

24. If you are incontinent, does it affect your everyday activities ?  
Never  
Occasionally  
Sometimes  
Often  
Always

25. When you feel the need to have a bowel motion, how long can you wait before going?  
Need to go immediately  
Can hold on for a few minutes only  
Can hold on at least 15 minutes

26. Do you need assistance with toileting?  
Yes  
No

Figure 1 Colostomy and Quality of Life Questionnaire

**Table 1** Summary of mean scores for all QoL questions

| Question number           | Mean stoma patients response | Mean control response | P value |
|---------------------------|------------------------------|-----------------------|---------|
| <i>Systemic symptom</i>   |                              |                       |         |
| Question 1                | 2.9                          | 3.0                   | 0.90    |
| Question 2                | 2.8                          | 3.3                   | 0.34    |
| Question 3                | 2.8                          | 2.3                   | 0.50    |
| Question 4                | 3.3                          | 2.8                   | 0.18    |
| <i>Emotional function</i> |                              |                       |         |
| Question 5                | 2.8                          | 2.7                   | 1.00    |
| Question 6                | 2.1                          | 2.3                   | 0.74    |
| Question 7                | 2.4                          | 2.3                   | 0.79    |
| Question 8                | 1.9                          | 2.2                   | 0.46    |
| Question 9                | 2.1                          | 2.2                   | 0.57    |
| Question 10               | 1.6                          | 2.1                   | 0.43    |
| Question 11               | 3.2                          | 3.1                   | 1.00    |
| <i>Social function</i>    |                              |                       |         |
| Question 12               | 1.8                          | 1.9                   | 0.83    |
| Question 13               | 1.9                          | 2.1                   | 0.50    |
| Question 14               | 1.6                          | 1.6                   | 0.44    |
| Question 15               | 2.2                          | 1.9                   | 1.00    |
| <i>Work function</i>      |                              |                       |         |
| Question 16               | 1.5                          | 1.5                   | 1.00    |
| Question 17               | 1.8                          | 1.6                   | 0.69    |
| Question 18               | 1.8                          | 1.5                   | 0.31    |
| Question 19               | 2.1                          | 2.3                   | 0.65    |
| Question 20               | 3.4                          | 3.7                   | 0.73    |
| <i>Bowel function</i>     |                              |                       |         |
| Question 22               |                              |                       |         |
| Yes                       | 11                           | 8                     | 0.81    |
| No                        | 8                            | 9                     |         |
| Question 22               |                              |                       |         |
| 24 h                      | 1.8                          | 1.6                   | 0.08    |
| Weekly                    | 9.6                          | 5.5                   |         |
| Question 23               |                              |                       |         |
| Perfect control           | 12/16                        | 14/17                 | 0.75    |
| Leakage (Gas)             | 9/17                         | 13/17                 |         |
| Leakage (Mucus)           |                              |                       |         |
| Never                     | 6                            | 4                     | 0.56    |
| Occasionally              | 6                            | 10                    |         |
| Frequently                | 4                            | 3                     |         |
| Leakage (Solid)           |                              |                       |         |
| Never                     | 10                           | 11                    | 0.65    |
| Occasionally              | 5                            | 5                     |         |
| Frequently                | 1                            | 1                     |         |
| Question 24               | 1.9                          | 1.8                   | 0.74    |
| Question 25               |                              |                       |         |
| Immediately               | 7                            | 6                     | 0.50    |
| Minutes                   | 2                            | 5                     |         |
| > 15 min                  | 0                            | 7                     |         |
| Question 26               |                              |                       |         |
| Yes                       | 16                           | 11                    | 0.45    |
| No                        | 4                            | 6                     |         |

them for their bowel management. Therefore, the patient's bowel dysfunction prior to surgery may have been significantly poorer than post-colostomy. This was commented upon by many participants. Hence, the lack of a significant difference between control and subject may reflect the stoma patients acquisition of the degree of bowel function already experienced by the control group. A longitudinal study assessing QoL before and after stoma formation would be required to investigate this question further.

In conclusion, we observed no difference in QoL between stoma SCI patients and matched control subjects without stoma but with a similar level of disability from SCI. As it is likely that a stoma was only formed in these patients experiencing significant difficulties with bowel function these results support the use of a colostomy in the management of SCI patients and suggest that this mode of treatment should not be viewed as the treatment of last resort.

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