Bowel Management Strategies used by Veterans with Long-standing Spinal Cord Injuries

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Purpose
To describe strategies used by veterans with spinal cord injury (SCI) to achieve control over their bowel function and fit their bowel programs into their lifestyles in the years following the initial injury.

Background
- About 270,000 Americans have spinal cord injuries (SCI) and about 15% of them are treated in Veterans Affairs (VA) hospitals.
- SCI causes loss of voluntary control over defecation.
- Loss of bowel control causes embarrassment and anxiety, and prevents people from working, leaving the house or engaging in social activities.
- Predictable defecation to prevent incontinence can be achieved by learning to stimulate defecation digitally or with irritant suppositories, and remove the feces manually.
- Since bowel function is influenced by diet and lifestyle, it continues to change after the person goes home. Unfortunately, our knowledge about SCI patients’ adaptations following discharge is insufficient to help new patients and they are forced to learn on their own.
- Few studies have examined long-term bowel management in patients with SCI and all relied on surveys to collect quantitative information about bowel function.
- Health care providers rarely solicit patients’ input or even consider their knowledge and experience when a problem arises, even though they are experts in their own self-management.

Research Questions
1. How does the SCI influence the veterans’ bowel function?
2. What are the SCI veterans using to manage bowel function?
3. How effective are the bowel management strategies?
4. How has bowel management changed over time?
5. What problems have the veterans encountered with bowel management and how have they solved them?
6. How do veterans emotionally cope with bowel problems?
7. How does bowel function influence quality of life, specifically mobility, social life and employment?

Sample Characteristics
- Males = 16; Females = 2
- Age range: 29 – 72
- Age range when SCI occurred: 21 – 64
- Range of years living with SCI: 3 – 33

Conclusions/Implications for Practice
- SCI patients are able to adapt strategies such as BM timing, food intake, digital stimulation, and laxatives to control bowel function over many years.
- People with a disability are the experts in their care.
- HCP should refer patients to SCI support groups, wheelchair sports, or encourage visits from others with SCI. Best support comes from people similar to the patient with the same disability.
- Advice for health care providers: Encourage new SCI patients to solve and see what works for them. Listen to patients, respect patients, recognize their expertise in self care and be flexible so you adapt to their needs.
- Advice for endoscopy personnel: Seek input from individuals with SCI scheduled for procedures that require bowel cleansing.

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References
- Beck T, Gomberg, R, Griffith E, et al. (2011). A standardized survey contains 32 questions from the International Spinal Cord Injury Bowel Function Basic and Extended Data Sets. Content validity was established during development and the reliability of the data sets was established in four countries (USA, Italy, United Kingdom, and Denmark).
- Interview: Major questions about bowel activity and follow up probes were developed with the help of a veteran who has had a SCI for over 45 years.
- Standardized survey: contains 32 questions from the International Spinal Cord Injury Bowel Function Basic and Extended Data Sets.
- Content validity was established during development and the reliability of the data sets was established in four countries (USA, Italy, United Kingdom, and Denmark).

Interview Questions
1. Tell me about your spinal cord injury. How does it influence your bowel function?
2. Tell me about your bowel program. What strategies do you use to manage bowel function?
3. How well is your bowel program working? Do you have any problems with constipation, diarrhea, or incontinence?
4. How have your bowel function and bowel program changed over time?
5. What problems have you encountered with bowel management and how have you solved them?
6. How did you come to terms with the loss of voluntary defecation? How do you cope with the feeling of incomplete evacuation?
7. What is the influence of your bowel function on your quality of life, specifically mobility, social life and employment?

Making Adjustments
In rehab, when they would do the suppository and come back in half an hour, I had already emptied on the bed. So, I learned to tell them right away, “You be back in less than 10 minutes as you’re the clearing out”. …I figured that out on my own.

It took about a year or so for me to get my routine down. I had a few accidents, especially that first year, but now it’s rare. It is what it is . . . Just another problem to solve.

Common Themes During Interviews
- Positive attitude
- Regular contact with others who have a SCI
- Being as active as possible
- Independence and control
- Adapting bowel program to lifestyle following discharge from rehabilitation (e.g. changed schedule, stopped using laxatives)
- No choice; had to adjust. Listening to body
- Being assured during hospitalization
- Embarrassment with incontinence of flatus and feces
- Veterans with traumatic injury adapted to their SCI and loss of bowel function
- Veterans with chronic injury did not adapt as well
- Encouragement from others

Coping
It took about a year or so for me to get my routine down. I had a few accidents, especially that first year, but now it’s rare. It is what it is . . . Just another problem to solve.

I didn’t have any choice. What are you going to do, do it at your bowels?

I have learned that the years that I still, stools and all these--one thought control, and they have to take it that patient care changes and also the guidelines. The people that are dealing with a SCI’s lifestyle better because there are other ways to take care of yourself. It’s a bit and nice.

I’ve talked to a lot of guys who don’t like to perform bowel care. But they have to try to explain to everybody that’s it’s a way of life.

Probably need a sit. And other than that, I just really don’t have our house and that way I don’t have to deal with it as much.

What problems have you encountered with bowel management and how have you solved them?

Setting & Sample
- Conducted in an outpatient setting at a VA hospital in the Southwest
- A convenience sample of 18 veterans with SCI were recruited by word of mouth and an IRB approved email from the local chapter of the Paralyzed Veterans of America.
- Inclusion criteria: cognitively intact veterans with history of SCI more than a year, could read English, and had a loss of control over defecation.

Design
Exploratory, mixed methods approach using face to face interviews and data from standardized surveys.

Human Subjects Protection
- The proposal was approved by the IRB.
- Participants received a $25 gift card.