SELF MANAGEMENT OF FAECAL CONTINENCE
BY PEOPLE WITH SPINAL CORD INJURY

FINAL REPORT

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FUNDIED BY NATIONAL CONTINENCE MANAGEMENT STRATEGY, FAECAL CONTINENCE GRANT PROGRAM

2004
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ACKNOWLEDGEMENTS

Several people and organisations are acknowledged for contributing to the success of this project. Firstly, without funding from the National Continence Management Strategy Faecal Continence Grants Program the project would not have been possible. Secondly, feedback from the Independent Evaluation Adviser has been helpful in ensuring the ongoing quality of the project.

The design of the patient education material and implementation of the project was facilitated by many people. Dr James Middleton and Marc Johns provided valuable feedback on the content of the program. Anna Kauter, in addition to providing administrative support for the project, skilfully and tirelessly developed several prototypes of the booklet, *Solving common bowel problems*, before the content and design was finalised. The implementation of the patient education program was undertaken willingly by the nursing staff at the Royal Rehabilitation Centre Sydney’s Spinal Unit, under the leadership of Marc Johns. Their continued participation in the project enabled the aspirations of the research team to become a reality.

Lorraine Stephenson enhanced the project in the role of research assistant. Her quiet diligence, pleasant persistence and attention to detail contributed in no small way to the success of the quality of the data.

John Bidewell is also acknowledged for his assistance with the design of the project and statistical analysis. His skills and commitment have ensured that the project outcomes can be reported against and that further research to study bowel activities across time is possible. In addition, his willingness to go the extra mile demonstrated that patient compliance with data collection was not as poor as first thought. Consequently, opportunities for further work in this area are being explored.
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1. **INTRODUCTION**

This is the final report on the project, *Self-management of faecal continence by people with spinal cord injury*, funded by the National Continence Management Strategy Faecal Continence Grants Program.

This report is presented several sections, commencing with a summary of the project, a review of the background literature and the objectives of the project. Following this the processes of the research are outlined, followed by findings, discussion of the problems encountered, review of the project objectives, comments about the portability/adaptability of the patient education program and recommendations.

2. **PROJECT SUMMARY**

This project sought to promote lifelong faecal continence for people with spinal cord injury by the establishment of a client driven bowel management program in the inpatient rehabilitation setting that would also be appropriate for use in the community. The program includes a client and family education program – namely an introduction to bowel care; laminated individualised flowcharts of bowel management regimes; an information booklet for solving common bowel problems; and a ‘train the trainer’ program to prepare clients to train their community carers. Data was collected to measure the effectiveness of this program in both the inpatient and community settings. Staff and patient focus groups were also used to evaluate the value of this program.

3. **BACKGROUND**

Faecal incontinence is a distressing, embarrassing and costly problem. It is a common and significant lifelong problem for people with spinal cord injury or impairment. These injuries commonly happen to younger people who are otherwise well and have a life expectancy similar to the general population. Therefore, while the spinal cord injured population may be relatively small, ie, about 260 new injuries per annum in Australia, the potential magnitude of their faecal continence issues is significant, both in the cost of equipment and carer support, and quality of life.

Before discharge from hospital an effective bowel management program is established for each client. While each client may require an individualised bowel management program, the literature indicates that the situation is complicated by other factors. The smooth running of the bowel program following discharge is totally dependent on patient compliance and dedicated care providers who must ensure constant and meticulous attention to detail. Commonly, however, clients change their bowel program after discharge. Kirk et al (1997) found that clients changed their previously effective bowel programs due to evacuation difficulties, convenience issues, efforts to decrease frequency of defaecation and chronic concerns about incontinence. Unfortunately fuller explanations of these reasons were not indicated, nor was the source of information upon which these decisions were made identified. More worrying is the evidence suggesting that people with spinal cord injury...
appear to largely self administer bowel medications on a trial and error basis (Doraisamy, 1984 cited in Harari et al 1997), and inadequate practices of evacuation are known to be undertaken with inherent risk and complications (Correa & Rotter 2000; Glickman & Kamm 1996).

In addition, difficulty with evacuation and constipation related symptoms are highly prevalent in people with spinal cord injury, despite laxative use (Harari et al 1997), and there is generally a high incidence of gastrointestinal symptoms and evacuation difficulties associated with spinal cord injury (Kirk et al 1997). While according to the literature gastrointestinal problems are infrequent within the first five years (Stone et al 1990), evidence from care providers demonstrates problems before that time frame. Nonetheless, an increase in bowel dysfunction and related complications has been identified amongst long term survivors (Menter et al 1997; Kirk et al 1997), particularly acquired megacolon (Harari & Minaker 2000).

The ramifications of bowel dysfunction are not limited to physical problems. The presence of constipated related symptoms can have a negative impact on a patient’s life style (Harari et al 1997; Kirk et al 1997; Lynch et al 2000; Correa & Rotter 2000;) and may be major physical and psychological problems (Glickman & Kamm 1996). Persons with the greatest disability in bowel function also scored the highest on anxiety and depression scales (Glickman & Kamm 1996). The White et al (1993 cited in Kirk et al 1997) study identified that the top concern amongst females with spinal cord injury was the chance of a bowel or bladder accident related to sexual activity.

The literature also supports anecdotal evidence that the hours of assistance required for bowel care increase as time passes from the injury (Correa & Rotter 2000; Lynch et al 2000; Kirk et al 1997; Harari et al 1997). As time devoted to bowel management increases, the time available for other activities, eg, work, sport, education and leisure decreases. In addition, the cost of carers also increases as the time devoted to bowel management increases. Furthermore, there is a flow on effect for other actual or potential users of the service as scarce resources, ie, carer hours, are consumed in greater number by a few clients. Glickman and Kamm (1996) identified that bowel function was not only taking up a considerable part of a person's day but was also a source of distress for the person.

In summary, the problems associated with faecal elimination following spinal cord injury are many and complex. While these problems have physiological manifestations, the causes are multifactorial. One important factor in the successful management of faecal elimination is informed and responsible self management. This program aimed to maximise self determination, build collaborative relationships between specialist spinal nurses and clients with spinal cord injury throughout inpatient rehabilitation and in the community, minimise problems, reduce costs and improve quality of life.

4. Objectives

The stated objectives of this project were to seek to promote lifelong faecal continence for people with spinal cord injury by:
• Establishing a client driven bowel management program that is appropriate for the
hospital and community setting,
• Reducing the number of episodes of faecal incontinence,
• Increasing the likelihood of planned and predictable faecal elimination,
• Reducing the amount of time spent each day on the management of faecal elimination,
• Reducing the costs associated with faecal elimination,
• Reduce the incidence of inappropriate manual evacuation of faeces,
• Identifying reasons why people with spinal cord injury change their bowel management
program,
• Identifying the sources of information that people with spinal cord injury use to inform
their decision to change their bowel management program, and
• Increasing the use of specialist spinal nursing support.

5. THE RESEARCH PROCESS

Discussion of the research process covers ethical clearance, the project team, patient
education materials, staff education, data collection and data analysis. Each will be discussed
separately.

5.1 Ethical clearance

Approval to conduct the research was granted by the Royal Rehabilitation Centre Sydney
Ethics Committee. A variation in the design of the research was also approved to extend the
design of the project to include patient and nursing staff focus group discussions to evaluate
the usefulness of the patient education program. Both letters of approval are contained in
Appendix 1.

5.2 Project team

A team of experienced registered nurses undertook the project. The chief investigator is a
nurse academic who is recognised for her leadership in the development of rehabilitation
nursing scholarship in Australia, including research, publication and teaching. The remaining
three nurses are recognised for their expertise in spinal nursing. One has extensive
experience in acute and rehabilitation settings and the other two have extensive experience in
community settings. The composition of the team has made a major contribution to the
success of the project and the quality of the patient education materials produced.

5.3 Patient education materials

The intervention in this project was a three-stage patient education program, specifically
designed for patients with a neurogenic bowel following spinal cord injury. The project was
designed to further develop the patient education program already in place. One module of
the existing patient education program became stage one of this project. However, no formal
evaluation of learning tool was available for these patient education materials.

To complement the existing patient education material three algorithms have been developed
as part of this project (see Appendix 2). These algorithms relate to using a suppository, using
an enema and digital stimulation. Each patient is provided with individualised algorithm/s relevant to his/her needs.

The patient education materials for stages two and three of the patient education have been developed as part of this project. Stage two comprises an information booklet, titled *Solving Common Bowel Problems* (see Appendix 3). This booklet was developed by the project team, in consultation with nursing and medical staff from the inpatient spinal rehabilitation unit at the Royal Rehabilitation Centre Sydney as well as a representative from ParaQuad who were producing an education program for personal carers at the same time. The booklet discusses eight common problems in lay language, as well as addressing autonomic dysreflexia, a medical emergency that may be associated with bowel problems in people with spinal cord injury. To facilitate handling and access to the booklet for patients with limitations in upper limb function, the booklet has been produced as a cardboard flip chart.

Stage three of the patient education program consists of a *Train the Trainer* module (see Appendix 4). This module involves nursing staff coaching patients to become trainers of their own personal care assistants after discharge. Training guidelines have been prepared for seven personal care skills that people with spinal cord injury commonly require carers to perform.

In addition, guidelines for the evaluation of learning for each of the three stages of the patient education program have been developed to support the implementation of the program. (see Appendix 5 and the staff *Train the trainer* package in Appendix 4)

### 5.4 Staff education

Several inservice sessions about the project in general and about specific stages of the patient education program have been run for nursing staff. To support the implementation of stages two and three, a template for recording teaching and learning, that includes all topics from all three stages of the program, has been developed for use by the nurses (see Appendix 6).

A nursing staff education program relating to the management of faecal continence was run concurrently with, but separate to, this project. This aimed to raise staff knowledge and skills in the area of faecal continence, as well as sharpen staff focus on this project. This program was general and broad in focus. It essentially corresponded to stage one of the patient education program and the nurse’s role in the management of faecal continence.

Ongoing contact between the research team and the nursing staff has been facilitated by regular visits to the inpatient unit by the research assistant and holding the monthly meetings of the research team in the Spinal Unit.

### 5.5 Data collection

Three forms of data collection were used in the project. These were patient bowel diaries, post discharge follow-up interviews and focus group discussions.

#### 5.5.1 Patient bowel diary

The primary data collection tool, a patient bowel diary (see Appendix 7), was designed specifically for this project. It was designed for patients to record information about their
bowels on a daily basis both in inpatient and community settings. Patient bowel diary data collection began on 21 January 2002 and continued for the duration of the project.

5.5.2 Follow-up interviews

An interview schedule was designed and used to collect information about patient decision making after discharge (see Appendix 8). The interviews were conducted by phone at four weekly intervals when patients had returned to the community following inpatient rehabilitation. The interview schedule sought to collect information about changes in patients’ bowel management practices, why changes were made and sources of information used to make decisions. Community follow-up phone interviews were commenced in May 2002 and were conducted across the duration of the project.

5.5.3 Focus groups

Focus groups discussions were also used to collect feedback about the usefulness of the patient education program from both patients and nursing staff. Three patient and two staff focus group discussions were conducted over a four month period from September to December 2002. See Appendix 9 for details of the focus group discussion plans.

5.6 Data analysis

Data from the patients’ bowel diaries have been analysed using descriptive statistics describing the participants and calculating for the group as a whole:

- the mean frequency of planned bowel care in 24 hours,
- the mean frequency of planned bowel results in 24 hours,
- the mean frequency of unplanned bowel results in 24 hours,
- the mean frequency of manual bowel evacuations in 24 hours, and
- the mean time (in minutes) spent on bowel care in 24 hours.

Comparison between inpatient and community data for each of the means was also attempted. Each of these means was also calculated at one month intervals for three sub-groups, upper motor neurone bowels, lower motor bowels and mixed bowels, to compare trends across time since injury between groups.

Compliance with collection of data in the form of daily bowel diaries has also been calculated.

In addition, description of the categories of people who assist people with the spinal cord injury with their bowel care has been provided.

Patterns about patient decision making regarding their bowel management programs are described from the community follow-up interviews data.

Thematic analysis was performed on the data collected during the staff and patient focus group
6. FINDINGS AND DISCUSSION

In this section the findings of the study are presented. In addition, some discussion will be included.

6.1 Participants

There were two types of participants in the project, patients with spinal cord injury and their nurses.

6.1.1 Patients

Twenty-two patients were recruited to participate in the project, however, only 19 provided data. All patients had recently sustained spinal cord injuries and were participating in an inpatient rehabilitation program following hospitalisation in an acute spinal unit. On average, patients had sustained their injuries about 6 months previous to recruitment as research participants. Twelve of the 22 patients were classified as having tetraplegia and 10 with paraplegia. Eighteen of the 19, ie, 95% were male; 84.2% had an upper motor neurone bowel and 15.7% had a lower motor neurone bowel. The mean age of patients participating in the study was 38.42 years, with a range of ages from 16 to 71 years.

Only 10 of the 19 patients were discharged to the community during the study. Two of these 10 were discharged from the inpatient rehabilitation unit to other hospitals to await discharge home. Nine remained in the inpatient rehabilitation unit for the duration of their participation in the study.

Eighteen of the 19 provided data in the form of bowel diaries completed in the inpatient setting. One patient’s diary was packed on discharge and the patient does not currently have access to the diary as he is residing in another hospital awaiting return home. Only four of the 19, however, continued to provide data in the form of bowel diaries following discharge. Together, across inpatient and community settings, these 19 patients returned 82 bowel diaries containing 1691 days of data about their bowel activities. Of the 1691 days of data, 91.9% were about upper motor neurone bowels and 8.1% about lower motor neurone bowels.

Of the 19 patients, 10 have participated in follow-up phone interviews after discharge from the inpatient rehabilitation setting. All these patients were males. The number of interviews per patient ranged from one to seven. Together these ten patients completed 27 interviews.

Eight of the 19 patients also participated in focus group discussions. Seven of these were males; three had paraplegic and five tetraplegic injuries.

6.1.2 Nurses

All of the nine nurses who participated in the focus group discussions worked regularly with the patients participating in the study. Three were registered nurses and six were enrolled nurses. One enrolled nurse participated in both focus groups.

6.2 Patient bowel activity
6.2.1 **Planned and unplanned bowel activities**

The mean number of planned bowel care episodes undertaken by these patients in 24 hours was 1.13, ie, on average patients undertook planned bowel care about once a day. Most of these episodes of planned bowel care produced a bowel result. The mean number of planned bowel results in 24 hours was 0.94. The mean number of unplanned bowel results, commonly known as bowel accidents, in 24 hours was low (mean = 0.11). This is equivalent to a patient experiencing a bowel accident every nine days.

6.2.2 **Manual evacuations**

The mean number of manual evacuations in 24 hours was 0.84, ie, patients performed a manual evacuation of their bowels most days. This is line with the recommended bowel regime taught to patients and demonstrated on the algorithms (see Appendix 2). As anecdotal reports indicate the number of manual evacuations increases over time collection of more longitudinal data is required to demonstrate the maintenance of this behaviour over time.

6.2.3 **Time spent on bowel care**

On average, patients spent about 25 minutes a day attending to bowel care (mean = 23.4 minutes), with a range of 7.2 to 37.68 minutes. This time is in line with the time patients were instructed to spend on the algorithms. As the literature indicates time spent on bowel care increases over time, collection of more longitudinal data is required to demonstrate the maintenance of this behaviour over time.

6.2.4 **Comparison of patient bowel activity between inpatient and community settings**

A comparison of patients’ bowel activity in the inpatient and community settings revealed some differences. However, given the small patient numbers no conclusions can be drawn from these figures. Of the four patients who provided community data, three were classified as having upper motor neurone bowels and one as mixed. Table 1 provides a summary of the mean scores for patient bowel activity for inpatient and community data.

<table>
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<th></th>
<th>Inpatient (n=19)</th>
<th>Community (n=4)</th>
</tr>
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<tr>
<td>mean number of planned bowel care in 24 hrs</td>
<td>1.19</td>
<td>0.64</td>
</tr>
<tr>
<td>mean number of planned bowel results in 24 hrs</td>
<td>0.99</td>
<td>0.59</td>
</tr>
<tr>
<td>mean number of unplanned bowel results in 24 hrs</td>
<td>0.11</td>
<td>0.02</td>
</tr>
<tr>
<td>mean number of manual evacuations in 24 hrs</td>
<td>0.84</td>
<td>0.47</td>
</tr>
<tr>
<td>mean time (in minutes) spent on bowel care in 24 hrs</td>
<td>23.84</td>
<td>21.56</td>
</tr>
</tbody>
</table>

6.2.5 **Pattern of patient bowel activity by bowel type over time since injury**

The means for each these five aspects of patient bowel care were tracked across time since injury for each of the two types of bowel, ie, upper motor neurone and lower motor neurone.
Figures 1 – 5 depict these patterns at one month intervals since injury for the available data. While the patient numbers and available days of data were low, this analysis and these graphs demonstrate potential to track bowel activity over time, an important process in a patient population who are reported to develop significant bowel problems as time since injury increases.

Figure 1: Number of planned bowel care in the last 24 hours
Self management of faecal continence by people with spinal cord injury

Figure 2: Number of planned bowel results in the last 24 hours

Figure 3: Number of bowel accidents in the last 24 hours
Self management of faecal continence by people with spinal cord injury

Figure 4: Number of manual evacuations in the last 24 hours

Figure 5: Time spent on bowel care in the last 24 hours
6.3 People who assist with bowel care

In the inpatient setting nurses assisted patients who needed help to perform their bowel care. In the community, however, paid carers and family members provided assistance. It was hoped that information about the number of people assisting with bowel care each day would be gathered. However, some of the data provided in response to this item in the bowel diary was potentially inaccurate as in the inpatient setting, it is not uncommon for more than one nurse to assist a patient with bowel care. This does not mean that the assistance of more than one person was required, it simply means that more than one nurse may have assisted across the period of time that bowel care was provided. Consequently, no analysis of the number or cost of carers to assist with bowel care was attempted.

6.4 Patient compliance with data collection

In the inpatient setting, collection of complete bowel diary data sets was problematic. In each bowel diary a varying number of days of data was usually missing, despite frequent and regular visits by the research assistant. It was planned that patients would take responsibility for completion of the daily entries in the diary, however, this was commonly not the case. Nurses, who were originally thought to be responsible for the commencement of data collection and easing the patients into it, were also not overly enthusiastic data collectors. Nonetheless, on average 73.03% of the available days of data were collected when patients were in the inpatient setting.

Upon discharge from hospital, however, several patients (5 of the 9 patients discharged during the project) stopped providing data. Despite repeated phone follow-up and agreeing to do so, these patients did not return their bowel diaries. The four who continued to provide data were reliable with 78.12% of the available days of data collected.

Of the total number of inpatient and community patient bowel diaries returned, data was provided for 75.58% of the days. This figure does not take into account diaries from patients who stopped sending diaries but expressed a commitment to do so.

Pearson correlation was used to determine if a relationship existed between the number of days of participation in the study and compliance, defined as a percentage of days in a participant’s data collection period was provided. A correlation of −0.59 was found, indicating a moderately strong and statistically significant association between compliance and duration of involvement in the study. The negative correlation indicates that participants’ compliance reduced with increased periods of data collection. Therefore, longer periods of data collection were associated with lower compliance. Shorter periods of data collection were associated with higher compliance.

Patient participation in four weekly follow-up community interviews appears more promising than compliance with daily bowel diaries. Ten patients provided data via the follow-up phone interviews after discharge compared to four completing daily bowel diaries. These ten patients participated in a total of 27 phone interviews. Only five of the 10 patients had participated in more than one interview by the end of the study.
6.5 Decision making after discharge

Ten patients provided data through participation in follow-up phone interviews after discharge. Each interview asked about changes in patients’ bowel activities in the previous four weeks. Consequently, the twenty seven interviews asked for information about patients’ bowel activities about a period totalling 27 months.

In 10 of these 27 months patients reported changing their bowel management program. The reasons for these changes are provided in Table 2.

Table 2. Reason for changing bowel management program after discharge

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number</th>
<th>Reason</th>
<th>Number</th>
</tr>
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<tbody>
<tr>
<td>stools to fluid</td>
<td>0</td>
<td>stools too hard to pass</td>
<td>4</td>
</tr>
<tr>
<td>stools well formed but slow to pass</td>
<td>0</td>
<td>accidents or irregularity</td>
<td>0</td>
</tr>
<tr>
<td>stools too soft to pass</td>
<td>1</td>
<td>stools to high up and too soft</td>
<td>0</td>
</tr>
<tr>
<td>alternating diarrhoea and constipation</td>
<td>2</td>
<td>other</td>
<td>3</td>
</tr>
</tbody>
</table>

To make these decisions, patients reported using a number of sources of information. These sources are portrayed in Table 3. Patients predominantly relied on themselves for this information. Whether they were recalling information learned in the patient education program is uncertain. Only one patient reported using more than one source of information to make a decision. When patients were asked specifically had they referred to the problem solving booklet in the past four weeks, all patients answered “no” across the 27 interviews.

Table 3. Sources of information when changing bowel management program after discharge

<table>
<thead>
<tr>
<th>Source of information</th>
<th>Number</th>
<th>Source of information</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>specialist spinal doctor</td>
<td>2</td>
<td>friend</td>
<td>1</td>
</tr>
<tr>
<td>general practitioner</td>
<td>0</td>
<td>another persona with spinal injury</td>
<td>0</td>
</tr>
<tr>
<td>specialist spinal nurse</td>
<td>0</td>
<td>neighbour</td>
<td>0</td>
</tr>
<tr>
<td>generalist nurse</td>
<td>1</td>
<td>bowel problem solving booklet</td>
<td>11</td>
</tr>
<tr>
<td>untrained carer/home help</td>
<td>0</td>
<td>self</td>
<td>1</td>
</tr>
<tr>
<td>family member</td>
<td>1</td>
<td>other</td>
<td>1</td>
</tr>
</tbody>
</table>

6.6 Evaluation of patient education program

Eight patients participated in focus group discussions to evaluate the usefulness of the three-stages of the patient education program. There was general agreement that stage one contained a good introduction to bowel care following spinal cord injury and that the content was easy to understand. One patient thought the language was too basic. Feedback about the problem solving booklet was very positive. The content was considered informative and the language accessible. Using problems to organise the content was considered helpful. Some patients suggested including additional content about certain foods and drinks that can affect bowel patterns. The design of the booklet was also discussed with particular attention on the ease of page turning by people with upper limb limitations. Tabs as an alternative design and
various weights of cardboard were discussed but no agreement was reached. One patient suggested that if you really want to read the book you will find a way.

Some patients also commented on the *Train the trainer* module and the bowel diary. Once again feedback on the *Train the trainer* module was positive. However, the focus was on the information on the cards rather than their experience of actually training a carer, except for one patient who had used the cards while on weekend leave. Some suggestions were made about hanging the cards in the toilet and colour coding them. Comment was also made that laminating the cards was appreciated as they could be kept in the toilet and wiped clean. The bowel diaries, on the other hand, were generally not popular. Patients found completing the diaries tedious and preferred a method that was less monotonous.

Nine nursing staff also participated in focus group discussions to evaluate the usefulness of the three stages of the patient education program. Nurses reported variations amongst the patient group in their participation in the education program. No nurse reported seeing patients reading the problem solving booklet, but some noted that patients seemed to be aware of the content. Other nurses said patients do not refer to the booklet, preferring to rely on nursing staff to solve their problems. Feedback about the *Train the trainer* module confirmed the value of the content, but once again client use of this material was variable. The suggestion was made to keep a set of these cards in the toilets.

The nurses themselves found the problem solving booklet valuable and a valuable tool for not only patient education, but for the education of students and new staff. They also explained that mobility seems to be more of a priority than bowel care for these patients. A consistent theme was that while patients may be aware of bowel care they rely heavily on the nurses when they are inpatients for this aspect of their care.

### 7. Difficulties Encountered

Several difficulties were encountered during the design and implementation of the project. Each challenge and how it was addressed is discussed separately.

#### 7.1 Design of teaching materials

The design of the teaching materials for the project created some challenges for the team. Stage two was intended to comprise a number of problem solving flow charts. However, the project team found it difficult to present all the necessary information in a flow chart format that would be accessible to patients. Factors that influenced accessibility were the content, the layout and the physical design of the product. Instead, a booklet, titled *Solving common bowel problems*, was developed. Consultation about the content as well as the design and production of the booklet delayed the commencement of participant recruitment and data collection. Permission was sought, and granted, to re-distribute the project budget to cover the production costs of the booklet.

Development of resources for stage three of the patient education program, the *Train the trainer* module also required more resources than originally planned. Initially, it was envisaged that only staff coaching would be required. On further consideration, it was
decided to provide written information to the patients. The development of these resources did not exceed the budget or delay the project, but required additional input from the team.

7.2 Evaluation of the project

The design of the project was subsequently extended to incorporate evaluation of the three stages of the patient education program, particularly the teaching materials that had been produced. This required an additional submission for ethical clearance as well as additional time for the conduct, recording and analysis of focus group discussions. All this was achieved within budget, because employment of the research assistant was delayed.

7.3 Implementation of the patient education program

Implementation of the patient education program was also more challenging than originally thought. Despite involvement of the Spinal Unit nursing staff in the planning and design phases of the project, implementation of the education program was less straightforward than we had hoped. The greatest challenge was compliance with the documentation of teaching and learning evaluation. Regular visits by the research assistant as well as members of the research team appeared to make little difference. Neither did, additional staff education sessions. More success in overcoming this problem was achieved when the research team offered to design similar recording sheet for the staff to use for the other topics covered of patient education addressed on a regular basis in the unit.

7.4 Data collection

Several items in the patient bowel diary were confusing and were consequently problematic for the data analysis. The questions asking about changes in the bowel regime caused confusion in the inpatient setting where bowel program were frequently changed before the final regime was decided. Responses to these questions were not analysed. In addition, the item about the number of people assisting with bowel care was problematic in the inpatient setting where more than one nurse may be involved over the period of bowel care in any one day. This was not a problem in the community. Responses to this question was not analysed.

Overall, data collection via the patient bowel diaries was particularly challenging. Generally speaking neither nursing staff nor patients were keen on this aspect of the project. For nursing staff, the task was an extra thing to do in a busy day. Some patients were totally reliant upon nurses to complete the daily diary entry due to upper limb dysfunction. Others showed little interest in documenting the information. The team had not foreseen the extent of patient and staff non-compliance that was encountered. To overcome this problem the research assistant made frequent visits to the clinical unit spending extended periods of time developing rapport with patients and assisting with the completion of the diaries.

Patients who were keen to participate, however, always found a way to have the information recorded. One patient, who could not write suggested data entry via computer. After consideration of any ethical concerns, a form was designed and subsequently used successfully by a couple of patients.

Compliance with data recording in the bowel diaries reduced markedly after discharge. Without frequent support and reminders from the research assistant many patients did not continue data collection. Despite provision of an addressed stamped envelope, phone
reminders and patients promising to return diaries, some patients did not do so. Repeated calls to patients to improve this situation failed with some patients. The team eventually lost contact with four of the nine patients discharged from the inpatient setting. Some of these patients moved house, but others, while polite, were simply not interested. While disappointing, this is not unexpected given the scope of adjustment required following spinal cord injury.

Nonetheless, data analysis reflected a higher than anticipated level of success with patient bowel diary data collection, especially in the inpatient setting. As senior members of the inpatient nursing team have expressed an interest in continuing the project, the design of the bowel diary is currently under review with a view to collecting information that is valuable to both the nursing staff and the research.

The extent of community interview data available for collection during the period of the project has been extremely limited. The extended length of inpatient rehabilitation required following spinal cord injury meant that only nine of the nineteen patients participating in data collection were discharged to the community during the project. This has restricted the drawing of conclusions about comparison of patient behaviours between these two settings.

7.5 Number of participants

The number of participants in the project was much lower than anticipated. The original prediction was based upon historical data identifying the number of patients admitted with new spinal injuries over the previous couple of years. During the period of data collection an unusually small number of patients with new injuries were admitted. This situation was out of the control of the research team.

7.6 Employment of a suitable research assistant

Given the current nursing shortage, difficulties were experienced attracting a suitable registered nurse to fill the role of research assistant on the project. Eventually a more experienced registered nurse was employed. This was managed within budget as the position was filled later than expected. Employing a very experienced registered nurses proved invaluable in the difficult negotiations to increase patient and nursing staff engagement in the project.

8. ANALYSIS OF HOW WELL THE OBJECTIVES OF THE PROJECT WERE MET

<table>
<thead>
<tr>
<th>Objective</th>
<th>Analysis</th>
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| Establishing a client driven bowel management program that is appropriate for the hospital and community setting | • A client driven bowel management program appropriate for inpatient and community settings was achieved.  
• Several requests have been received for access to the program or separate education materials by organisations and individuals not associated with the project. |
| Reducing the number of episodes of faecal incontinence | • Anecdotal reports suggest that this objective has been met by formalisation of patient education.  
• Insufficient longitudinal data was available to confirm these reports. |
| Increasing the likelihood of planned | • Anecdotal reports suggest that this objective has been met by |
Self management of faecal continence by people with spinal cord injury

| and predictable faecal elimination | formalisation of patient education, in particular provision of the algorithm assisted in the achievement of this objective.  
| - Insufficient longitudinal data was available to confirm these reports. |
| Reducing the amount of time spent each day on the management of faecal elimination | Comparison of the findings regarding time spent on bowel care and anecdotal reports about patients not on the program indicates that this objective has probably been met.  
| - Collection of longitudinal data is required to demonstrate the maintenance of this behaviour over time. |
| Reducing the costs associated with faecal elimination | Reduction in time spent on bowel care should translate into reduced costs associated with faecal elimination.  
| - Comparison of patients who have participated in the education program with a control group would confirm this hypothesis. |
| Reduce the incidence of inappropriate manual evacuation of faeces | Anecdotal reports suggest that this objective has been met by formalisation of patient education, in particular provision of the algorithm assisted in the achievement of this objective.  
| - Insufficient longitudinal data was available to confirm these reports. |
| Identifying reasons why people with spinal cord injury change their bowel management program | This objective has been met, however, the number of patients participating in follow-up interviews was too small to draw any conclusions. |
| Identifying the sources of information that people with spinal cord injury use to inform their decision to change their bowel management program | This objective has been met, however, the number of patients participating in follow-up interviews was too small to draw any conclusions. |
| Increasing the use of specialist spinal nursing support | This objective has been met by providing access to the expertise of specialist spinal nurses through the development of a three-stage patient education program, in particular, hard copy patient education materials which can be accessed by a wider audience. |

9. Portability / Adaptability of the Patient Education Program

The three-stage patient education program was designed for delivery by registered nurses to patients participating in inpatient rehabilitation programs following spinal cord injury. Used for this purpose the program has immediate portability to other spinal rehabilitation units across Australia.

Broken down into its component parts the project has much wider portability. Several requests have been received for access to the booklet, *Solving common bowel problems*, by organisations and individuals not associated with the project. It is regarded as a valuable resource for an aspect of life following spinal cord injury that is seldom spoken about. Once feedback from the evaluation of the booklet has been considered, the booklet will be redesigned and made available to this wider audience. There may also be potential for the *Train the trainer* module to also be redesigned and made available.

These two particular modules may also have potential for adaptation for a non-spinal cord injured population faced with the challenge of managing faecal continence. The original design of the booklet, *Solving common bowel problems*, took this into account. Removal of the spinal specific sections would make the booklet relevant to any person wishing to solve common bowel problems. The *Train the trainer* module also has this potential. Nurses working in other non-spinal rehabilitation units have expressed an interest in the
redevelopment of these materials for use with other patients. Potentially there is also a large community market for these materials.

10. RECOMMENDATIONS

This small study has provided a useful beginning for further research in this area. It has produced valuable patient education resources that have potential for wide application. It has also provided helpful insights into the problems associated with education of, and collection of data from, people following catastrophic injury about a sensitive aspect of body dysfunction and personal care.

Based upon the processes and outcomes of this study, the project team makes the following recommendations:

10.1 Feedback from the evaluations of the patient education modules be used to refine the *Solving common bowel problems* booklet and the *Train the trainer* module to enable access to these resources by more people. This includes people with spinal cord injury and agencies who provide carers to perform bowel care for people with spinal cord injuries at home.

10.2 Consideration be given to adaptation of the *Solving common bowel problems* booklet and the *Train the trainer* module for a wider non-spinal cord injured audience.

10.3 The patient bowel diary be reviewed and an alternative form of data collection for inpatient and community patients be designed so further research can be undertaken using this research design.

10.4 Funds be sought to continue longitudinal data collection with the patients currently in the study and recruitment of additional patients.

10.5 Funds be sought to compare time spent on bowel care and the cost of community based assistance with bowel care for patients who have participated in the education program and patients who have not, including patients with long standing spinal cord injuries.
REFERENCES


| APPENDIX 1 | Ethics clearance |
APPENDIX 2  Algorithms (see attached)
APPENDIX 3    Solving common bowel problems booklet (see attached)
APPENDIX 4  Train the trainer module (see attached)
APPENDIX 5 Guidelines for the evaluation of patient learning
Self management of faecal continence by people with SCI

Nursing staff guidelines

Many patients in this unit will be participating in a research project that aims to better prepare them for the self management of their faecal continence. The project involves a three stage patient education program and has the support of the Medical Director, Dr James Middleton and the Nurse Unit Manager, Marc Johns. The project also has the approval of the RRCS Ethics Committee.

You have a very important role in this project. You are the patient educators.

Your role in patient education

Stage 1 patient education refers to the bowel module in the existing patient education program. We expect you are already familiar with this program as it is already in place. For this project continue to implement this module as usual and record your teaching and evaluation sessions on the teaching and learning summary in the patient’s medical record. A learning evaluation tool has been developed to help you evaluate if learning has taken place and we ask that you use this for patients participating in the research.

Stage 2 patient education involves preparing patients to solve common bowel problems. An information booklet has been prepared by the research team for the patient. Your role is to work through the booklet with the patient, discussing each problem in depth. Evaluation of patient learning will entail a quiz based on “what would you do if” type questions. Once again a learning evaluation tool is provided for use with patients participating in the study.

Stage 3 patient education takes “a train the trainer” approach, preparing the patients to become trainers of their own carers in the community. Materials have been developed to help you implement this stage of the education program. Evaluation of learning will entail the training of a new carer by the patient. It is envisaged that family, casual and agency staff could be the new carer for this exercise. A learning evaluation tool is provided for you to record patient learning in this module.

Your role in data collection

To evaluate the effectiveness of the patient education program, patients on this study will have information about their bowel care recorded every day in a patient diary. The diaries will be kept with each patient. Whilst the patient is in Moorong, nursing staff are asked to help complete the diary. The intention is for the patient to eventually take responsibility for completion of the diary. The diary should go on leave with the patient and home on discharge. A new diary will be provided every 28 days. Data collection will continue when the patient goes home.

Questions about the project can be directed to Georgia Cairns or Julie Pryor (ext 223).

RESEARCH TEAM: JULIE PRYOR (RRCS & UWS); GEORGIA CAIRNS (RRCS); WENDY JANNING (NORTHERN SYDNEY HOME NURSING); JANE TEMBLETT (PARAQUAD).
APPENDIX 6  Summary of patient teaching and evaluation of learning
## Summary of patient teaching and evaluation of learning

Stage 1 Patient education - bowel module of patient education program

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<tr>
<th>Teaching</th>
<th>Learning evaluation</th>
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</tr>
<tr>
<td><strong>Topic</strong></td>
<td><strong>Date</strong></td>
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<tr>
<td>Example</td>
<td>5.12.01</td>
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<tr>
<td>Normal anatomy &amp; physiology</td>
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<td>What does this mean now?</td>
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<td>Taking responsibility</td>
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<td>Teaching</td>
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<td><strong>Topic</strong></td>
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<td>• Diet</td>
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<td>• Fluids</td>
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<td>• Regularity</td>
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<td>• Exercise</td>
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<td>Ways you can empty your bowel</td>
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<td>Common medications</td>
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<td>Common bowel problems</td>
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<td>• Constipation</td>
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<td>• Diarrhoea</td>
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<td>• Haemorrhoids</td>
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### Teaching

<table>
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<tr>
<th>Topic</th>
<th>Date</th>
<th>Duration</th>
<th>Signature</th>
<th>Comments</th>
<th>Date</th>
<th>Outcome (satisfactory/unsatisfactory)</th>
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<tbody>
<tr>
<td>Example</td>
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<td>20 mins</td>
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<td>Understand well</td>
<td>10.1.02</td>
<td>satisfactory</td>
<td>B Nurse</td>
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<td>Stool moves to the rectum but is too soft to pass out</td>
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<td>Stool is well formed but high up and doesn't move through or seems very slow to pass</td>
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<td>Stool is too hard to pass out of the rectum</td>
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### Teaching

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<tr>
<td>Stool is too hard and too high up</td>
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<tr>
<td>Stool is too high up and soft</td>
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<td>Accidents and irregularity</td>
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<td>Alternating diarrhoea and constipation</td>
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### Learning evaluation

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Self management of faecal continence by people with spinal cord injury
Stage 3 Patient education - train the trainer

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<td><strong>Topic</strong></td>
<td><strong>Date</strong></td>
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<td>Abdominal massage</td>
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<td>Suppository</td>
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<td>Enema</td>
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<td>Manual removal</td>
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<td>Haemorrhoids</td>
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APPENDIX 7  Patient bowel diary (see attached)
APPENDIX 8 Follow-up interview schedule
Community Follow up Questionnaire

Participant Identification:

Date Interviewed:

Interview No.:

1. **What is your current bowel management program?**

2. **Has this changed in the last four weeks?**  
   Yes/No  
   (If No proceed to Q.5)

3. **What are the reasons for the change in your bowel management?**
   - Stools too fluid
   - Stools too soft to pass
   - Stools too hard and too high up
   - Accidents or irregularity
   - Other
   
   - Stools well formed but seems very slow to pass
   - Alternating diarrhoea and constipation
   - Stools too hard to pass out of rectum
   - Stools too high up and too soft

4. **What were the sources of information that influenced your decision in changing your bowel program?**
   - Specialist Spinal Doctor
   - Specialist Spinal nurse
   - Untrained carer/ Home help
   - Friend
   - Neighbour
   - Self
   - General Practitioner
   - Generalist Nurse
   - Family member
   - Another person with SCI
   - Book on solving common bowel problems
   - other

5. **Have you referred to the book on Solving Common Bowel Problems in the last four weeks?**
   - Yes
   - No  
   (If Yes proceed to Q. 6)  
   (If No terminate interview)
6. Did you find the booklet helpful? Yes/No

7. How was it helpful?

8. Is the book easy to hold, open & turn pages?
APPENDIX 9  Focus group discussion plans
Focus group discussion plans

Patient focus groups

- Patients’ perceptions of the usefulness of the first stage of the patient education program (the usefulness of the information, the ease of understanding of the content, the appropriateness of the content and the ease of handling of the booklet),
- Patients’ perceptions of the usefulness of the Solving Common Bowel Problems booklet (the usefulness of the information, the ease of understanding of the content, the appropriateness of the content and the ease of handling of the booklet), and
- Patients’ perceptions of the usefulness of the Train the Trainer module of the program (the usefulness of the information, the ease of understanding of the content, the appropriateness of the content and the ease of handling of the cards).

Nursing staff focus group

- Nurses’ observations of changes in patients’ understanding of the management of faecal continence since the implementation of the patient education program,
- Nurses’ observations of changes in patients’ behaviour relating to the self management of faecal continence since the implementation of the patient education program,
- Nurses’ perceptions of the usefulness of the first stage of the patient education program,
- Nurses’ perceptions of the usefulness of the Solving Common Bowel Problems booklet, and
- Nurses’ perceptions of the usefulness of the Train the Trainer module of the program.