



ORIGINAL RESEARCH

Long-Term Outcomes and Longitudinal Changes of Neurogenic Bowel Management in Adults With Pediatric-Onset Spinal Cord Injury

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Abstract

Objectives: To describe long-term outcomes of neurogenic bowel dysfunction (NBD), determine changes over time in the type of bowel program, and determine changes in psychosocial outcomes associated with NBD-related factors in adults with pediatric-onset spinal cord injury (SCI).

Design: Longitudinal cohort survey. Follow-up occurred annually for a total of 466 interviews, with most participants (75%) contributing to at least 3 consecutive interviews.

Setting: Community.

Participants: Adults (N=131) who had sustained an SCI before the age of 19 years (men, 64.1%; tetraplegia, 58.8%; mean age \pm SD, 33.4 \pm 6.1y; mean time since injury \pm SD, 19.5 \pm 7.0y).

Interventions: Not applicable.

Main Outcome Measures: Type and evacuation time of bowel management programs; standardized measures assessing life satisfaction, health perception, depressive symptoms, and participation. Generalized estimating equations were formulated to determine odds of change in outcomes over time.

Results: At first interview, rectal suppository/enema use was most common (51%). Over time, the likelihood of using manual evacuation (odds ratio [OR]=1.077; 95% confidence interval [CI], 1.023–1.134; $P=.005$), oral laxatives (OR=1.052; 95% CI, 1.001–1.107; $P=.047$), and colostomy (OR=1.071; 95% CI, 1.001–1.147; $P=.047$) increased, whereas the odds of rectal suppository use decreased (OR=.933; 95% CI, .896–.973; $P=.001$). Bowel evacuation times were likely to decrease over time in participants using manual evacuation (OR=.499; 95% CI, .256–.974; $P=.042$) and digital rectal stimulation (OR=.490; 95% CI, .274–.881; $P=.017$), but increase for rectal suppository/enema use (OR=1.871; 95% CI, 1.264–2.771; $P=.002$). When the level of injury was controlled for, participants using manual evacuation and digital rectal stimulation were more likely to have increases in community participation scores ($P<.05$).

Conclusions: Changes in type of bowel program over time may be associated with the time required to complete bowel evacuation in this relatively young adult SCI population.

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Neurogenic bowel dysfunction (NBD), a common secondary health condition resulting from a spinal cord injury (SCI), can negatively affect physical function, social participation, and overall quality of life (QOL).^{1,2} The type and severity of NBD vary, depending on the

level and completeness of SCI as well as the duration of injury.^{1,3,4}

The goals of an effective bowel program are to complete bowel evacuation in a timely manner and to prevent complications. Bowel programs range from conservative measures (oral laxatives [LAX], rectal suppositories, digital stimulation [DS], or manual evacuation) to surgical interventions (Malone antegrade continence enema, sacral root stimulator, or colostomy), and more than 1 type of program is often used concomitantly.⁵⁻⁷

Research on colorectal function in chronic SCI indicates an increasing prevalence of constipation and perianal problems over

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time, but a decrease in fecal incontinence.^{3,8} As patterns of NBD change with time, management methods must change accordingly to ensure efficient evacuation and normalcy in daily activities. Adults who sustained an SCI during childhood have a longer duration of time living with NBD and may experience greater changes over the course of their lives. Such changes would likely affect their independence, social participation, and psychological well-being over time.⁹ It is intuitive that the bowel management programs of these individuals would change in accordance to the changes in their bowel patterns. The objectives of this study were to (1) describe long-term NBD management programs, (2) determine changes in the type of bowel program, and (3) assess psychosocial outcomes over time in relation to bowel program and NBD-related factors in adults with pediatric-onset SCI.

Methods

This study was a part of an ongoing longitudinal study on long-term medical and psychosocial outcomes of adults with pediatric-onset SCI. Participants were community-dwelling adults who had sustained their SCI before the age of 19 years and were at least 23 years of age at first interview. Informed consent was obtained, and annual telephone interviews were conducted with enrolled participants. Medical and injury-related information was collected from medical records and the Shriners Hospitals for Children database. This study was approved by the institutional review board.

A structured questionnaire was used to determine the type of bowel management program, time (minutes) required to complete bowel evacuation, and occurrence of fecal incontinence (frequency ≥ 1 episode per month) and abdominal pain (frequency ≥ 1 episode per week). Types of bowel management program were as follows: (1) none—controlled bowel; (2) none—uncontrolled bowel with occasional incontinence; (3) DS; (4) manual evacuation; (5) rectal suppositories/enemas; (6) oral LAX; (7) Malone antegrade continent stoma; (8) colostomy; (9) other; and (10) a combination of 2 or more of the above programs. Standardized measures used to assess psychosocial outcomes were the Satisfaction With Life Scale, Patient Health Questionnaire-9, Short Form-12 version 2 Health Survey, and the Craig Handicap Assessment and Reporting Technique (CHART).¹⁰⁻¹³

Analysis

Descriptive statistics were used to present demographic and injury-related information. Comparisons of bowel program duration among the bowel programs and between levels of injury were performed using the Kruskal-Wallis H test and Mann-Whitney U test, respectively. Generalized estimating equations (GEEs) were used for longitudinal analyses to account for repeated

Table 1 Demographic characteristics of participants at first interview (N=131)

Characteristics	Values
Sex	
Male	84 (64.1)
Age (y)	33.4 \pm 6.1 (25–48)
Age at time of injury (y)	13.4 \pm 4.6 (0–18)
Duration of SCI (y)	19.5 \pm 7.0 (8–41)
Interval between first and last interviews (y)	3.2 \pm 1.3 (1–5)
Race	
White	112 (85.5)
African American	5 (3.8)
American Indian	1 (0.8)
Hispanic	11 (8.4)
Asian	2 (1.5)
Etiology	
Vehicular/pedestrian	67 (51.1)
Violence	7 (5.3)
Falls/flying objects	11 (8.4)
Sports	33 (25.2)
Medical/surgical	12 (9.2)
Unknown/other	1 (0.8)
Level	
Tetraplegia	77 (58.8)
Completeness	
Complete	100 (76.3)
Employment	
Employed	66 (50.4)
Marital status	
Married	41 (31.1)
Independence in bowel program	66 (50.4)

NOTE. Values are mean \pm SD (range) or n (%).

measurements correlated within a subject over time.¹⁴ GEE models were formulated to determine annual odds of change in (1) type of bowel program, (2) time required to complete bowel program, (3) incidence of fecal incontinence and abdominal pain, and (4) psychosocial outcome scores. For *type of bowel program*, the outcome variables were types of bowel programs, dichotomized as used or not used; the predictor variables were completeness (complete vs incomplete) and level (tetraplegia vs paraplegia) of injury. For *time required to complete bowel program*, the outcome variable was bowel program duration in minutes; the predictor variables were the types of bowel program. For *incidence of fecal incontinence and abdominal pain*, the outcome variable was dichotomized as presence or absence of fecal incontinence and abdominal pain, respectively; the predictor variables were the types of bowel program. For *psychosocial outcome scores*, the outcome variables were the scores for each respective measure, and the predictor variables were the types of bowel program, presence of fecal incontinence, and presence of abdominal pain; GEE models were obtained controlling for level of injury, as previous investigations report differences in outcome measure scores depending on the level of neurologic impairment.¹⁵ The autoregressive correlation matrix was used in all models to account for correlation of observations between sequential time points, and the interaction between duration of injury and predictor variables was tested to observe change over time.

List of abbreviations:

CHART	Craig Handicap Assessment and Reporting Technique
DS	digital stimulation
GEE	generalized estimating equation
LAX	laxative
NBD	neurogenic bowel dysfunction
QOL	quality of life
SCI	spinal cord injury

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