

ORIGINAL RESEARCH

Outcomes of Neurogenic Bowel Management in Individuals Living With a Spinal Cord Injury for at Least 10 Years



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Abstract

Objective: To describe bowel management and its outcomes in individuals living with a spinal cord injury (SCI) for at least 10 years.

Design: Cross-sectional multicenter study.

Setting: Dutch community.

Participants: Individuals (N=258; age range, 28–65y) who acquired their SCI between 18 and 35 years of age, who were at least 10 years post-SCI, and who used a wheelchair for their daily mobility.

Interventions: Not applicable.

Main Outcome Measures: The International SCI Bowel Function Basic Data Set, the neurogenic bowel dysfunction (NBD) score, and a single item on satisfaction with bowel management.

Results: Mean time since injury (TSI) was 24±9 years. Seventy-four percent used ≥1 conservative bowel management method, specifically digital evacuation (35%) and mini enemas (31%). Transanal irrigation (TAI) and surgical interventions were used by 11% and 8%, respectively. Perianal problems were reported by 45% of the participants. Severe NBD was present in 36% of all participants and in 40% of those using a conservative method. However, only 14% were (very) dissatisfied with their current bowel management. Dissatisfaction with bowel management was significantly associated with constipation and severe NBD. With increasing TSI, there was a nonsignificant trend observed toward a decline in dissatisfaction with bowel management and a significant decline in severe NBD.

Conclusions: Although satisfaction rates were high, more than a third of the participants reported severe NBD and perianal problems. Apart from severe NBD, there were no significant associations between bowel problems and TSI. Conservative methods were most often used, but some of these methods were also significantly associated with the presence of severe NBD. Longitudinal research is necessary to provide more knowledge concerning the course of NBD with increasing TSI.

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In patients with spinal cord injury (SCI), neurogenic bowel dysfunction (NBD) causes colonic and anorectal dysfunction, resulting in constipation and fecal incontinence. NBD is one of the main secondary health conditions (SHCs) resulting from SCI that hampers an

active lifestyle and impacts negatively on quality of life.¹⁻⁵ In a Dutch survey, for instance, bowel problems were rated by 42% of 454 participants with SCI as one of the most important SHCs they experienced.⁵ Coggrave et al⁶ assessed NBD with a postal questionnaire among 1334 persons who had suffered an SCI at least 1 year ago. The most commonly reported problems were constipation (39.0%), hemorrhoids (36.0%), and abdominal distension (31.0%). In another study, no less than 39.4% of 142 individuals with SCI reported severe NBD according to their NBD score.⁷ To date, only 1 study of NBD

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after SCI with a longitudinal design has been performed. Faaborg et al⁸ assessed NBD 10 years apart, with a mean time since injury (TSI) of 14 years at the first assessment. The proportion of participants defecating less than every second day increased significantly from 11% to 16% over time, whereas the number of participants reporting fecal incontinence at least once a month decreased significantly from 22% to 17%. The mean NBD score did not change.

Although NBD is common in persons living with SCI, studies have shown that satisfaction with bowel management appears high (80%–85%).^{6,9} In both studies, satisfaction was significantly associated with the duration and frequency of bowel care.

Bowel management is an individualized bowel routine aimed at a predictable and regular evacuation of the feces, continence, and prevention of constipation and perianal problems. It has a stepwise hierarchical approach, beginning with conservative methods such as digital anorectal stimulation, digital evacuation, and/or the use of rectal laxatives (eg, suppositories, mini enema). If this does not lead to a satisfactory situation, the next step is transanal irrigation (TAI).¹⁰⁻¹² Finally, surgical interventions such as sacral anterior root stimulation (SARS) and ostomy surgery provide an option when other methods have failed.^{13,14}

Several studies, mostly cross-sectional in design and with mean TSI ranging between 3 and 29 years, have described bowel management and its associations with demographic characteristics, injury-related characteristics, and bowel problems in groups of individuals with SCI living in the community.^{2-4,6,9,15-19} However, most studies used self-constructed questionnaires so that their results are difficult to compare.^{2,4,6,9,17,19} had small sample sizes ($N \leq 100$) and therefore lacked precision,^{3,17-19} or only described the use of the conservative approaches.^{9,15,16,19}

The aim of the current study was therefore to describe long-term bowel management and NBD in individuals who have been living with an SCI for at least 10 years in The Netherlands. This study is part of the Dutch multicenter research program called Active Lifestyle Rehabilitation Interventions in aging Spinal Cord injury.²⁰ Research questions of the current study were as follows. First, which bowel management methods are currently used by individuals with long-term SCI? For this purpose, bowel management was divided into 4 categories: no intervention, conservative bowel management, TAI, and surgical bowel management. Second, what is the prevalence of perianal problems, constipation, fecal incontinence, severe NBD, and dissatisfaction with current bowel management? Finally, what are the associations between demographic and injury-related characteristics and bowel management, severe NBD, and satisfaction with bowel management?

Methods

Design

This study was a TSI-stratified cross-sectional study among individuals with long-term SCI living in The Netherlands. TSI strata

were 10 to 19, 20 to 29, and ≥ 30 years after SCI. It was aimed to include 100 individuals per stratum.

Participants

Inclusion criteria were as follows: (1) traumatic or nontraumatic SCI with a TSI of at least 10 years; (2) age at injury between 18 and 35 years; (3) current age between 28 and 65 years; and (4) using a wheelchair (hand-rim propelled, electric), at least for longer distances ($>500\text{m}$). Persons were excluded if they had insufficient mastery of the Dutch language to respond to an oral interview.

Procedure

Eligible individuals were identified through databases from all 8 Dutch rehabilitation centers specializing in SCI rehabilitation. In the first round, 62 individuals per center were invited for the study. If the number of eligible individuals allowed it, a random sample per center was drawn. If the response was <30 to 35 individuals per center, an additional sample was drawn at that center.

The study consisted of a 1-day visit to the rehabilitation center for a check-up, including an extensive medical assessment and physical examination performed by a rehabilitation physician and an oral interview and several physical tests performed by a research assistant.²¹ Two weeks before the visit to the rehabilitation center, participants were asked to complete a self-report questionnaire.²¹

The research protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent.

Instruments

Data on medication use were extracted from consultation with the physician and medical file.

Bowel management and bowel problems were described using the International SCI Bowel Function Basic Data Set, a standardized 12-item assessment of bowel function.²² Digital evacuation was defined as the need to dig out stools from the bowel with a finger. Digital anorectal stimulation was defined as digital (manual) triggering of rectal contractions and anal relaxation to cause rectal emptying. In contrast with the Data Set, we did not differentiate between main and supplementary defecation methods. For the categorization of the 4 bowel management strategies (no intervention, conservative, TAI, surgical), we only reported the use of the most invasive defecation method. For instance, if a participant used a combination of TAI and digital evacuation, he/she was included in the TAI category and not in the conservative category. Furthermore, we used a time frame of 3 months instead of 4 weeks to avoid short-term fluctuations in the chronic situation.

In addition to this Data Set, constipation during the last 3 months was recorded according to the Rome III criteria²³; 2 items regarding the participant's ability to perform bowel management were included from the Spinal Cord Independence Measure, version III²⁴; and 1 question was asked about the participant's satisfaction with current bowel management on a 5-point scale from very satisfied to very dissatisfied.

The International Standards for Neurological Classification of Spinal Cord Injury were used to assess lesion characteristics.²⁵ Tetraplegia was defined as a lesion at or above the first thoracic segment, and paraplegia was defined as a lesion below

List of abbreviations:

NBD	neurogenic bowel dysfunction
OR	odds ratio
SARS	sacral anterior root stimulation
SCI	spinal cord injury
SHC	secondary health condition
TAI	transanal irrigation
TSI	time since injury

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