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Bowel Control Strategies Used by Veterans With Long-Standing Spinal Cord Injuries

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Abstract

Study Purpose: The aim of the study was to describe strategies used by veterans with spinal cord injury to achieve control over bowel function and fit their bowel programs into their lifestyles in the years following the initial injury.
Methods/Design: Using a qualitative descriptive design, 18 outpatient veterans with spinal cord injuries were interviewed at a Veteran's Administration hospital. Recorded interviews were transcribed verbatim and analyzed to determine major themes.
Findings/Conclusions: Fourteen of 18 participants had gained control over bowel function and led active lives. They emphasized the importance of positive attitudes, listening to their bodies, being physically active, taking charge, and using trial and error to find the best bowel control strategies. Findings also highlighted the value of peer support and the problem of military service connected back injury leading to spinal cord injury.
Clinical Relevance: Participants provided practical advice for adapting strategies learned during rehabilitation for long-term bowel control after discharge home.

Keywords: Spinal cord injury; bowel management; military veterans; chronic back injuries; rehabilitation; peer support; coping strategies; independence; physical activity; bowel training; adjustment following discharge.

Loss of bowel control is one of the most devastating effects of spinal cord injury (SCI), because it causes embarrassment, shame, and anxiety and prevents people from leaving home, working, and engaging in social activities (Burns, St-Germain, Connolly, Delparte, & Guindon, 2015). Fortunately, SCI patients can achieve predictable defecation and prevent incontinence despite the loss of voluntary control (Adriaansen, van Asbeck, van Kuppevelt, Snoek, & Post, 2015). Rather than feeling the natural urge and finding a suitable place for defecation, they first find a suitable place and then initiate the defecation reflex with digital stimulation, suppositories, or enemas. They learn to use diet, fluids, and laxatives to keep stools soft and remove feces manually if necessary (Coggrave, Norton, & Cody, 2014).

Bowel management begins during hospitalization and rehabilitation but is refined after discharge home. People with SCI must learn to (a) incorporate their bowel programs into their lifestyles so they can maintain relationships and leave home without fear of incontinence, (b) manage diet and laxatives so that feces is the ideal consistency for continence, and (c) prevent diarrhea and constipation (Preziosi & Emmanuel, 2009). Unfortunately, our knowledge of 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 people with SCI, and most relied on surveys to collect information (Forchheimer et al., 2016; Kim, Koh, Leigh, & Shin, 2012). Surveys provide useful quantitative data but are influenced by the prejudgments of the survey developer and do not solicit the qualitative data needed to discover new interventions. In contrast, interviewing people who have been managing their own bowels and who are experienced in self-management could provide detailed information about long-term bowel management and useful advice for those

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with recent SCIs. Therefore, this study's purpose was to describe strategies used by veterans with SCI to achieve control over bowel function and fit their bowel programs into their lifestyles in the years following the initial injury.

Methods

A qualitative descriptive design was used to collect data by interviewing veterans with SCIs in order to learn how they manage bowel function. The study was approved by the Veterans Affairs (VA) Medical Center and university institutional review boards.

Setting and Sample

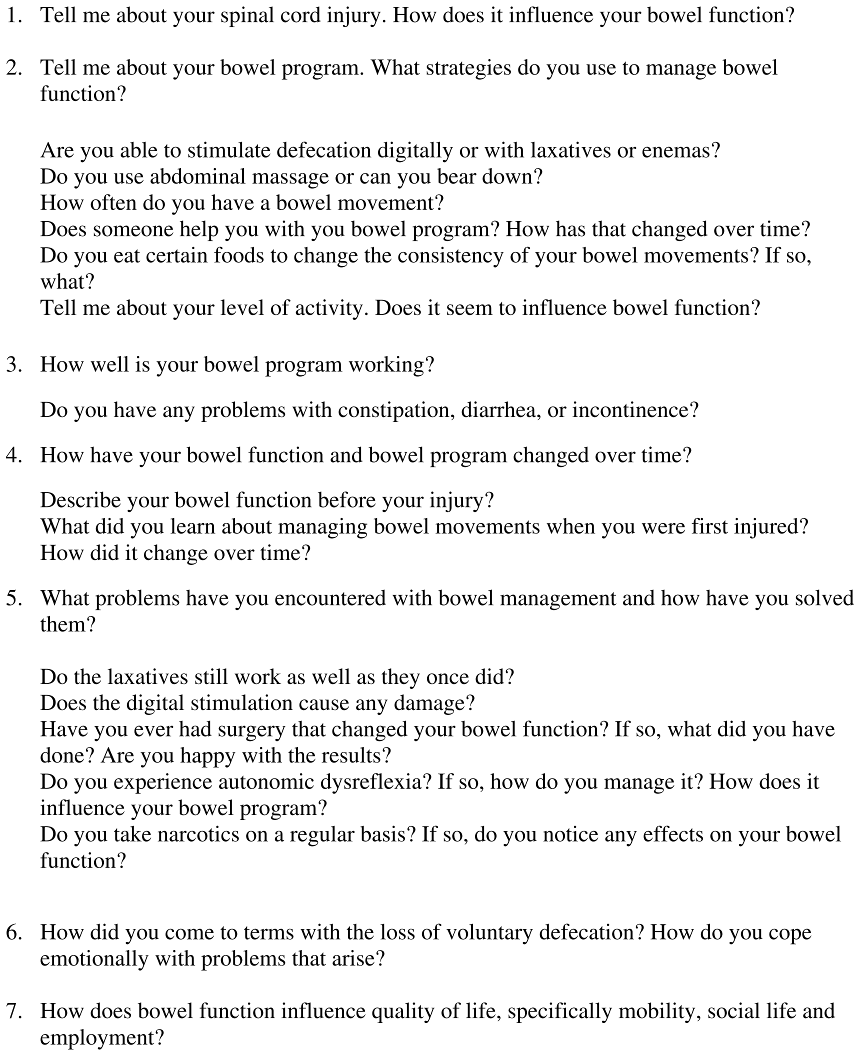
The setting was a regional SCI center at a VA Medical Center in a large metropolitan area, readily accessible by automobile and train. The SCI center provides comprehensive services to veterans in the surrounding area and includes an Internet cafe where outpatient veterans with SCIs gather for conversation, games, coffee, etc.

Nineteen outpatient veterans with SCI were recruited by word of mouth and e-mails sent by the local Paralyzed Veterans of America (PVA) chapter. Inclusion criteria included cognitively intact veterans over 18 years old with an SCI that influenced bowel function and occurred at least a year earlier. No interview data were available for one person because of an audio recorder malfunction; therefore, the final sample consisted of 18 individuals.

Data Collection Instruments

Data collection instruments included an interview guide and a demographic questionnaire.

Interview guide. The interview guide contained seven broad, open-ended questions with follow-up questions for each one (Figure 1). The researchers developed the questions with the help of a veteran who sustained a



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?

   Are you able to stimulate defecation digitally or with laxatives or enemas?
   Do you use abdominal massage or can you bear down?
   How often do you have a bowel movement?
   Does someone help you with you bowel program? How has that changed over time?
   Do you eat certain foods to change the consistency of your bowel movements? If so, what?
   Tell me about your level of activity. Does it seem to influence 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?

   Describe your bowel function before your injury?
   What did you learn about managing bowel movements when you were first injured?
   How did it change over time?

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

   Do the laxatives still work as well as they once did?
   Does the digital stimulation cause any damage?
   Have you ever had surgery that changed your bowel function? If so, what did you have done? Are you happy with the results?
   Do you experience autonomic dysreflexia? If so, how do you manage it? How does it influence your bowel program?
   Do you take narcotics on a regular basis? If so, do you notice any effects on your bowel function?

6. How did you come to terms with the loss of voluntary defecation? How do you cope emotionally with problems that arise?

7. How does bowel function influence quality of life, specifically mobility, social life and employment?

Figure 1. Interview schedule: Major questions about bowel activity and follow-up questions.

cervical SCI 40 years ago while on active duty and had successfully managed his bowel function over time. A second veteran with a cervical SCI reviewed the questions and verified that they were pertinent and readily understandable. The questions were designed to collect information about the SCI's effect on bowel function, the veterans' strategies for managing bowel activity over time, factors that influence bowel function (e.g., diet, physical activity), coping strategies, and the effects of bowel function on lifestyle.

Demographic questionnaire. The demographic questionnaire contained objective questions designed to describe the characteristics of the sample (e.g., gender, age, race, age at time of injury, years since injury, bowel movement frequency, method used to stimulate defecation, reported quality of life). The questions were taken from the International SCI Bowel Function Basic and Extended Data Sets that were developed by the American Spinal Injury Association and the International Spinal Cord Society (Juul et al., 2011).

Data Collection Procedure

One researcher, who is a veteran, collected all data. She developed rapport with the participants during the process of recruiting them for the study and answering all their questions. After obtaining informed consent, she conducted the interview using the questions in Figure 1 and used communication techniques such as nodding, silence, clarification, and reflection to encourage the veterans to elaborate. Participants then completed the questionnaire and received a $25 gift card to compensate them for their time. The entire meeting lasted approximately an hour. Later, the interviewer transcribed the interviews verbatim using voice recognition technology (DragonSpeak), and a second researcher verified each transcription's accuracy by reading the transcript while listening to the audio recording.

Data Analysis

All the participants' original responses were combined under each interview question. Interview data also underwent content analysis in order to identify underlying themes. To remove individual researcher bias, the three researchers independently reviewed the written transcripts, identified themes, and then met over several months to discuss the themes and reach a consensus. To verify that the identified themes fit the data, the researchers returned to the transcripts to identify representative quotations that fit each theme. Questionnaire data were analyzed using descriptive statistics.

Results

The sample consisted of 16 male and 2 female veterans whose SCI occurred 3–40 years earlier and resulted in changes in bowel function. Two distinct groups were identified. Individuals in Group 1 (*n* = 14) had an acute injury with immediate SCI, whereas those in Group 2 (*n* = 4) had back injuries that later progressed to SCI. Because the SCI etiology, resulting bowel function, and coping were quite different for the two groups, they will be discussed separately.

Group 1: Veterans With Acute Injury With Immediate SCI

Of the 12 men and 2 women in Group 1, six had cervical injuries (all incomplete), seven had thoracic injuries, and one had a lumbar injury. None of the injuries occurred during combat. All 14 participants were in wheelchairs. Eleven were Caucasian, and three were African American. Eleven of the 14 injuries occurred over 10 years ago, and half of the group were under 30 years old when injured (Table 1). One man was paralyzed following a

Table 1 Age at time of injury, years since injury, and cause of injury (frequencies)

	Group 1: Acute Spinal Cord Injury (*n* = 14)	Group 2: Chronic Back Injury Progressing to Spinal Cord Injury (*n* = 4)
Age at time of injury (years)		
21–29	7	1
30–39	1	2
40–49	2	0
50–59	2	1
60–69	2	0
Years since injury		
3–5	3	2
6–10	1	2[a]
11–15	2	0
16–20	1	0
21–25	1	0
26–30	1	0
31–35	4	0
36–40	1	0
Cause of injury		
Trauma (3 sports injuries, 6 car accidents, 1 motorcycle accident, 2 work related)	12	0
Acute infection	2	0
Chronic spine injury that deteriorated over time	0	4

[a] During the interview, one man described his initial back injury occurring 30 years earlier but, on the questionnaire, put the response of 7 years because that is when he first experienced symptoms of spinal cord injury.

work accident but regained sensation and movement on one side and voluntary control of defecation. Two people eventually had colostomies, one due to the inability to gain control with laxatives and digital stimulation and the other because of a pressure ulcer.

The other 11 had neurogenic bowels, learned bowel control strategies in a rehabilitation facility, and adjusted them after returning home. They maintained predictable defecation using conservative measures, namely, digital stimulation (n = 4), digital evacuation (n = 3), mini enema (n = 1), suppository (n = 1), suppository plus digital stimulation (n = 1), and mini enema plus occasional digital stimulation (n = 1). Eight conducted their bowel program in the morning and three in the evening, and no one switched back and forth between the two. All but four conducted their bowel program independently. Those four had physical limitations (e.g., injured or short upper extremities) and relied on a spouse (n = 3) or a healthcare provider (n = 1) for help. Of the 12 participants who did not have colostomies, 11 defecated while sitting on a commode or shower chair and 1 defecated while in bed.

After the initial adjustment period, all 14 veterans learned to manage bowel function well. Twelve either never or rarely experienced constipation, one was occasionally constipated, and one attributed recent constipation to a new medicine for bladder spasms. Although five people reported having autonomic dysreflexia at least once, no one experienced it during digital stimulation, enemas, or manual evacuation, and only one man had it from a bowel related problem—constipation. Stimulation methods (e.g., digital stimulation, laxatives, enemas) remained effective over time. Everyone in Group 1 led active lives; five were employed or in school, and five worked as volunteers. With regard to the effects of bowel dysfunction on quality of life, one person reported that it had a major impact, four reported some impact, seven reported little impact, and two reported no impact.

Group 2: Veterans With Chronic Back Injury That Progressed to SCI

Group 2 was composed of one Native American and three African American men, ranging in age from 29 to 62, all with back injuries that eventually caused SCI (Table 1). Two men suffered repeated back strain and injury as soldiers that progressed to degenerative arthritis of the cervical spine and pressure on the spinal cord over 30 years later, one man had repeated back injuries and surgical complications with damage at the thoracic, lumbar, and sacral spine resulting in decreased sensation and loss of proprioception in his legs, and one man had partial paralysis from herniated lumbar and sacral discs. One of the men walked independently, two walked a little but mainly used wheelchairs, and one was completely wheelchair bound.

Although one man had been in a helicopter crash and another had been in a car accident, all four men attributed their back injuries to the rigors of life as a soldier (e.g., wearing body armor, carrying heavy backpacks). One veteran had no voluntary bowel control and relied on laxatives, enemas, and digital stimulation to empty his bowels. The other three had some control. One of them found that coffee was an adequate defecation stimulus but used stool softeners occasionally. A second man used only dietary fiber. The third man fasted to prevent incontinence when he had to leave home and only defecated on weekends when he could take laxatives and stay close to the toilet.

Two men expressed feelings of hopelessness: one said he stayed home 99% of the time, could not control his bowels, and basically "didn't have a life," and the other remained home "90% of the time" and said "there was no way to deal with it". Both men's neurological status was still changing, they denied knowing anyone else with an SCI, and their only social supports were family members. The other two veterans were able to control bowel function and leave home, interacted with other veterans with SCI at the VA facility, and participated in sports. Of the four men in Group 2, three reported that bowel dysfunction had a major impact on their quality of life and one reported that it had some impact.

Themes From Interview Data and Resulting Recommendations for People With a Recent SCI

Fourteen people (13 from Group 1 and 1 from Group 2) had adapted to changes in bowel function and were eager to describe their experiences in the hope that they would help others with SCI. They were enthusiastic, positive, and led full and active lives. Of the remaining four, one man in Group 1 had almost normal bowel function and three men in Group 2 were still learning to cope with bowel changes and had not achieved bowel control. Several themes emerged from analysis of the interview data including (1) initial difficulty adjusting; (2) choosing an attitude for action; (3) using trial and error to discover what worked best; (4) paying attention to body signals, responses, and patterns; (5) desiring independence; (6) being as active as possible; and (7) valuing help from others. The following sections describe the interview data that support each of the seven themes.

Initial difficulty adjusting. Loss of control over defecation was "pretty hard" to deal with in the beginning. One man explained why he thought it was difficult:

Quality-of-life is driven by what society thinks is okay, so if we grow up in a society where it's okay to…have a little bowel movement in your pants, then everything would be fine. But if you grow up in a society where…the person that smells a little bit bad that day…is ostracized…If you've got a spinal cord injury and you have always been a reasonably clean person, when your lifestyle changes and someone else has to do it for you or you can't quite get it all done yourself, then it's a major issue.

The initial disgust changed over time, as one man explained: "It was kind of humiliating and disgusting, but you finally learn to just deal with it…it's second nature now". Another had similar feelings: "I wore two or three different gloves on top of each other. Over time, I was down to a single glove. So it was not so scary, not so icky."

Choosing an attitude for action. Participants explained how their attitudes helped them overcome the initial emotional shock and take action to gain control over their bowels and be as independent as possible. The veterans adjusted their attitudes by (1) recognizing that they had no choice, (2) putting bowel changes in perspective, and (3) focusing on the solution. Lack of choice was expressed as "I didn't have a choice," "it is what it is," "just part of life so deal with it," and "just something that had to be done." One man explained: "At first, I didn't want to do it. I told people I wasn't going to stick my hand there and I wasn't going to do it, but then you learn real quick that if you don't, you are going to get sick or you're going to have issues."

Putting the bowel change in perspective diminished its emotional impact. A veteran whose initial injuries were life threatening explained: "I look at it this way. I'm still alive because I flat-lined a couple of times when I was originally injured so I just look at each day as another day that I get to do something that I enjoy." Others realized that things could be worse: "You learn how to live and function with what you've got. I always say that there's always people who are worse off than you are. I thank God for what I can do and keep on moving." Some focused on solutions: "Instead of saying I'm going to be angry about this, I just said, how is the best way to fix this? How can I get this under control?" and "It's about asking the right question and the question is: How can I overcome this, not why is this happening?"

Attitude helped veterans cope with occasional incontinence in the years following the SCI. They learned to take it in stride, even if society had difficulty dealing with it. One participant said: "You can't ever control what people do or what people say, but you can control your reaction to it. That's what I live by." Another veteran commented: "I don't get embarrassed as much anymore. You know it's like, hey, I'm sorry but let's go on." The veterans found that it was best to not admit to incontinence openly, but just leave immediately and take care of it.

Some of the veterans wore pads in case of incontinence even though they initially disliked the idea: "I don't think that my worth right now is dictated by whether or not I have a pad on in my pants. Initially, I might have thought so, but right now my mindset is that I'm not a lesser man…I'm still a man. I just have to wear a pad. So it's about understanding and accepting what is, and some people have a harder time accepting what is."

Using trial and error to discover what worked best. The participants described how they adapted the bowel care techniques learned in rehabilitation to their home environment in order to achieve predictable defecation that fit their lifestyles. They tried different strategies and paid attention to their bodies' responses in order to find the most effective methods for them. For example, everyone followed a consistent defecation schedule but used trial and error to find the best frequency and time of day. One man initially learned to perform his bowel care every 2 days, but when he got home: "I started doing bowel care every day…It takes a little bit more time in getting ready daily but I don't have any accidents." A second man changed his program from evenings to mornings after he got home: "It was not a good thing to do the bowel program at night because I often had accidents the next morning. I began doing my bowel program first thing in the morning and…[now] I typically don't have any bowel issues." The veterans also found the most convenient time for their lifestyles. As one veteran explained, "I'm not a real good morning person so it's easier to do it in the evening. That way, I don't have to get up in the morning and do the bowel care and all that other stuff."

The veterans experimented with laxative doses. For example, one man said: "The first two months, we had to adjust the schedule of the senna and the docusate to try to get me stabilized. And since then, it's been very, very regular." A second man had used suppositories and digital stimulation while in rehabilitation, but they started irritating his hemorrhoids. He discovered that a mini enema was nonirritating and just as effective. The trial and error process could take time: "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…My body figured it out finally."

Paying attention to body signals, responses, and patterns. The veterans learned to pay attention and listen to their bodies. The old urge might be gone, but some noticed new body signals. As one veteran said: "my body had to find new ways to let me know that I've got a problem." For example, one man felt back pressure and another man experienced "sweats or goosebumps" when their rectums were full. A third man explained how severe leg spasms warned him of impending diarrhea: "I feel a chill in my back and my legs will tighten up. Once I get that, I have maybe one minute to get on the toilet."

The veterans paid attention to the effects of food on their bowels. One woman started a vegetarian diet to improve her health and lose weight but found that the extra beans, fruits, and vegetables also decreased her need for stool softeners. Others found that dairy products and greasy foods tended to cause diarrhea. Most of the subjects noted the relationship between eating and defecation. Two said that they fasted or at least decreased food intake when they traveled in order to decrease the risk of incontinence.

The veterans noticed that defecation was usually regular, but occasional irregularities occurred. One man described his experience: "I usually have the same amount every day but sometimes I may go two or three days without a movement. And that's usually when I get scared that I'm going to have a bowel movement before the next morning." A second man had a similar experience: "If I have a large bowel movement…like if I eat greasy foods, I clear myself out. I may go a day or two with nothing and then usually I can get it back to normal."

Desiring independence. The veterans described how the desire for independence drove them to take control of bowel care. As one man explained, "I was the typical spinal cord patient who refused to accept the fact that he had to do his own bowel and bladder care…but you learn in a hurry that if you want to be independent, you have to do it." Another veteran agreed: "You need to do as much as you can for yourself because when you have that independence, and you have that confidence, there's nothing you can't do…I don't have to worry because I don't have to depend on anybody else to get it done. Totally independent!"

Becoming independent required a willingness to take risks and trust themselves rather than strictly follow rehabilitation protocols. One man immediately took control: "They…had me on stool softeners and laxatives and it was a pretty messy situation…When I left rehab, I was given the advice to continue taking stool softeners, and I just didn't do it." In contrast, another man was afraid to stop the laxatives after he got home despite terrible diarrhea and only did so out of desperation: "We were scared to change, were afraid I'd get constipated because they taught us that constipation is pretty bad. Over time, I felt like having diarrhea every day and taking that [laxative] was just not the kind of life…I wanted....We needed to do something." He gradually stopped taking laxatives, never had constipation, and discovered that daily digital stimulation was all he needed for normal bowel function. He had this advice for others: "You need to experiment… Be willing to take chances".

The veterans also exerted their independence by thinking things through and planning ahead, as one man described: "If I'm going to fly…I pretty much work on having my bowel completely empty before I leave because there's really no getting to the little restrooms on the airplanes…I try to think my way through things."

It took time for the veterans to realize that they were the experts in their own care. Then they were ready to take charge, even when interacting with healthcare providers. A veteran described his experience in a hospital several years after his SCI: "The staff will come in and say we're going to do bowel care every two days. No you're not. You're going to do it every night because that's what I do at home. I want to keep on schedule as close as possible…it makes my life easier."

Being as active as possible. The 14 who were adapting well valued exercise and participated in a variety of activities, including sports, jobs, volunteer work, household chores, shopping, physical and occupational therapy, and competitive games with other veterans in wheelchairs. All 14 recited a list of activities, and 9 of the 14 considered themselves very active. Most of them used a manual chair: "I try to stay active and be involved and that's why, even at my age, I still use a manual chair." Another person described exercising in an electric chair: "A lot of people say that you cannot exercise in an electric chair, but there are ways you can do it. Like when I'm rolling with my dogs, and I hit a hill, I'll do a slalom like a skier does. My body is going from side to side so I am building up my core and stimulating the bowel."

The participants described various forms of physical exercise. A man with paraplegia said: "I ride the [hand propelled] bike about three or four times a week. It's out on the road. I ride a minimum of 15 miles and I like to average about 25 each time." Two men with paraplegia had enough upper body strength to swim. Some of the men participate in national veteran wheelchair games which provide both social and physical activity.

Valuing help from others. The veterans discussed the importance of emotional and social support from family, healthcare providers, and others with SCI. For example, one man described his relationship with his wife: "My wife and I have been married 43 years this year…we are very close and very open, and talk about everything… and she has been my absolute angel to take care of me. I know that there have been some people that we know whose wives could not handle it and left which is a tragedy”. Another man credited his wife with helping him cope: “What made me go ahead and accept [the SCI] was my wife. I was in a wheelchair, and she made a joke out of it…She said you can’t run from me now.” One of the veterans was grateful for a supportive healthcare team: “If you have a good medical team that’s able to work with you and are listening to you, then you don’t have much of a problem.” His doctor gave him the confidence to try different things until he found the strategies that worked for him.

Veterans described their interactions with others with SCIs in such activities as wheelchair sports and games, PVA membership, peer support programs, and socializing in the Internet café. These interactions provided camaraderie, hope, and practical advice. One man liked the Internet cafe because: “It’s good being around other people in a wheelchair who kind of get what’s going on.” Another described how being “around a bunch of guys” on a wheelchair sports team let him discuss bowel issues freely. A third man explained how peer mentors helped the newly injured know what to expect and gave them hope for the future “because it’s a scary thing when you first get hurt - because of the unknown.”

A man with a cervical injury described how the PVA and others helped him become independent. After his injury, he felt like he was “locked in a prison” in his own body. Then, members of the PVA came to see him and gave him a track chair. “They showed me a videotape of people playing basketball, pushing track, swimming, weightlifting, table tennis all from chairs. Showed me quads and paras.” He was so weak when he first started using the track chair that he’d go only a short distance and pass out, but his family, the PVA, and the physical and occupational therapists just kept encouraging him. “Come on, let’s go, let’s go, let’s go…each day, they would get me back in it, and push some more. You push some more until you build up your tolerance. You build up your confidence. When your confidence level builds, you want to try more things.”

Recommendations Based on the Interview Data Analysis

Analysis and synthesis of interview data resulted in the following recommendations for people with a new SCI. (Figure 2 lists the seven themes, representative quotations, and recommendations that stemmed from each theme.)

1. Recognize that it is normal to feel sad, overwhelmed, and disgusted in the beginning.
2. Develop an attitude for action.
3. Experiment until you find the defecation schedule that maintains continence and matches your lifestyle. Then follow the schedule consistently.
4. Try different things to see what works for you. If you take laxatives, titrate them to find the dose that produces the best stool consistency and frequency. Pay attention to the

Theme	Representative Quotation	Recommendations
Initial difficulty adjusting	*You just get sick and tired . . . of doing the bowel program.*	1. Recognize that it is normal to feel sad, overwhelmed, and disgusted in the beginning.
Choosing an attitude for action	*It was a slow dawning that this was the way life was going to be. You do what you’ve got to do.*	2. Develop an attitude for action.
Using trial and error to discover what works best	*I would play around and experiment and try new things.*	3. Experiment until you find the defecation schedule that maintains continence and matches your lifestyle. 4. Don’t be afraid to try different things (e.g. laxative doses) to see what works for you.
Paying attention to body signals, responses, and patterns	*I stay away from really greasy food because it creates a runny stool . . . And you don’t have control of it.*	5. Pay attention to your body which may give you new signals. Watch for patterns.
Desiring independence	*Over time, I learned how to do it myself.* *My mind is constantly moving to find ways to do things.*	6. Find ways to take charge of your life and become as independent as you can. 7. Have a plan for managing potential incontinence.
Being as active as possible	*The more you stay active, the more you’ll fire those muscles that normally wouldn’t be used. They become stronger.*	8. Be as physically active as you can and continually find ways to increase your activity.
Valuing help from others including those with SCI	*They [peers] showed me that I could get up and do if I just worked hard enough and tried hard enough.*	9. Be open to help from others. Find opportunities to be with people with SCI

Figure 2. Themes, representative quotations, and resulting recommendations for people with new spinal cord injury.

relationship between laxative ingestion time and the resulting defecation time.

5. Pay attention to your body, which may give you new signals that warn you about impending defecation, constipation, or diarrhea. For example, some people experience chills, sweats, or goosebumps. Watch for patterns. What foods tend to make your stools loose? Which ones are more constipating?
6. Find ways to take charge of your life and become as independent as you can.
7. Have a plan for managing potential incontinence episodes. Wear pads or briefs for added security. If you experience incontinence, don't say anything about it, just leave and take care of it.
8. Be as physically active as you can and continually find ways to increase your activity.
9. Be open to receive help from others. Find opportunities to be with people with SCI for social and emotional support, camaraderie, and advice for living with an SCI.

Advice for Healthcare Providers

The interview data also led to recommendations for healthcare providers:

1. Be sensitive to the patient's embarrassment when incontinent and provide privacy for defecation.
2. Recognize that bowel control is vital for a good quality of life and make bowel training a priority.
3. Encourage patients to (a) think things through, plan ahead, and experiment to find what works best for them; (b) pay attention to body signals and the effects of food, activity, etc., on their bodies; and (c) interact with others with SCI. Reassure them that independence with bowel function may improve over time especially as activity increases.
4. Institute programs to facilitate interactions among people with SCIs such as those proven successful with veterans: (1) peer mentoring programs for newly injured patients, (2) designated gathering places for people in wheelchairs to socialize on a regular basis, and (3) sports and other recreational activities designed for people in wheelchairs.
5. Recognize that people with long-term SCI are experts in their own care and ask how they would like hospital or clinical routines adapted to their needs.

Discussion

The study identified several factors that helped participants regain control of bowel function and lead active lives following SCI: a positive attitude, using trial and error to discover what works best for them, paying attention to their bodies, striving for independence, being physically active, and valuing help from others, especially peers with SCIs. Munce et al. (2014) discovered similar strategies for success following SCI: a positive outlook, emotional support from caregivers, peer support and feedback, taking control of care, and independence. People who believe they have control over problems are more likely to manage their care, but it takes knowledge, time, and encouragement from others to get to this point.

Peer Support From Others With SCI

The first year home is especially difficult for those with a new SCI because they need to emotionally come to terms with their disability, adjust to their new bodies, and discover how to live life with a disability (Dickson, Ward, O'Brien, Allan, & O'Carroll, 2011; Munce et al., 2014). The camaraderie they experienced during rehabilitation is lost after discharge, and the individual feels isolated and alone. However, when individuals have opportunities to interact with peers, including those who have learned to live with an SCI, they learn what is possible, what is expected, and how to gauge their own progress. They receive practical, credible advice for success and a sense of belonging, which in turn builds confidence, independence, and comfort with their altered bodies (Bourke, Hay-Smith, Snell, & DeJong, 2015). The person who projects confidence is more likely to be accepted and successful in the larger society. Success, involvement with others, and feeling valued, accepted, and in charge of one's life lead to a higher quality of life (Ljungberg, Kroll, Libin, & Gordon, 2011).

The veterans in our study had many opportunities to socialize with their peers. Healthcare services for inpatients and outpatients were in close proximity, which facilitated interactions between the two groups. Veterans with long-standing SCIs visited veterans in the in-patient unit to give hope and advice. The facility had an Internet cafe, which was staffed by volunteers with SCIs who were willing mentors and who provided an environment of conviviality, camaraderie, and fun. The VA system encourages veterans with SCIs to participate in sports and sponsors national wheelchair games designed to improve physical function, confidence, and independence in the company of their peers (Lundberg, Bennett, & Smith, 2011).

Chronic Back Injuries Progressing to SCI

Finding subjects who suffered SCI from chronic back problems was unexpected. Although the researchers found no studies of SCI as a complication of chronic back injury, the high incidence of back injury among military members resulting in medical discharge is well documented (Malish, Arnett, & Place, 2014; Roy, Lopez, & Piva, 2013; Schoenfeld, 2011). Back injury is especially common among infantry in combat areas, where soldiers wear body armor weighing 30–35 pounds in addition to back packs, weapons, and other gear. Infantrymen frequently carry more than 50 pounds and occasionally lift more than 100 pounds. The overall weight and time spent carrying it, together with uneven terrain, contribute to the likelihood of back injury and lead to degenerative changes to the vertebral discs.

Back injuries have a worse prognosis than other musculoskeletal injuries. Malish et al. (2014) tracked the progress of 2,490 soldiers who could not return to duty because of medical problems over the course of a year and found that 437 (17.6 %) had low back injuries. Low back injury accounted for 26.7% of the medical discharges. Chronic neck and back injuries (e.g., herniated discs, cauda equina syndrome, spinal stenosis due to disc degeneration) are potential but rare causes of SCI (Kavanagh & Walker, 2013; Nouri, Tetreault, Singh, Kardimas, & Fehlings, 2015). Although only a small percentage of chronic back and neck injuries progress to SCI, a significant increase in back injuries could lead to a significant increase in the number of cases of SCI. Certainly preventing both back injuries and their progression to SCI needs further attention.

Limitations of the Study

Limitations of the study include (1) a small sample limited to military veterans and (2) lack of control over intervening factors which could influence bowel function (e.g., quality of rehabilitation, individual personalities). As veterans, the participants may have received services not available to the general public (e.g., financial help, healthcare services, adaptive equipment), which may have influenced their ability to adapt to the loss of bowel control. Seven participants had cervical injuries, some as high as C-5, but all of the cervical injuries were incomplete. People with higher injuries or complete cervical injuries might not have achieved such a high level of bowel function control.

Recruitment was directed toward veterans who were coping successfully with their SCI bowel program and had advice to share, so naturally most of the samples were healthy, active people with good control of bowel function and were not meant to be reflective of the entire SCI population. The sample was limited geographically so veterans could come to one SCI facility for the interviews. The study was also limited by reliance on participants' honesty and memories and the lack of objective measures of bowel function.

Credibility of the findings was enhanced by veteran involvement when developing interview questions and planning the study; participants' openness, frankness, and eagerness to share their experiences; and the consistency of having one individual conduct all interviews. Researcher bias was reduced by independent review of transcripts, discussions to reach agreement about identified themes and recommendations, and a return to the data to gather representative quotations and ensure that the identified themes and recommendations were grounded in the data.

Key Practice Points

- Bowel control is vital for a good quality of life; therefore bowel training must be a priority following spinal cord injury.
- People with spinal cord injury are able to maintain long term control over defecation and achieve a good quality of life, especially if they have a positive, can-do attitude, and strong physical and social supports.
- People who have experienced a spinal cord injury should be encouraged to experiment with their bowel programs and pay attention to the results in order to discover what works best for them.
- Social interactions with others with SCI (including participation in sports) helps the more recently injured individual develop confidence, achieve independence and have a good quality of life.
- Healthcare providers should view people who have lived with a spinal cord injury for years as experts in their own care.

Summary

Two distinct groups of veterans with SCI were identified. One group initially had an acute SCI, and the second group initially had a back injury, which eventually progressed to SCI. Fourteen of the 18 participants had gained control over bowel function and had a good quality of life. Overall, they valued physical activity and independence and appreciated support from others with SCI, their families, and healthcare providers. The veterans were eager to give advice to those with new SCI injuries and to the healthcare providers who care for them. They recommended that the people with SCI try to have a positive attitude, listen to their bodies, use trial and error to find what works best for them, be as active as possible, take charge of their bowel programs, be open to receive help from others, and find opportunities to be with peers with SCI. The study results also highlighted the importance of interacting with peers who have SCI and the issue of chronic back injury in the military that can potentially advance to SCI.

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