

ORIGINAL ARTICLE

Phenomenological Study of Neurogenic Bowel From the Perspective of Individuals Living With Spinal Cord Injury



Anthony S. Burns, MD, MSc,^{a,b} Daphney St-Germain, PhD,^c Maureen Connolly, PhD,^d Jude J. Delparte, MSc,^b Andréanne Guindon, MA,^e Sander L. Hitzig, PhD,^f B. Catharine Craven, MD, MSc^{a,b,g}

From the ^aDivision of Psychiatry, Department of Medicine, University of Toronto, Toronto, ON; ^bBrain and Spinal Cord Rehabilitation Program, University Health Network-Toronto Rehabilitation Institute, Toronto, ON; ^cFaculty of Nursing Science, Laval University, Pavillon Ferdinand-Vandry, Quebec City, QC; ^dFaculty of Applied Health Sciences, Brock University, Saint Catharines, ON; ^eInterdisciplinary Center in Rehabilitation and Social Integration, Quebec City, QC; ^fInstitute for Life Course and Aging, Faculty of Medicine, University of Toronto, Toronto, ON; and ^gNeural Engineering and Therapeutics Team, University Health Network-Toronto Rehabilitation Institute, Toronto, ON, Canada.

Abstract

Objective: To gain greater insight into the lived experience of individuals with spinal cord injury (SCI) and neurogenic bowel dysfunction (NBD).

Design: Qualitative (phenomenologic) interviews and analysis.

Setting: Community.

Participants: Individuals with SCI and NBD (N=19) residing in the community.

Interventions: Not applicable.

Main Outcome Measure: Concerns related to living with NBD after SCI.

Results: Challenges related to living with SCI and NBD included costs and requirements, emotional impact, diet, education and employment, intimacy and interpersonal relations, social participation, spontaneity and daily schedule, travel, lack of appropriate and consistent assistance, loss of autonomy (independence, privacy), lack of predictability and fear of incontinence, medical complications, pain or discomfort, physical effort of the bowel routine, physical experience, and time requirements.

Conclusions: Living with NBD presents many challenges. When categorized according to the *International Classification of Functioning, Disability and Health*, identified domains include body functions and structures, activity, participation, environmental factors, and personal factors. Identified issues have implications for improving clinical management and should be assessed when determining the impact and efficacy of interventions.

Archives of Physical Medicine and Rehabilitation 2015;96:49-55

© 2015 by the American Congress of Rehabilitation Medicine

Bowel function is dramatically altered after spinal cord injury (SCI). Changes include impaired gastrointestinal motility, impaired volitional control, and increased risk of long-term complications. More than 98% of individuals residing in the community with SCI report at least 1 bowel problem related to their SCI,¹ and 40% to 60% report that bowel dysfunction

adversely impacts day-to-day activities, lifestyle, and quality of life (QOL).²⁻⁵ Bowel incontinence is also the greatest source of social discomfort after SCI.⁶ Neurogenic bowel dysfunction (NBD) is a barrier to community reintegration. NBD can preclude individuals with SCI from reentering the workplace, resuming studies, and participating in recreational activities; the recovery of bowel function has been rated as more important than walking.² NBD is therefore an issue of central importance to individuals living with SCI.

Supported by the Ontario Neurotrauma Foundation (grant nos. 2008-ONF-REPAR-601, 2009-SCI-NEURBOW-802, and 2011-ONF-REPAR2-885).

Disclosures: none.

Despite its importance, NBD is understudied. A recent Cochrane review⁷ concluded that “there is still remarkably little research on this common and, to patients, very significant issue...”^(p2) There is also a paucity of literature examining NBD from the perspective of individuals living with SCI. Understanding the lived experience of individuals with SCI and NBD is important because it will help investigators and clinicians target the aspects of NBD most troublesome to individuals with SCI. Addressing these concerns will positively impact health, well-being, and QOL after SCI. This study therefore used a phenomenologic (qualitative) design to investigate the experience of living with NBD after an SCI. Phenomenology describes phenomena as experienced by the individual (perceiving consciousness).⁸

Methods

The study was conducted in the Canadian provinces of Ontario, Quebec, and approved by the Research Ethics Boards of the University Health Network - Toronto Rehabilitation Institute, Toronto, Ontario and Quebec Rehabilitation Institute for Physical Deficiency, Quebec City, Quebec.

Participants

Inclusion criteria included the following: adults (age ≥ 18 y) fluent in the primary language of the interviewer (English in Ontario, French in Quebec); history of a discrete and identifiable injury to the spinal cord; an impaired or absent ability to volitionally defecate; and discharged from inpatient rehabilitation for at least 3 months. Exclusion criteria included the presence of a cognitive or communication deficit (eg, traumatic brain injury) or other medical conditions that would confound bowel function and defecation (eg, inflammatory bowel disease).

Interviews

Phenomenologic interviews were approximately 45 minutes long and conducted in privacy, an important issue for a socially, culturally, and relationally laden phenomenon such as bowel function and care. Participants were given the option of completing interviews in their homes or at either of the 2 rehabilitation centers associated with the study sites. Prior to the initiation of interviews, the interviewers participated in a 2-day training to ensure a consistent approach to the performance of interviews across the 2 study sites. Content (SCI) and methodologic experts (phenomenology) fluent in French and/or English were present during training to facilitate communication and maximize training effectiveness. Specific activities included a background discussion of phenomenology, mock interviews, and peer feedback. Interviews used open-ended and loosely structured questions to let participants' thoughts emerge unencumbered by the preexisting beliefs of the interviewer (appendix 1).

List of abbreviations:

ICF	International Classification of Functioning, Disability and Health
NBD	neurogenic bowel dysfunction
QOL	quality of life
SCI	spinal cord injury

Phenomenologic (qualitative) analysis

A 3-day training session addressed qualitative (phenomenologic) analyses and was facilitated by 2 experts in phenomenology (D.S.-G. and M.C.). During the first 2 days, the research team reviewed multiple phenomenologically oriented analytical methods. Using actual interview transcripts, team members were led through facilitated analysis using the candidate methods. On the third day, the research team chose 2 distinct but complementary approaches for analysis: deep analysis and identification of indigenous typologies. Indigenous typologies were used as the primary methodology; deep analysis (subset of interviews) was the additional complementary measure used to ensure full exploration of the topic.

Interviews were analyzed by 1 primary bilingual qualitative analyst, with assistance from 2 additional analysts who participated in cross checks to validate the analyses. Consistent with phenomenology, epoché (bracketing) was used to control for possible biases and assumptions. Fourteen transcripts were analyzed using indigenous typologies.⁹ Typologies are classification systems that divide some aspect of the world into parts. Indigenous conveys that what a particular group has experienced and contributed is uniquely theirs. In the first iteration of the analysis, the qualitative analysts reviewed the transcripts and coded salient excerpts in the informant's original language using NVivo 10 software.³ Coded text (meaning units) was then organized into categories. French text was then translated to English, and a resulting English document was circulated to the research team. Categories were then collapsed and reorganized through consensus.

One in 4 interviews (n=5) was assigned for deep analysis, which combined the descriptive methodology of Giorgi¹⁰ with additional steps from the methodology of Van Manen.^{11,12} Each transcript underwent multiple readings before being coded into meaning units, which were then organized (NVivo 10 software) to address categories of interview questions (see appendix 1). Specific descriptions were then constructed for each interview question category, keeping true to the interviewees original words as best as possible. Specific descriptions were then summarized into general descriptions using language closer to that used by professionals. The goal was to create narratives which spoke to the interview questions. Specific and general descriptions were translated into English.

Results

Participant demographics

Nineteen individuals participated in the study. The mean age of the study participants was 42 ± 13.4 years, and the mean duration of injury was 10.4 ± 9.2 years. Thirteen (68%) participants were men, 9 (47%) had paraplegia, and 14 (74%) had complete injuries.

International Classification of Functioning, Disability and Health classification of identified challenges and issues

Phenomenologic analysis identified many important challenges associated with living with NBD after SCI. Expressed concerns were relatively consistent between participants, suggesting that study saturation (identification of pertinent issues) was achieved.

Download English Version:

<https://daneshyari.com/en/article/6149623>

Download Persian Version:

<https://daneshyari.com/article/6149623>

[Daneshyari.com](https://daneshyari.com)