



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)¹ and about 15% of them are treated in Veterans Affairs (VA) hospitals².
- SCI causes loss of voluntary control over defecation^{3,4}.
- 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^{3,5}.
- 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.⁶

Research Questions

- How does the SCI influence the veterans' bowel function?
- What strategies are the SCI veterans using to manage bowel function?
- How effective are the bowel management strategies?
- How has bowel management changed over time?
- What problems have the veterans encountered with bowel management and how have they solved them?
- How do veterans emotionally cope with bowel problems?
- How does bowel function influence quality of life, specifically mobility, social life and employment?

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

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.

Measurements

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 40 years.

Standardized survey: contains 32 questions from the International Spinal Cord Injury Bowel Function Basic and Extended Data Sets⁷. 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

- Tell me about your spinal cord injury. How does it influence your bowel function?
- Tell me about your bowel program. What strategies do you use to manage bowel function?
- How well is your bowel program working? Do you have any problems with constipation, diarrhea, or incontinence?
- How have your bowel function and bowel program changed over time?
- What problems have you encountered with bowel management and how have you solved them?
- How did you come to terms with the loss of voluntary defecation? How do you cope emotionally with problems that arise?
- How does bowel function influence quality of life, specifically mobility, social life and employment?

Data Collection

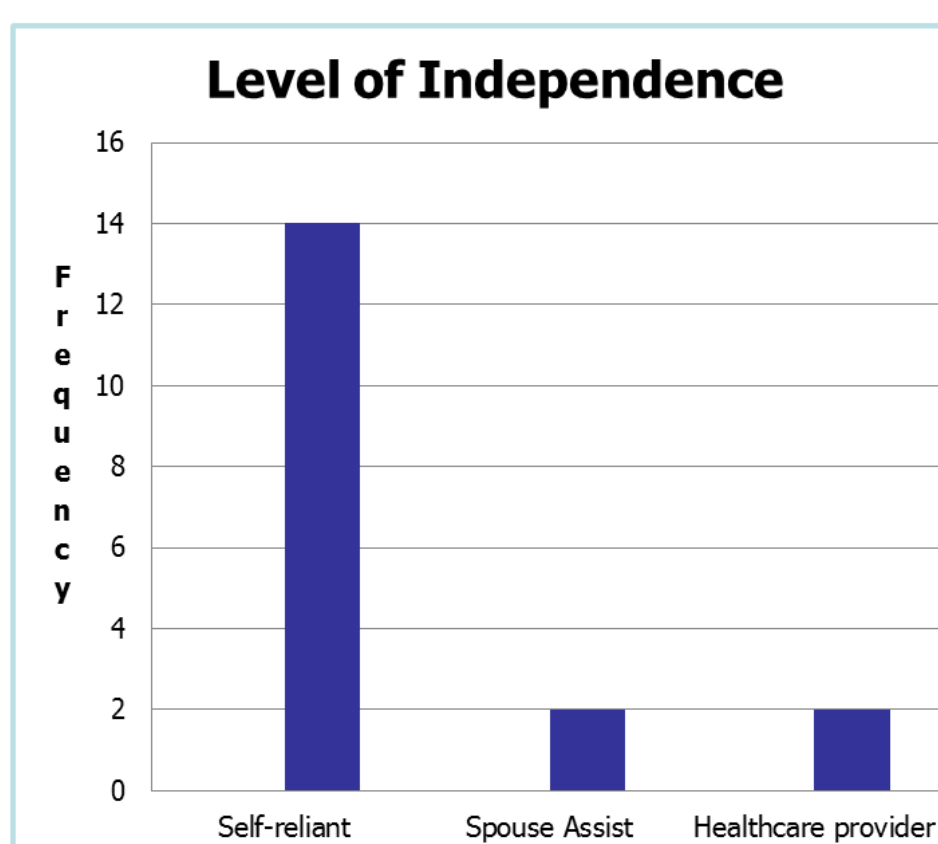
- One researcher collected all data.
- Participants provided informed consent, answered interview questions, and completed the standardized survey.
- Interviews were audio-recorded.

Data Analysis

Interview Data

- Recorded interviews were transcribed into written form using computer software.
- 3 researchers independently reviewed transcripts to identify themes and then met later to discuss them.
- 3 researchers met together to discuss themes.

Survey Data Analyzed using descriptive statistics.



Nature of Injury

4 chronic spine injuries with deterioration in function over time

14 traumatic injuries with immediate loss of function
3 sports
6 automobile
1 motorcycle
4 work-related accidents

Level of injury:
6 cervical
7 thoracic
2 lumbar
1 unknown
1 thoracic, lumbar, sacral
1 cervical, lumbar

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 assertive 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, be mad at your bowels?

I have learned over the years that the SCI staff, rehab and all them...are taught certain protocols and they have to tell the patient certain things and stay within the guidelines. The patients have to learn to go outside the box and make their lifestyle better because there are other ways to take care of yourself. It's a hit and miss.

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

Probably get mad a lot. And other than that, I just really don't leave our house and that way I don't have to deal with it as much.

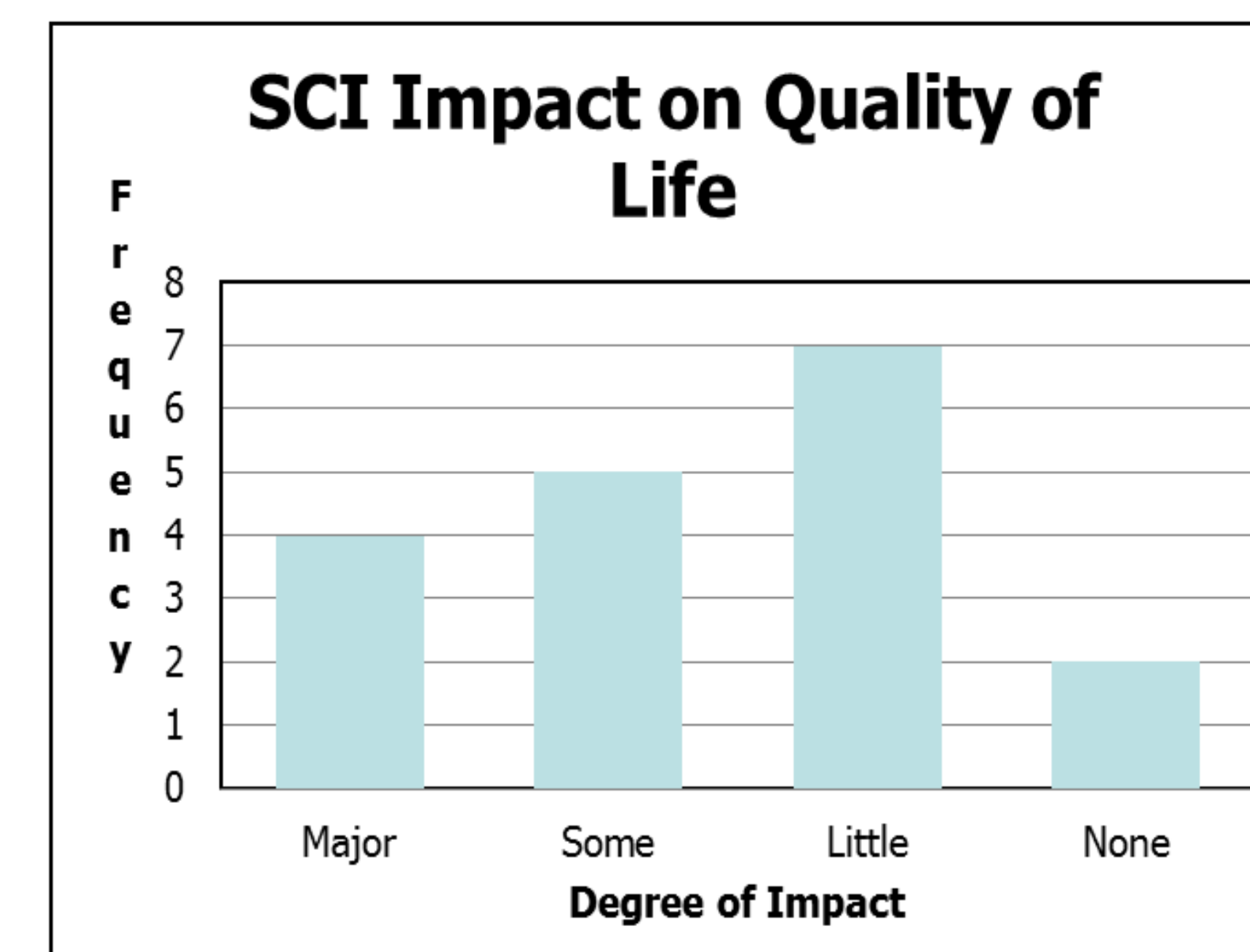
Making Adjustments

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 or you'll be cleaning up".

...figured out that 3 laxatives worked, then I figured out that they took 8 to 10 hours to work, so now I take them every evening . . . I figured that out over time.

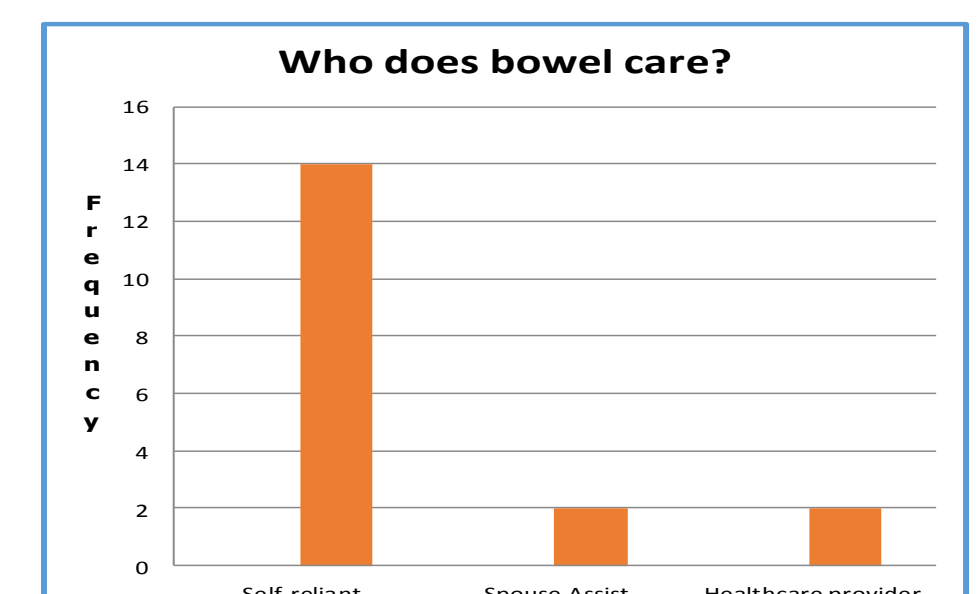
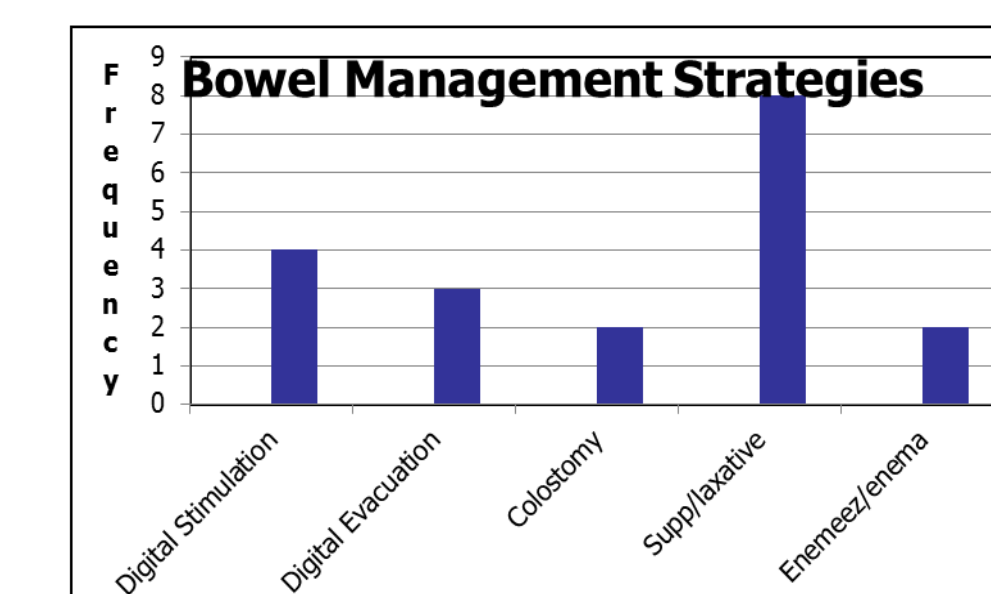
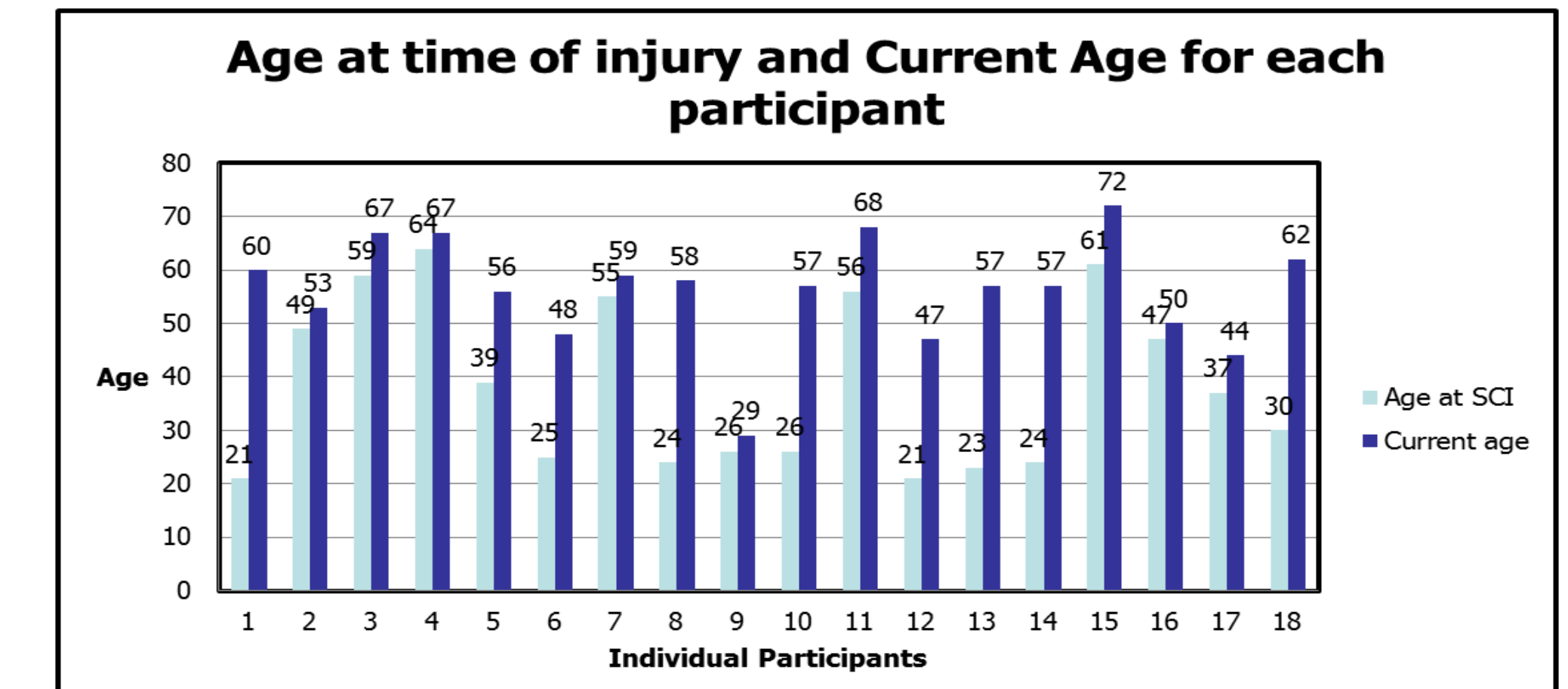
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I discovered one thing that was bringing it on [incontinence], I was eating some cold cuts, ... and I noticed every time I would eat [them], and they would bring it on. And I left that cold cut alone. And I haven't had it since.



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



Limitations

Recruitment technique tended to gain participants who might have been more active than usual.

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 others with the same disability.
- Advice for health care providers: Encourage new SCI patients to problem 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.

Acknowledgement: This study was partially funded by the Society of Gastroenterology Nurses and Associates (SGNA).

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