

AWARD NUMBER: W81XWH-17-1-0494

TITLE: Neurogenic Bowel and Bladder Management After Spinal Cord Injury:
Examining Factors Involved in Successful Decision-Making Processes

PRINCIPAL INVESTIGATOR: Denise G. Tate, Ph.D., ABPP

CONTRACTING ORGANIZATION: Regents of the University of Michigan, Ann Arbor, MI

REPORT DATE: September 2021

TYPE OF REPORT: Annual Report

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release; Distribution Limited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

REPORT DOCUMENTATION PAGE		<i>Form Approved</i> OMB No. 0704-0188	
Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.			
1. REPORT DATE September 2021	2. REPORT TYPE Annual	3. DATES COVERED 15Aug2020-14Aug2021	
4. TITLE AND SUBTITLE Neurogenic Bowel and Bladder Management After Spinal Cord Injury: Examining Factors Involved in Successful Decision-Making Processes		5a. CONTRACT NUMBER W81XWH-17-1-0494	
		5b. GRANT NUMBER W81XWH-17-1-0494	
		5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Denise G. Tate, Ph.D., ABPP E-Mail: dgtate@med.umich.edu		5d. PROJECT NUMBER	
		5e. TASK NUMBER	
		5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) The Regents of the University of Michigan 3003 South State Street Ann Arbor, MI 48109-1274		8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012		10. SPONSOR/MONITOR'S ACRONYM(S)	
		11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Limited			
13. SUPPLEMENTARY NOTES			

14. ABSTRACT

Living with SCI requires the ability to make extensive and complex decisions to address the many associated health issues and complications. Persons with SCI make daily decisions about their care that directly and indirectly impact the management of their condition, especially in relation to neurogenic bladder and bowel (NBB) dysfunction. Very few studies discuss decision-making on NBB management among persons with SCI. Of those, none focus on patient decision-making and enactment. This study aims to examine veterans and civilians NBB management decisions and resulting outcomes. The aims are: 1) to identify the factors influencing the decision-making process and potential changes across time considering age and time since injury; 2) to assess participants' abilities and coping styles in carrying out NBB management decisions; and 3) to assess the outcomes of these decisions on their health and wellbeing, overall satisfaction, and quality of life (QoL) while comparing these decisions to clinical practice guidelines. To address these aims we interviewed 61 SCI participants. Data is being analyzed using content analysis to identify topics, themes and patterns. Matrices are being for each aim. Data counts will be compared to scores from selected quantitative assessments. Implications for treatment will be drawn from this study and specific recommendations will be made for clinician care on how to educate and share the decision-making process with their patients. It is anticipated that findings may impact existing clinical practice guidelines by suggesting patient involvement in their future development and revisions. An earlier study by our team found that veterans with SCI more frequently chose surgical and more invasive methods for NBB management than did civilians with SCI. By comparing the narratives from veterans in terms of factors related to decision making, their cognitive and coping strategies and resulting outcomes with a civilian cohort, we will better understand factors that influence decisions and propose recommendations for NBB management, treatment of complications and implications for NBB clinical practice guidelines.

15. SUBJECT TERMS

Neurogenic bladder and bowel. SCI. Decision making. Qualitative methodology. Mixed methodology.

16. SECURITY CLASSIFICATION OF:**17. LIMITATION
OF ABSTRACT****18. NUMBER
OF PAGES****19a. NAME OF RESPONSIBLE PERSON**

USAMRMC

a. REPORT**b. ABSTRACT****c. THIS PAGE**

Unclassified

48

19b. TELEPHONE NUMBER *(include area code)*

Unclassified

Unclassified

Unclassified

Standard Form 298 (Rev. 8-98)

Prescribed by ANSI Std. Z39.18

Table of Contents

	<u>Page</u>
1. Introduction	5
2. Keywords	7
3. Accomplishments	7
4. Impact	18
5. Changes/Problems	19
6. Products	20
7. Participants & Other Collaborating Organizations	20
8. Appendices	25

1. INTRODUCTION

Living with spinal cord injury (SCI) requires extensive personal decision making to address the many associated health issues and complications^{1,2}. These decisions become particularly complex in that neurogenic bladder and bowel (NBB) broadly affect the *whole person* across multiple domains of daily life. As a result, NBB dysfunction remains one of the most life changing and stigmatizing consequences of SCI³. Complications of NBB can affect all aspects of life including physical functioning, pain, mental health, sexual functioning and overall life satisfaction⁴⁻⁷. The most frequent complications associated with neurogenic bladder include urinary tract infections (UTIs), bladder incontinence, and bladder and renal stones; while bowel complications include constipation, incontinence and hemorrhoids⁸. The effects of these complications on quality of life (QoL) highlight the importance of avoiding complications through appropriate NBB management decision making.

NBB dysfunction has a deeply personal and intimate impact, which heightens the salience of decision-making enactment for improved management. New research on patient-centered and self-management approaches to care emphasize the importance of patients as decision makers. Little is known about how patients with SCI make these complex decisions regarding NBB issues, and the related outcomes of these decisions. Making decisions is particularly difficult given the high number of attendant medical and cognitive issues due to the accelerated aging process in SCI⁹. For example, the Veterans Administration (VA) sees a large number of aging and long-term SCI patients, for whom treatment of secondary medical conditions is the primary focus, including pressure ulcers, UTIs, constipation, pain and spasticity¹⁰. Finally, there is no clarity about recommendations regarding clinical practice guidelines (CPGs) for NBB, especially for bowel management, which were issued in 1998 and do not include patients' personal perspectives as a factor to consider when selecting management methods^{11,12}.

Three aims guide this investigation. The first aim seeks to identify and describe the factors influencing the decision-making process and changes in NBB management and related complications across time, considering age and time since injury. The second aim seeks to assess participants' abilities and coping styles in carrying out NBB management decisions. The third aim seeks to assess the outcomes of these decisions on improving problems related to the management of NBB and reducing associated complications.

During the first year of the project the team organized a data collection plan including several qualitative and quantitative tasks, codebooks, interviewers' training, regulatory approval was obtained from both sites, and investigators received guidance from the Advisory Council. Recruitment began using strategies outlined in the proposal. Consent was obtained and interviews began. Recruitment through the Ann Arbor VA was challenging and during the project's second year, we obtained assistance from the National Office of Paralyzed Veterans of America (PVA) to engage new participants into this study. All interviews were completed during Years 2 and 3 of the project and data stored in REDCap and NVivo for analysis. Data analysis began in Year 2 with coding. Coding interviews using a workable conceptual framework proceeded but because of the length of transcripts this step had taken longer than first anticipated. Streamlined coding has helped facilitate this process, identify key areas of import in the data, and allowed us to begin conceptualizing our findings. The team has focused its efforts on reviewing the quantitative data and analyzing surgical cases with NVivo. Year 3 has also included initial discussions about focus groups planning and preparation steps. These are now being revised due to COVID-19 restrictions. Dissemination activities continued as planned with presentations and work on a scoping review paper. Year 4 included the development of a large qualitative data table for final analysis of themes and patterns regarding factors, mechanisms and outcomes of decisions made in relation to neurogenic bladder and

bowel. We also started the quantitative analyses by aims looking at associations of factors with demographic and neurological attributes. We completed focus groups with veterans and civilians, began the process of gathering clinical practice data and developing a table summarizing this data in relation to decisions. We also held our final advisory council meeting and submitted two manuscripts for publication. IRBs have been submitted accordingly and approved.

References cited

1. Adriaansen JJ, Post MW, de Groot S, van Asbeck FW, Stolwijk-Swuste JM, Tepper M, Lindeman E. Secondary health conditions in persons with spinal cord injury: a longitudinal study from one to five years post-discharge. *Journal of Rehabilitation Medicine*. Nov 2013;45(10):1016-1022.
2. Derrett S, Beaver C, Sullivan MJ, Herbison GP, Acland R, Paul C. Traumatic and non-traumatic spinal cord impairment in New Zealand: incidence and characteristics of people admitted to spinal units. *Injury Prevention*. Oct 2012;18(5):343-346.
3. Nevedal A, Kratz AL, Tate DG. Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel. *Disability and Rehabilitation*. 2016;38(6):573-581.
4. Liu CW, Huang CC, Yang YH, Chen SC, Weng MC, Huang MH. Relationship between neurogenic bowel dysfunction and health-related quality of life in persons with spinal cord injury. *Journal of Rehabilitation Medicine*. Jan 2009;41(1):35-40.
5. Liu CW, Attar KH, Gall A, Shah J, Craggs M. The relationship between bladder management and health-related quality of life in patients with spinal cord injury in the UK. *Spinal Cord*. Apr 2010;48(4):319-324.
6. Forsythe E, Horsewell JE. Sexual rehabilitation of women with a spinal cord injury. *Spinal Cord*. Apr 2006;44(4):234-241.
7. Sale P, Mazzarella F, Pagliacci MC, Agosti M, Felzani G, Franceschini M. Predictors of changes in sentimental and sexual life after traumatic spinal cord injury. *Archives of Physical Medicine and Rehabilitation*. Nov 2012;93(11):1944-1949.
8. Tate DG, Forchheimer M, Rodriguez G, Chiodo A, Cameron AP, Meade M, Krassioukov A. Risk Factors Associated with Neurogenic Bowel Complications and Dysfunction in Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*. OCT 2016;97(10):1679–1686.
9. Bauman WA, Spungen AM. Disorders of carbohydrate and lipid metabolism in veterans with paraplegia or quadriplegia: a model of premature aging. *Metabolism: Clinical and Experimental*. Jun 1994;43(6):749-756.
10. Walter JS, Sacks J, Othman R, Rankin AZ, Nemchausky B, Chintam R, Wheeler JS. A database of self-reported secondary medical problems among VA spinal cord injury patients: its role in clinical care and management. *Journal of Rehabilitation Research and Development*. Jan-Feb 2002;39(1):53-61.
11. Consortium for Spinal Cord M. Bladder management for adults with spinal cord injury: a clinical practice guideline for health-care providers. *Journal of Spinal Cord Medicine*. 2006;29(5):527-573.
12. Clinical practice guidelines: Neurogenic bowel management in adults with spinal cord injury. Spinal Cord Medicine Consortium. *Journal of Spinal Cord Medicine*. Jul 1998;21(3):248-293.

2. KEYWORDS

DECISION MAKING, SCI, NEUROGENIC BLADDER AND BOWEL, QUALITATIVE METHODOLOGY, MIXED METHODOLOGY

3. ACCOMPLISHMENTS

What were the major goals of the project?

The project examines neurogenic bowel and bladder decision making for both veterans and civilians with SCI. Accomplishments are described based on the submitted SOW. Revised due dates have been inserted in italics for the no cost extension period August 15 2021 – Sept 14 2022.

Major Task 1: Administrative Tasks

Subtask 1: Project Start Up and Maintenance Tasks

- 1.1a. Award notification and site meetings to coordinate – **completed** (Month 1)
- 1.1b. Grant administration accounts, faculty appointments - **completed** (Months 1-3)
- 1.1c. Supplies and equipment purchases – **completed** (Months 1-3)
- 1.1d. Design and implement electronic databases for participant and data tracking – **completed** (Months 1-6)
- 1.1e. Finalize contract(s) with transcription services – **completed** (Month 4)
- 1.1f. Team training for standardized use of data collection instruments – **completed** (Months 4-6)
- 1.1g. Follow-up meetings for feedback and corrections in data collection – **completed and ongoing** (Months 9, 15, 21, 27, 32, 38, 44)

Subtask 2: Regulatory Documents and Research Protocol Maintenance

- 1.2a. Prepare IRB protocol submission for both sites – **completed** (Months 2-5) and **on going as needed**
- 1.2b. Submit amendments, adverse events, and protocol deviations – **completed and ongoing as needed**
- 1.2c. HRPO/ACURO Approval process – **completed** (Months 4-6)
- 1.2d. Coordinate with Sites for annual IRB reports for continuing review – **completed and ongoing** (Annually)
- 1.2e. Prepare and submit quarterly reports to the HRPO/CDMRP – **completed and ongoing** (Quarterly)

1.2f. Prepare and submit annual progress report to the HRPO/CDMRP – **completed and ongoing** (Annually)

Subtask 3: On-going Quality Assurance and Progress Review

1.3a. Administrative meeting for progress updates – **completed and ongoing** (Weekly)

1.3b. Project leadership meetings to assure progress along projected timeline – **completed and ongoing** (Quarterly)

1.3c. Collaborators/Advisory Council meetings to assess data collection & analysis – **completed** (Biannually) Final meeting - Month 47

Major Task 2: Data Collection Design Refinement

Subtask 1: Design Interview Guides for Qualitative and Quantitative Data Collection

2.1a Develop, refine, and review qualitative & quantitative interview guides – **completed** (Months 1-3)

2.1b Pilot of interviews and survey instruments with volunteer participants – **completed** (Months 4-6)

Subtask 2: Development of Data Collection Tracking Databases

2.2 Design and implement electronic databases for data collection tracking – **completed** (Months 1-6). Database for longitudinal analyses under construction (Months 48-49)

Major Task 3: Recruitment

Subtask 1: Identify Potential Research Subjects

3.1a Develop, refine, and finalize recruitment procedures, including letters – **completed** (Months 1-4)

3.1b Identify potential research subjects from UMHS & VAAHS – **completed** (Months 6-8)

3.1c Identify and confirm additional potential research subjects – **completed** (as needed)

3.1d Mail first batch contact letters (additional batches mailed as needed) – **completed** (Months 6 and 36-37 for focus groups)

Subtask 2: Formal Screening and Enrollment of Research Subjects

3.2a Develop, refine, and finalize screening forms and procedures – **completed** (Months 1-3)

3.2b Screen potential research subjects for eligibility; enroll those who qualify – **completed and ongoing** (Months 6-9)

3.2c Screen additional potential research subjects, following letters – **completed** (Months 37-38 for focus group only)

Major Task 4: Data Collection and Processing

Subtask 1: Schedule and Conduct Interviews; Administer Instruments

4.1a Develop, refine, and finalize informed consent forms and procedures – **completed** (Months 1-6)

4.1b Schedule and conduct interviews, administer standardized instruments – **completed** (Months 9-21; 36-37 for focus groups)

Subtask 2: Develop and Implement Transcript-processing Procedures

4.2a Send electronic audio files to transcriptionist; log and de-identify transcripts – **completed and ongoing** (as needed)

4.2b Check accuracy of transcripts by comparing text to audio – **completed and ongoing** (Quarterly)

Subtask 3: Schedule and Conduct Focus Group (Months 24-32) *(Months 37-40)*

4.3a Assess Transcriptions and select appropriate representative participants – **ongoing** (Month 24) (Months 36-37)

4.3b Develop, refine, and review focus group guide; invite participants – **ongoing** (Months 25-27) (35-37)

4.3c Schedule and implement focus group; transcript audio & review transcripts – **ongoing** (Months 30-32) (Months 37-40)

Major Task 5: Data analysis and evaluation

Subtask 1: Coding Scheme Refinement (Months 16-20) *(Months 20-40)*

5.1 Meet with consultants to refine and finalize coding scheme and manual – **completed**

Subtask 2: Coding of Interview Data (Months 18-26) *(Months 18-41)*

5.2 Conduct inter-rater reliability training for coding work – **completed** (Months 18-20)

5.3 Code interview transcripts in NVivo – **completed** (Months 20-26) *(Months 20-41)*

Subtask 3: Analysis of Interview and Standardized Instrument Data (Months 16-32) (Months 25-46) and **ongoing**

5.4 Upload standardized instrument data to SPSS and conduct analyses - **ongoing** (Months 16-22) (Months 25-48)

5.5. Analyze coded data for the identification of themes and patterns – **ongoing** (Months 20-28) (Months 30-48)

5.6 Identify and analyze cases; generate case reports - **on going and to be completed** (Months 26-32) (Months 45-48)

5.7 Compare PVA clinical practice guidelines to participants' responses – **to be completed** (Months 26-32) (Months 50-55)

Subtask 4: Triangulate Data between Data Sets (Months 28-30) (Months 50-56)

5.8 Compare major themes and patterns to statistical analyses – **to be completed** (Months 50-57)

Major Task 6: Dissemination and Data Sharing

Subtask 1: Disseminate Findings to Lay Audience (Months 25-35) (Months 49-60)

6.1 Generate lay language reports for dissemination of findings – **to be completed** (Months 50-55)

6.2 Work with MPVA and PVA to identify venues for dissemination – **to be completed and ongoing** (Months 47-53)

Subtask 2: Disseminate Findings to Professional Audience (Months 24-36) (Months 37-60)

6.3 Attend and present findings at professional meetings - **ongoing** (Months 24-60)

6.4 Prepare manuscripts for publication – **ongoing** (Months 35-60)

Subtask 3: Prepare final report to CDMRP – to be completed (Months 59-60)

Subtask 4: Discuss with PVA project findings related to current CPGs, submit brief report with suggestions – to be completed (Months 55-56)

What was accomplished under these goals?

Major Task 1: Administrative Tasks

As the project entered its fourth year, the study team has used its administrative time to ensure significant progress was made across all remaining aspects of the project. The team met approximately 45 times using virtual meetings through Zoom technology during the reporting period to discuss data analyses, data collection for focus groups and identify population sub-groups and cases, plan for qualitative coding and data analysis, data visualization options, and plan for advisory council meeting, publications, and presentations. Regular team meetings continued, on a weekly basis, with structured agenda and data reporting. The advisory council meeting was also conducted using Zoom as were the planned focus groups.

Staff changes during this reporting period included the departure of our project coordinator, Ms. Suzanne Walsh, who took a new position in January 2021 but continued with very limited effort (10%) on the project until the end of April 2021. Ms. Wolgat, research assistant and trained interviewer assisted the project temporarily with scheduling focus groups meetings and consenting and recruiting participants. She also assisted Mr. Forchheimer with basic quantitative analyses and database development. Ms. Lynn Charara, our qualitative interviewer, also left the project in September of 2020 to join another research project at Columbia University in New York. She had been temporarily furloughed from May through July 2020 due to personal circumstances related to family illness.

UM IRB amendments were filed and approved for all members added to the study during this reporting period. Both the VA and UM IRB Continuing Reviews were submitted and approved, on 2/11/2021 and 1/7/2021 respectively. In addition, an amendment to the UM IRB was approved on 9/17/2020 to add the focus group protocol to the study. A further amendment was approved on 10/23/2020 to add a standardized measure, the Consumer Health Screening Interview to the focus group protocol.

On July 19th of 2021, the study team met virtually with the Advisory Council and project consultant to discuss the current state of the project, to share data analysis progress, and to elicit suggestions for enhancing data analysis and dissemination. Project staff and investigators presented data analyzed so far and plans for the future. Minutes were generated and team members followed up with Lisa DiPonio MD (site PI at the Ann Arbor VA Health Systems) and consultant, Mark Luborsky PhD. See minutes attached **as Appendix B.**

Major Task 2: Data Collection Design Refinement

All subtasks as reported in the SOW for Major Task 2 related to individual qualitative and quantitative data collection are completed. Data collection tasks related to focus group activities are described below and are now completed. Data retrieval from transcripts related to CPGs is almost completed. The qualitative data collected from project interviews is currently under a process of quality assurance review to identify possible inaccuracies as well as missing data.

Major Task 3: Recruitment and Screening

Study screening and recruitment was completed during the second quarter of the reporting period. Of the one hundred and thirty-five (135) potential subjects screened, seventeen (17) were UM past participants, thirty-nine (39) were UM new, twenty-three (23) were VA past participants, and fifty-six (56) were VA new. The study team determined sixty-four (64) were eligible to enroll. Of those eligible, sixty-one (61) completed both the quantitative and qualitative interviews, which is one more participant than originally

planned. Recruitment of veterans with SCI for interviews was completed with assistance of the Paralyzed Veterans of America (PVA) national office. The project achieved all projected recruitment/screening goals. For focus groups, 9 participants were successfully recruited and screened (5 veterans and 4 civilians).

Task 4: Data Collection and Processing

Data collection and processing was completed during the second quarter of Year 3. The study team enrolled and interviewed thirty-one (31) civilian participants and thirty (30) veteran participants, for a total of sixty-one (61) participants. Each participant, whether civilian or veteran, completed one long-form qualitative interview and one quantitative interview. Every qualitative interview was recorded and submitted to a HIPAA-compliant transcription service for processing. Quantitative interviews were administered after the qualitative interviews were completed using REDCap to record and securely store responses. Focus groups activities started during Spring of Year 4. Participants were identified based on their transcripts, issues raised, their ability to express themselves clearly, and contributions in terms of commentary related to decision making process. Data from the 9 selected participants was collected via Zoom recordings and transcribed accordingly. Transcripts were reviewed for accuracy and missing information.

The study team followed a timeline of tasks for conducting the focus group, including assembling the materials to submit for a UM IRB amendment and the selection criteria for participants as well as a guide to conduct such interviews. An UM IRB amendment, which included a virtual protocol, was submitted in July 2020 and approved in August. Participants were instructed in advance on how to use Zoom technology during these focus groups. Information was e-mailed to them in advance as well to avoid confusion during the actual focus group encounters. Two project investigators, Drs. Tate and Rohn, conducted these interviews with the assistance of Ms. Wolgat for technical issues. The focus group guide provided a structure and consistency to this process identifying similar questions for both groups. In addition, a consumer questionnaire was administered to participants prior to attending the groups asking their opinions about the process of decision making. The Consumer's Health Info Preferences measure, developed by Maibach et al. is not "scored" in the general sense of the term. Instead, it is used to classify respondents into one of four categories, based on their relative orientation to being independent in health decision making and being engaged in health enhancement. Clinical Practice guidelines related information was abstracted from the existing 61 transcripts when available.

Task 5: Data Analysis and Evaluation

All qualitative data has been coded and reviewed as planned. Using this coding system, the team engaged in a coding work and data extraction to develop our analysis process with 18 participants for whom the main NBB management decision was to have surgery as a test process. These surgical cases were richly detailed, focusing on a clear problem and significant decision. This process involved numerous careful readings of the text, an extraction of the participant quotes that identified the reported factors, mechanisms, and outcomes of these surgical decisions, and the export of this data into tables. From these tables, we produced a reporting matrix that enabled us to identify thematic patterns within this subset. These analyses are based on project aims.

Qualitative analysis is ongoing, focusing now on the entire sample across aims. Team members completed a matrix table by aim summarizing qualitative information obtained through interviews with the 61 study participants. This process included in-depth reading and engagement with the transcript and coded data that provided the necessary data to address the project's 3 aims. Following completion of the matrix, we are currently conducting a quality review of data entered to ensure data accuracy and consistency. Next, an inductive approach to thematic content analysis will be used to identify themes and patterns across the entire sample. The result will be a comprehensive list of factors used in the sample in making decisions (aim 1), detailed processual behaviors, cognitive steps and emotional responses to decision making (aim 2), and description of the outcomes of the decision (aim 3). We have reviewed each case for decision-making style (doctor-led, participant-led, or shared) and satisfaction scores or ratings with decision outcomes and quality of life. Moving forward, we will complete this analysis for main thematic patterns in the entire set, towards final reporting and dissemination.

Quantitative analyses for the surgery and whole samples have been conducted for demographic characteristics, based on selected study's measures, and examining their associations. Quantitative analyses included importing the study data into SPSS and preparing it for analysis. Findings described surgery participants being on average 54.7 years old and 25 years' post-injury. Most participants were diagnosed with complete paraplegia (37.7%). Their demographic characteristics are displayed below. These were used for a manuscript submitted and accepted for the Journal of Spinal Cord Medicine. See **Appendix C**.

Table 2: Demographic and Injury Characteristics for Surgery Cases (n=61)

Sample Characteristics	% Distribution (frequency)
Gender - Male - Female	78.7% (48) 21.3% (13)
Race/Ethnicity - White - Black - Asian - White Hispanic - Unspecified Hispanic	80.3% (49) 6.6% (4) 1.6% (1) 1.6% (1) 4.9% (3)
Etiology - Vehicular - Sports - Fall - Violence - Other Traumatic - Medical - Non-Traumatic	36.1% (22) 18.0% (11) 16.4% (10) 9.8% (6) 4.9 % (3) 9.8% (6) 3.3% (2)
Military - Veterans - Civilians	49.2% (30) 50.8% (31)
Current Marital Status - Single - Married - Divorced	23.0% (14) 55.7% (34) 14.8% (9)

• Widowed	6.6% (4)
Education	
• <HS	1.6% (1)
• HS/GED	37.7% (23)
• Associates	16.4% (10)
• Bachelors	36.1% (22)
• Masters	4.9% (3)
• Doctorate	3.3% (2)
Neurological Status	
• Incomplete Paraplegia	21.3% (13)
• Incomplete Tetraplegia	21.3% (13)
• Complete Paraplegia	37.7% (23)
• Incomplete Tetraplegia	19.7% (12)

The proposed quantitative analysis plan focuses on the project aims. Quantitative measures have been classified in terms of whether they assess factors, decision-making mechanisms and outcomes. In addition, descriptive analysis of the standardized measures collected through the quantitative interviews was conducted, along with bi-variate analyses, which assessed relationships among measures and between these measures and other subject attributes. See some findings below.

There was no relationship between any of the measures of Decision Making (MDM) and age, either age was treated as a continuous variable or when it was bracketed into three groups. There were also no significant correlations between MDM and years since injury. The only significant relationship between any of the MDMs and years since injury was found when the latter was bracketed into three groups for the Melbourne Buck Passing scale ($p < .05$), for which the group with the shortest duration of injury (<10 years) had substantially lower scores than did others, indicating that they used Buck Passing less.

There were no significant relationships between any of the MDM and Neurological Classification, whether assessed using a 4-way classification scheme, or simply as paraplegia vs. tetraplegia. There were also no significant differences in any of the MDM as a function of gender, military service, level of education, having a caregiver and marital or employment status. The only significant difference in any of the MDMs as a function of income was for the Melbourne Buck Passing Scale ($p = .01$), with those with the highest incomes being significantly less likely to adopt this method of decision-making. There were trends for those with incomes in the middle categories to have lower scores on both COMRADE scales, indicating a tendency for these participants to have less satisfaction with their communication with their doctors and less confidence in their decision-making.

Scores on the COMRADE Confidence in Decision Scale differed significantly as a function of Satisfaction with Bowel Management as collected by the BBTI ($p < .05$), with those having greater confidence having greater Satisfaction and those with who were very dissatisfied have much lower scores on this COMRADE scale. There were no differences in scores on any of the MDM as a function of satisfaction with bladder management. No subjects in this sample were very dissatisfied with their Bladder Management and only two were dissatisfied. The PROMIS Cognitive scale had substantial negative associations with the three Melbourne Decision Making (MDM) Scales that our counterproductive: Hypervigilance ($r = -.377$), Buck Passing ($r = -.303$) and Procrastination ($r = -.461$). These were the only factors with significant relationships with any of the measures of Decision Making (DM).

The SCI-QOL Ability to Participate in Social Roles & Activities Scale had significant relationships with the two COMRADE scale, Satisfaction with Communication with Clinicians ($r=.311$) and Confidence in Decision ($r=.253$). The MOS Social Support Scale (MOS SSS) Emotional Scale was significantly associated with Satisfaction with Communications with Clinicians ($r=.325$). Similarly, the MOS SSS Tangible Scale was significantly associated with the same COMRADE scale ($r=.262$). The MOS SSS Positive Interaction Scale was associated with both the Satisfaction with Communications with Clinicians ($r=.345$) and the Confidence in Decisions ($r=.318$). Finally, The MOS SSS Total Score was associated with both the Satisfaction with Communications ($r=.339$) and the Confidence in Decisions ($r=.257$). The Measure of the Quality of the Environment (MQE) was also significantly associated with the Satisfaction with Communications with Clinicians ($r=.296$).

The COMRADE Confidence in Decision Scale was significantly associated with all four items on the International SCI QOL Dataset ($r = .318 - .499$). Similarly, the Satisfaction with Communication with Clinicians scale was significantly correlated with all but one of these four items, Satisfaction with Life as a Whole ($r = .299 - .454$ for the other three). Use of neither Vigilance nor Buck Passing were associated with any of the International SCI QOL Dataset items. Higher use of Hypervigilance was only associated with the Psychological Health Item ($r = -.285$) while higher use of Procrastination was associated with both the Psychological Health Item ($r = -.438$) and the Social Well-Being Item ($r = -.238$).

Focus Group Analyses: Qualitative data has been abstracted by case and by project aims. This information is summarized on a table. Data will be compared in relation to findings from the entire sample to note differences, similarities and patterns as well as new contributions arising from group dynamics. This will be taking place at the start of our second no cost extension, Fall 2021. Data from our consumer questionnaire used prior to focus groups resulted in some interesting findings. Based on their responses participants are grouped as “high” or “low” in terms of both of these constructs, leading to four possible classifications, which are described below.

- Independent actives place a high value on health information and preventative efforts, report a high degree of self-efficacy for understanding health information, and find doctors a reliable source of information. They collaborate with doctors but leave the health decision-making authority to themselves.
- Doctor-dependent actives place high importance on health information but find it hard to understand. They collaborate with their doctors and leave most of the decision-making up to them.
- Independent passives are less engaged in prevention than members of other segments. They are the least likely to have a collaborative relationship with their doctors and retain health decision-making authority for themselves.
- Doctor-dependent passives are also less involved in prevention and health information. They are the most likely to have difficulty understanding health information. They don't collaborate much with their doctors and allow them to make most of the healthcare decisions.

“Independent” refers to those who retain health decision-making authority for themselves. “Doctor-dependent” refers to those who leave the decision making to their doctor. “Active” refers to those that are more involved in health information and preventative efforts and “passive” refers to those who are less engaged.

Of the 10 participants that completed this measure, seven were identified as “Doctor-dependent active,” and three as “Independent-active.” None of our participants were classified as “Independent passive” or

“Doctor-Dependent passive” All of our sample is likely to be engaged in health information and preventative efforts. 67% of our sample leave the final decision-making up to their doctors although they collaborate with them. 33% retain health decision-making for themselves although they still collaborate with doctors. The responses to the 10 questions comprising the Consumer’s Health Information Preference measure are show on the next page along with the classification of respondents.

CPG Analyses: This data has been abstracted using standard forms created by the PI with the assistance of project investigators. These summary forms contain the current CPG guidelines for bladder and bowel after SCI. Thirty-seven CPG forms have been completed for bowel and 36 for bladder so far. Not all transcripts have sufficient information allowing to complete these forms. These analyses are planned for fall/winter of 2021/22 (months 50-52).

Longitudinal Analyses: In the coming year, we will conduct longitudinal comparisons of bladder and bowel health, QoL, and relevant decision-making issues among the 21 participants who were involved in both our 2012 DOD study and the current study. Targeted analysis will compare QoL outcomes, NBB symptoms and complications at the two points in time, changes in NBB management, factors of the decisions as they appeared in the previous study as compared to now, and overall shifts in decision-making styles (if available). Issues of stability and resilience, change and adaptation will likely provide insight into long-term coping with SCI, providing a context for decision-making.

Case Studies: We have identified 5 special cases in the data, further addressing each aim, that illustrate unique experiences and critical instances relative to NBB decision making. Identification of cases has been based on participants’ stories that most challenge the normative procedures of decision-making as seen in the wider literature and/or who cogently demonstrate the proposed theoretical relationship between aims as proposed in our original grant narrative. In particular, we have selected two civilians with incomplete injuries – one facing a bowel decision, the other a bladder decision – who both convey clear stories of their decision-making processes, with particular focus on participant-led versus shared decision-making. Further, we have selected three veterans with a range of both bowel and bladder issues as case studies – one, in particular, highlights the challenges of having a low, partial injury that outwardly signals less disability, but he still struggles with the challenges of bladder and bowel management and the confusion around decision-making in his care. Decisions made include the use of Botox, decisions to join a bowel routine clinical trial, balancing pain meds versus bowel continence needs, and weighing options around both bladder and bowel surgeries. These cases reveal the challenges of completing a decision and moving on, different points of view on patient agency with their healthcare team, and complications in outcomes that challenge future decision-making. Ideally, components of the theoretical model will have representative case reports, illustrating each of the study aims. These case studies will complement analyses about longitudinal data and/or CPG applications/discussions.

Major Task 6: Dissemination and Data Sharing

A number of dissemination products and data sharing activities occurred during the reporting period focusing on professional audiences. These are described below.

Virtual Presentations and Courses

- **Tate, D., Rohn, E., Walsh, S., Forchheimer, M., DiPonio, L., Rodriguez, G. and Cameron, A.**
Factors related to Decision Making About Surgery after Neurogenic Bowel and Bladder (NBB)

Following Spinal Cord Injury (SCI). 59th International Spinal Cord Society Annual Scientific Meeting, September 2020. Virtual Meeting.

- **Tate D, Pilasky C, Hoatlin, T.** Spinal Cord Injury: Looking after Body and Mind. European Spinal Psychologist Association (ESPA). *Tate keynote speaker: Decision Making About Living with SCI Complications*; Pilarsky – Clinical Implications; Hoatlin – Consumer Perspective. May 2021.

Abstract: Living with spinal cord injury (SCI) requires extensive personal decision making to address the many health issues and complications. People with SCI make daily decisions about their care that directly and indirectly affect the management of their condition and related complications. These decisions become particularly complex in that neurogenic bowel and bladder (NBB) broadly affect the whole person across multiple domains of daily life including social participation, sense of control, competence and wellbeing. Research in SCI suggests that strong self-efficacy and resilience may protect individuals from symptoms of depression, stress and anxiety associated with managing complications. Similarly, researchers have found that a sense of control was protective of psychological wellbeing during COVID-19 crisis in a non-SCI sample. This presentation compares these results in relation to new findings from a recent study being conducted to examine decision making about living with NBB complications after SCI.

Publications

Submitted and Accepted for Publication:

- Tate DG, Rohn EJ, Forchheimer M, Walsh S, DiPonio L, Rodriguez G, Cameron AP. Factors influencing decisions about neurogenic bladder and bowel surgeries among veterans and civilians with spinal cord injury. *Journal of Spinal Cord Medicine*. (Fall/Winter 2022)

Submitted and Pending Review:

- Rohn EJ, Scott H, Riedman E, Walsh S, Tate DG. Patient-driven Decision-making for Bladder or Bowel Management Following Chronic Disease or Disability in the United States: A Scoping Review. *Disability and Rehabilitation* (submitted Summer 2021)

Consumer Publications

Discussions took place during the advisory council meeting and Mr. Michael Harris, Executive Director of the Michigan PVA, provided a number of suggestions of how our findings could reach veterans consumers. He suggested completing a newsletter to be available to all with final findings. The project is currently exploring additional sources of funds for this publication. The PI has had two virtual meetings with Sunny Roller to discuss the format of a brief consumer publication summarizing the project findings.

What opportunities for training and professional development has the project provided?

Preliminary qualitative data based on participants' narratives were shared with professional audiences of SCI psychologists, physicians and nurses through national and international meetings. These are listed under the dissemination section. Furthermore, the PI presented findings at the annual meeting of ISCoS and will do a keynote presentation at ESPA listed earlier about decision making skills and findings for SCI

psychologists worldwide about ways to best assess dysfunctionality related to neurogenic bowel and bladder after SCI/D and their impact on quality of life.

How were the results disseminated to communities of interest?

Findings have been disseminated at professional meetings as listed in our dissemination activities. Furthermore, discussions have taken place about these preliminary findings with our advisory council and Mr. Harris, Executive Director of Paralyzed Veterans of America (PVA), Thomas Hoatlin, Development Officer and a person with SCI working at the Ann Arbor Center for Independent Living and Urologists from the Division of Urology at Michigan Medicine (Drs. Cameron and Stoffel). The Advisory Council meeting took place in July 2021. Meetings with Sunny Roller who will design the consumer publication took place in the Spring of 2021.

What do you plan to do during the next reporting period to accomplish the goals?

In order to accomplish the major task goals during the next reporting period, the study team will complete the final qualitative and quantitative analyses by aims. Data triangulation will be conducted to assess some qualitative and quantitative data jointly, as appropriate.

During our second no cost extension year, we plan the following activities (activity months are inserted in italics under the accomplishments by SOW section above):

- Activity 1: Complete virtual focus groups analysis to address the validity of our findings as well as to seek input into how this project can assist those making these decisions with tools, interventions or recommendations to the researchers and clinicians working on neurogenic bladder and bowel after SCI.
- Activity 2: Complete the analyses of case series exemplifying issues in decision making and successful solutions to problems.
- Activity 3: Complete longitudinal analyses comparing outcomes on two time points among a selected cohort of participants from our previous study.
- Activity 4: Complete all qualitative analyses by aim for all 61 cases.
- Activity 5: Complete data triangulation analyses including both qualitative and quantitative data.
- Activity 6: Continue to comply with IRB regulations and HRPO requirements and complete quarterly and final reports.
- Activity 7: Present and publish our project findings.
- Activity 8: Provide recommendations for clinical practice guidelines.
- Activity 9: Disseminate results to lay audiences.

4. IMPACT

What was the impact on the development of the principal discipline(s) of the project?

Nothing to Report

What was the impact on other disciplines?

Nothing to Report

What was the impact on technology transfer?

Nothing to Report

What was the impact on society beyond science and technology?

Nothing to Report

5. CHANGES/PROBLEMS

Due to the impact of COVID-19, the University of Michigan has suspended all in-person data collection until further notice. Changes to the IRB had to be done to allow for virtual interfaces instead. These tool sometimes longer then expected since many other university projects faced similar restrictions. The analyses of data took longer than expected as well as many details had to be addressed including data quality procedures before moving into the analyses phase. Qualitative data analyses require a comprehensive process of review and in many cases, transcripts and coding were not consistent requiring new coding for data accuracy. Research staff faced some challenges with COVID requiring special accommodations to allow for care of children and recovery when needed.

Changes in approach and reasons for change

No changes are being made.

Actual or anticipated problems or delays and actions or plans to resolve them

A second no cost extension request was submitted and approved for Year 5. The purpose of this request is to extend the period of performance by 12 months (through August 2022) at no additional cost to the government. During this extension year, we will complete all analyses by aims (quantitative and qualitative), focus groups analyses, longitudinal analyses and case series. We plan for another manuscript describing the case series and possibly two more dissemination products (publications and/or presentations) on our findings regarding mechanisms of decision-making and outcomes. A publication for consumers is also planned.

A final annual technical report will be due no later than September 2022. Quarterly/annual technical reporting and submission of the SF425 Federal Financial Form will continue through this extension period.

Changes that had a significant impact on expenditures

Nothing to Report

6. PRODUCTS

Publications, conference papers, and presentations

- **Tate, D., Rohn, E., Walsh, S., Forchheimer, M., DiPonio, L., Rodriguez, G. and Cameron, A.** *Factors related to Decision Making About Surgery after Neurogenic Bowel and Bladder (NBB) Following Spinal Cord Injury (SCI)*. 59th International Spinal Cord Society Annual Scientific Meeting, September 2020.
- **Forchheimer M., Tate D.** Differences Between Veterans and Civilians with Spinal Cord Injury. 2020 Paralyzed Veterans of America Healthcare Summit. *Abstract accepted for poster presentation prior to cancellation of PVA Summit due to COVID-19 concerns.*
- **Rohn, E. J., Nevedal, A. L., & Tate, D. G.** (2020). Narratives of long-term resilience: two cases of women aging with spinal cord injury. *Spinal Cord Series and Cases*, 6(1), 1-11.
- **Tate, D., Rohn, E., Walsh, S., Forchheimer, M., DiPonio, L., Rodriguez, G. and Cameron, A.** *Factors related to Decision Making About Surgery after Neurogenic Bowel and Bladder (NBB) Following Spinal Cord Injury (SCI)*. 59th International Spinal Cord Society Annual Scientific Meeting, September 2020. Virtual Meeting.
- **Tate D, Pilasky C, Hoatlin, T.** Spinal Cord Injury: Looking after Body and Mind. European Spinal Psychologist Association (ESPA). *Tate keynote speaker: Decision Making About Living with SCI Complications*; Pilasky – Clinical Implications; Hoatlin – Consumer Perspective. May 2021
- **Tate DG, Rohn EJ, Forchheimer M, Walsh S, DiPonio L, Rodriguez G, Cameron AP.** Factors influencing decisions about neurogenic bladder and bowel surgeries among veterans and civilians with spinal cord injury. *Journal of Spinal Cord Medicine*. (Fall/Winter 2022)
- **Rohn EJ, Scott H, Riedman E, Walsh S, Tate DG.** Patient-driven Decision-making for Bladder or Bowel Management Following Chronic Disease or Disability in the United States: A Scoping Review. *Disability and Rehabilitation* (submitted Summer 2021)
- **Rodriguez G, Berry M, Lin P, Kamdar N, Mahmoudi E, Peterson MD.** Musculoskeletal morbidity following spinal cord injury: a longitudinal study cohort of privately insured beneficiaries. *Bone* 2021, Jan. 142:115700. doi: 10.1016/j.bone.2020.115700. Epub 2020 Oct 20. Publication not directly related to our findings but related to the topic of spinal cord injury and complications from which decisions have to be made.

Books or other non-periodical, one-time publications.

Nothing to Report

Other publications, conference papers, and presentations.

None

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Name:	Denise Tate, PhD, ABPP
Project Role:	Principal Investigator
Researcher Identifier (e.g. ORCID ID):	0000-0001-5210-3704
Nearest person month worked:	1.8
Contribution to Project:	Dr. Tate continues to provide guidance and oversight to the project team while ensuring that all activities are being implemented as proposed. She has reviewed the proposed data analyses, data accuracy and dissemination products. She developed clinical practice guide and forms to abstract information from transcript and thus compare with current guidelines for bowel and bladder. She coordinates meetings with consultants and Advisory Council members. She prepared, submitted and received acceptance of our first project publication on factors influencing decision making after bowel and bladder dysfunction. She will continue to lead and participate in future publications. Dr. Tate attends regular team meetings, presented on project findings so far, reviewed project budget and led the preparation of reports.

Name:	Edward Rohn, PhD
Project Role:	Co-Investigator/Project Manager
Researcher Identifier (e.g. ORCID ID):	0000-0002-6092-2301
Nearest person month worked:	3.0
Contribution to Project:	Dr. Rohn has continued to oversee qualitative data collection and analysis, as the project unfolds. He is leading efforts in qualitative analysis, implementing

	and refining the procedures. He is also leading efforts in the longitudinal and case study analyses. He continues to serve as point-of-contact for DoD HRPO requirements. He provides oversight on the operations of the study, helping guide the work of the study team towards completing data collection and developing the coding scheme for data analysis. He is the lead author of our scoping review publication.
--	--

Name:	Martin Forchheimer, MPP
Project Role:	Co-Investigator
Researcher Identifier (e.g. ORCID ID):	0000-0002-7709-9622
Nearest person month worked:	2.4
Contribution to Project:	Mr. Forchheimer has conducted and provided guidance on quantitative data analysis. He has prepared a master plan for these analyses by aims while conducting analysis of quantitative measures for the project. He has worked with the study coordinator and RA in the development of the REDCap database to capture responses on the quantitative measures and has participated in general planning for study analyses and continues to participate in publications and presentations related to the project. He has provided some assistance with the qualitative analysis as well as with planning for data triangulation.

Name:	Suzanne Walsh, MBA/MA
Project Role:	Research Associate/ Consultant
Researcher Identifier (e.g. ORCID ID):	0000-0001-5210-3704

Nearest person month worked:	3.0
Contribution to Project:	Ms. Walsh has worked assisting the project team with the analyses and coding of qualitative data and preparing databases. She also assisted with focus group data, IRB submissions and report preparations. She attended many regular meetings until her departure on April 30 th 2021.

Name:	Lynn Charara, MA
Project Role:	Research Assistant
Researcher Identifier (e.g. ORCID ID):	0000-0003-4978-606X
Nearest person month worked:	0.30
Contribution to Project:	Ms. Charara worked on coding qualitative interviews and ensuring transcript accuracy. She participated in the planning of focus groups as well. Ms. Charara left the project September of 2020.

Name:	Ellen Wolgat
Project Role:	Research Assistant
Researcher Identifier (e.g. ORCID ID):	0000-0003-4559-1644

Nearest person month worked:	1.2
Contribution to Project:	Ms. Wolgat assisted in scheduling and interviewing participants for the focus group interviews and preparing databases and data summaries for Mr. Forchheimer.

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Nothing to Report

What other organizations were involved as partners?

Nothing to Report

8. APPENDICES:

Summary of Appendices

Appendix A – Q4 Quad Chart

Appendix B – Minutes from advisory council meeting

Appendix C – Editor's proofs of accepted manuscript

Neurogenic Bowel and Bladder Management After Spinal Cord Injury: Examining Factors Involved in Successful Decision-Making Processes

SC160219

W81XWH-17-1-0494

PI: Denise Tate, PhD

Org: Regents of the University of Michigan

Award Amount: \$774,994

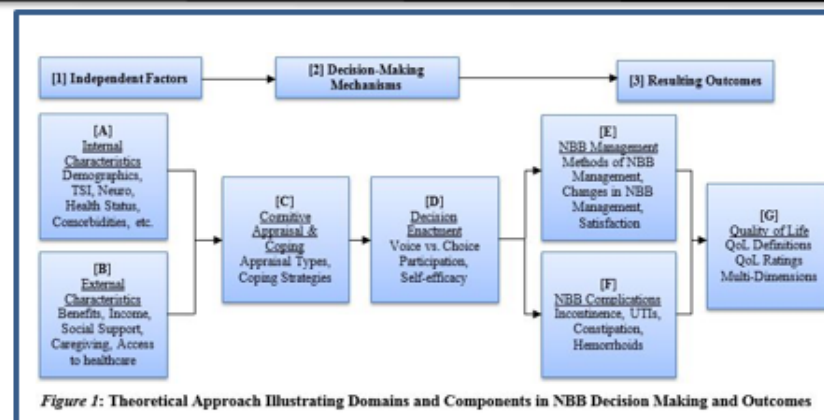


Study/Product Aim(s)

- **Aim 1 – Factors:** Identify and describe the factors influencing the decision-making process and changes in NBB management and related complications across time, considering age and time since injury.
- **Aim 2 – Mechanisms:** Assess participants' abilities and coping styles in carrying out NBB management decisions.
- **Aim 3 – Outcomes:** Assess the outcomes of these decisions on improving problems related to the management of NBB and reducing associated complications.

Approach

A qualitative methodology complemented by the use of selected quantitative measures. The sample consists of 60 persons with spinal cord injury; 30 recruited from our previous DOD study and 30 participants new to us. The objective is to investigate the factors, mechanisms, and outcomes of decision-making.



UM IRB is approved. VA IRB is approved. HRPO approved data collection for UM site and VA site. Data collection is completed at UM and VA sites. Data analysis is underway and manuscripts are being drafted.

Timeline and Total Cost

Activities	CY	17	18	19	20
Admin & instrument design					
Recruitment					
Data collection					
Analysis & dissemination					
Estimated Budget (\$K)		\$16,500	\$316,747	\$316,747	\$125,000

Updated: September 9, 2021

Goals/Milestones (Example)

CY17 Goal – Project start-up

✓ IRB development and submission

✓ Instrument design & finalization

CY18 Goals – Recruitment & data collection

✓ Implement recruitment strategies

✓ Begin data collection

CY19 Goal – Data collection & analysis

✓ Conduct interviews; adjusting for sample

✓ Begin coding of transcripts

CY20 Goal – Analysis & dissemination

✓ Identify and develop case reports

□ Disseminate findings to professional meetings and journals

Comments/Challenges/Issues/Concerns

• Study is finishing a one year NCXT; applying for 2nd NCXT

Budget Expenditure to Date through Y4Q (Total Costs)

Y4Q2 Projected Expenditure: \$71,329

Y4Q2 Actual Expenditure: \$39,021.04

Appendix B: Minutes from Advisory Council Meeting

U.S. ARMY/CDMRP/Department of SCIRP Sponsored Projects

Neurogenic Bowel and Bladder Management After Spinal Cord Injury: Examining Factors Involved in Successful Decision-Making Progress



2017-2021

Advisory Council Meeting Minutes

July 19, 2021 (2:00-3:30 pm)

Attendance: Anne P Cameron MD (Urology), Lisa Diponio MD (Ann Arbor VA), Michael Harris (MPVA), Gianna Rodriguez MD (Physical Medicine and Rehabilitation), Marty Forchheimer (Physical Medicine and Rehabilitation), Edward Rohn PhD (Oakland University), Denise Tate PhD (Physical Medicine and Rehabilitation).

Absent: John Stoffel MD (Urology) and Mark Luborsky PhD (Wayne State University)

Introductions and Updates

- Tate opened the meeting by welcoming everyone and asking for introductions. She proceeded to give a brief overview on the status of the project and reviewed the role of council members. This constitutes the final meeting of this council. Separate information will be sent to members as available.
- Next, she provided information on the project background and outcomes. The project is ending its first NCXT and has requested a second NCXT starting this September. This will cover analyses on case series, longitudinal comparisons, Clinical Practice Guidelines (CPGs), and analyses by aims.
- Two manuscripts have been submitted.

Review of Project Design and Aims

- Rohn described the project aims. These appear in the slide presentation made to the council and attached here. They include the identification of factors influencing these decisions, mechanisms adopted when making decisions related to NBB, and outcomes.

Review of Results

- Forchheimer reviewed the characteristics of the sample (n=61). When comparing civilians with veterans only a few differences were noted. Veterans were older, more likely to be male, married, and retired. They were also different in terms of insurance sponsorship with veterans being mostly covered by VA benefits.
- Rohn presented on the type of bladder and bowel decisions made. So far 36 decisions were identified as related to bladder and 22 in relation to bowel. Bladder decisions were mostly procedural, or surgery-related while bowel decisions included a high proportion of behavioral steps involved in changing routines or bowel program.
- Rohn also described the *factors* influencing these decisions and provided quotes from participants during their interviews. Next, he spoke about *mechanisms* and the processes of decision-making including decision making styles. Dr. Rodriguez asked how participants were classified into their role in making these decisions. She also brought up the objective and subjective aspects of decision making. Study classification was: a) participant led - the participant made the final decision; b) provider led – the doctor provided his/her recommendation on this decision and participant followed it without questioning; or c) shared-decision making, the participants was provided information by the doctor, he/she evaluated this information in relation to his/her expectations and values, preferences and made the final decision accordingly. This classification process is not precise and includes some grey zones, based on the information provided by the interviewee. Investigators reached final conclusions based on available information and/or discussed with colleagues when the situation was unclear, to reach consensus.
- Rohn lastly discussed data on *outcomes* (medical and psychosocial). There were no differences in quality-of-life ratings between veteran and civilian study participants. Similarly, there were no differences in their confidence in their clinician or their satisfaction with decisions. Rohn explained that linking “who” made the decision with the type of decision made would be interesting to examine. Tate reminded the group that based on data from surgery cases only, bowel cases included more shared decision-making enactment than bladder cases, possibly because there is less evidence with respect to bowel methods and treatments available to patients.
- Tate provided a summary of the data related to urinary tract infections (UTIs). Most bladder decisions included problems with recurrent UTIs. She presented an example of successful decision making and another of an unsuccessful outcome. Clear differences can be noted in terms of the quality of relationships with doctors, personality style and characteristics, cognition, and fear of outcomes.
- Tate then provided a brief description of information derived from these narratives regarding CPGs for bladder and bowel. PVA CPGs were used to identify critical components of these guidelines. This information was then transformed into a simple form used to extract data from these interviews. In most cases, CPGs seemed to have been followed.

Council Discussion and Recommendations

- Dr. Cameron explained that new guidelines for bladder will be available from the AUA in September. She did not think PVA bladder guidelines were updated. She will send these guidelines when they are available.
- Dr. Rodriguez asked about ways to evaluate cognition from a participants' perspective. The project used the PROMIS 4 items to evaluate cognitive functioning. This is a self-report measure and there were no differences between the veterans and civilians in scores, though those who discussed bowel decision had scores indicating better cognition. Tate explained that this could be due to bowel decisions requiring greater cognitive evaluation of each treatment recommendation since there is no clear evidence-based guidelines for bowel yet.
- Harris explained that when he goes to the doctor he simply asks for their recommendation on treatments since they are the experts and he trust his doctors with their knowledge about these issues. This was in response to issue raised earlier about some individuals being dissatisfied with their doctors' communication about their problems. In emergency situations, when participants had no choice but to accept a doctors' recommendations or to face greater health risks including mortality, participants later complained about having to accept outcomes and not having sufficient time to discuss them.

Implications for CPGs – educating professionals and consumers about these is essential. Harris brought up the issue of participants with SCI who had to be seen at smaller community hospitals where the medical staff is not educated about SCI. He mentioned some issues at Michigan Medicine. He suggested making information about CPGs readily easily accessible on websites and YouTube videos.

Dissemination for Professionals – Dr. Rodriguez brought up the issue of time required for more detailed communication with patients to help them make decisions. She said that it would be beneficial if physicians could get help from other clinicians, e.g. nurses and others to explain to patients the details of proposed treatments and answer their questions, as well as the possibility of decision-making tools for clinical use. Harris mentioned the importance of using social media to educate both consumers and professionals.

Dissemination for Consumers – Harris described his own experience using social media to learn about different procedures especially YouTube and websites. He prefers visual aids for this type of information. He also spoke highly of the use of telemedicine to address symptoms and questions patients may have to avoid waiting long time to get an answer. Lastly, he mentioned learning from other patients and peers as one of the best ways to feel confident about one's decisions. This includes support groups, blogs, etc. This is so important as many of these decisions require an individualized approach. As an example, he cited aging with SCI and bowel changes. There is very little information about that in the literature and yet this is such an important issue. He also asked about the

Appendix B: Minutes from Advisory Council Meeting

newsletter we used to produce on SCI relevant issues. Tate explained that there were no funds to produce such newsletters any longer. Harris offered to check with his board at MPVA if such funds would be available so a newsletter on projects findings could be produced. Decision making tools can be helpful in creating greater awareness of treatments and issues to consider when making such important decisions.

Conclusion and Future Steps

Tate thanked the group for their guidance and recommendations. She and the team will summarize this meeting and send to all council members in the future. They will keep updating the council as new findings or manuscripts (main aims findings, case series, longitudinal analyses) are available until project conclusion. They will prepare a tentative budget for producing a newsletter on project findings and will send to MPVA for possible consideration.

Respectfully submitted,

Denise G Tate PhD, Project Principal Investigator.

Appendix C – Editor’s Proofs of Accepted Manuscript

See pages that follow.

Factors influencing decisions about neurogenic bladder and bowel surgeries among veterans and civilians with spinal cord injury

Denise G. Tate, Edward J. Rohn, Martin Forchheimer, Suzanne Walsh, Lisa DiPonio, Gianna M. Rodriguez, Anne P. Cameron

QUERY SHEET

This page lists questions we have about your paper. The numbers displayed at left are hyperlinked to the location of the query in your paper.

The title and author names are listed on this sheet as they will be published, both on your paper and on the Table of Contents. Please review and ensure the information is correct and advise us if any changes need to be made. In addition, please review your paper as a whole for typographical and essential corrections.

Your PDF proof has been enabled so that you can comment on the proof directly using Adobe Acrobat. For further information on marking corrections using Acrobat, please visit <http://journalauthors.tandf.co.uk/production/acrobat.asp>; <https://authorservices.taylorandfrancis.com/how-to-correct-proofs-with-adobe/>

The CrossRef database (www.crossref.org/) has been used to validate the references. Changes resulting from mismatches are tracked in red font.

AUTHOR QUERIES

QUERY NO.	QUERY DETAILS
Q1	Please note that the ORCID has/have been created from information provided through CATS. Please correct if this is inaccurate.
Q2	A Quotation mark seems to be missing following ““ <i>Why don’t you just take me back ...</i> ”. Please indicate where it should be placed.
Q3	Funding details (USARMY) have been taken from information supplied with your manuscript submission and checked against the Open Funder Registry and we failed to find a match. Please check and resupply the funding details.
Q4	The CrossRef database (www.crossref.org/) has been used to validate the references. Mismatches between the original manuscript and CrossRef are tracked in red font. Please provide a revision if the change is incorrect. Do not comment on correct changes

Research Article

Factors influencing decisions about neurogenic bladder and bowel surgeries among veterans and civilians with spinal cord injury

Denise G. Tate¹, Edward J. Rohn^{1,2}, Martin Forchheimer¹, Suzanne Walsh¹, Lisa DiPonio^{1,3}, Gianna M. Rodriguez¹, Anne P. Cameron⁴

¹Department of Physical Medicine and Rehabilitation, Michigan Medicine, University of Michigan, Ann Arbor, Michigan, USA, ²Department of Interdisciplinary Health Sciences, Oakland University, Rochester, Michigan, USA, ³Veterans Administration Ann Arbor Health Care System, Ann Arbor, Michigan, USA, ⁴Department of Urology, Michigan Medicine, University of Michigan, Ann Arbor, Michigan, USA

Objective: This study investigated factors influencing surgical decision-making (DM) to treat neurogenic bladder and bowel (NBB) dysfunction for veterans and civilians with spinal cord injury (SCI) in the United States (US).

Design: Semi-structured interviews complemented by survey measures.

Setting: Community-dwelling participants who received treatment at a major Midwestern US medical system, a nearby Veterans Affairs (VA) facility, and other VA sites around the US.

Participants: Eighteen participants with SCI who underwent surgeries; completed semi-structured interviews and survey measures.

Interventions: Not applicable.

Outcomes Measures: Semi-structured interviews were coded to reflect factors, DM enactment, and outcomes, including surgery satisfaction and quality of life (QOL). Quantitative measures included COMRADE, Ways of Coping Questionnaire, Bladder and Bowel Treatment Inventory, PROMIS Global Health and Cognitive Abilities scales, and SCI-QOL Bladder and Bowel short form.

Results: Themes identified about factors influencing DM included: recurrent symptoms and complications; balancing dissatisfaction with NBB management against surgery risks; achieving independence and life style adjustments; participant's driven solutions; support and guidance and trust in doctors; and access and barriers to DM. DM enactment varied across surgeries and individuals, revealing no clear patterns. Most participants were satisfied with the surgery outcomes. Some differences in demographics were observed between veterans and civilians.

Conclusions: We have attempted to illustrate the process of NBB DM as individuals move from factors to enactment to outcomes. Attending to the complexity of the DM process through careful listening and clear communication will allow clinicians to better assist patients in making surgical decisions about NBB management.

Keywords: Spinal cord injury, Veterans, Neurogenic bladder and bowel, Surgery, Decision making, Quality of life outcomes

Introduction

Living with spinal cord injury (SCI) requires extensive decision-making (DM) in order to manage the complexities of care. DM is defined as a process of selecting

a course of action from a set of alternatives to manage complications associated with SCI.¹⁻³ Common complications associated with neurogenic bladder and bowel (NBB) include urinary tract infections (UTIs), incontinence, renal function deterioration, and bladder and renal stones; constipation, and hemorrhoids.⁴ Surgeries are one way of addressing a number

Correspondence to: Denise G. Tate, Department of Physical Medicine and Rehabilitation, University of Michigan, 323 E Eisenhower suite 101, Ann Arbor, MI 48109, USA. Email dgtate@umich.edu

of NBB complications for which other treatments have failed, yet the decision to move forward with a surgical intervention is often complex and requires consideration of numerous factors. NBB dysfunction remains one of the most life changing and stigmatizing consequences of SCI, affecting the *whole person* across multiple domains of daily life.⁵⁻⁷ The effects of NBB management decisions on quality of life (QOL) highlight the importance of understanding the process of DM, its influencing factors and potential outcomes.

Very little research has been conducted in this area for SCI. The findings described herein are part of a study funded by the US Department of Defense designed to address the various factors influencing DM related to NBB among veterans and civilians with SCI. Many factors play a role in DM related to NBB. Individual specific factors include physical, cognitive, psychological and behavioral characteristics such as personal values, cognitions, and beliefs. External factors in turn refer to systems-level structural and social forces that inform individual constructions of experiences, and on-going modulation, shaping social contexts and functioning.⁸ Specifically, access to community resources, income, benefits, and health care systems provide the broad context in which decisions are made.

Among personal factors, decisional involvement by patients in surgical treatment has been mentioned by Hawley *et al.*⁹ Initiatives to inform persons with SCI and involve them in decisions about their care may influence beliefs of self-efficacy and expectations about treatments received, and their role in DM. Closely related to involvement is the concept of enactment. Entwistle *et al.*⁸ operationalized decision enactment as involving two broad aspects in the DM process: *what* factors influence the decisions (*i.e.* severity of symptoms, need for autonomy, emotional support) and *who* ultimately influences the final decision (*i.e.* patient, provider, caregiver, family). Enactment can be complicated by the lack of standards of practice in managing NBB, especially bowel dysfunction, that often requires individualized solutions. In many instances, achieving personal wellbeing through practical solutions guides these decisions in absence of more clear guidelines related to treatments. Coggrave *et al.*⁵ found that 15% of patients seeking improved autonomy from bowel management needs underwent stoma surgery (ileostomy or colostomy) due to challenges in receiving assistance for bowel care.

In a meta-synthesis of qualitative studies of bladder management following neurologic diseases, Welk *et al.*¹⁰ found benefits and risks, a sense of control,

and the broader social circle having a voice in the decision were all factors in DM. While these studies provide insight into DM for NBB management, they do not provide a full picture of the processual nature of DM, wherein the complex factors, decision enactment, and resultant outcomes unfold through patient narrative data. This article attempts to provide this processual point of view, exploring decision factors and their influence on the DM process including enactment and satisfaction with outcomes in a sample of veterans and civilians with SCI. Data on personal characteristics, surgery type and external factors were used to further describe this process.

Methods

Design

This study utilized a multi-methods design using a purposive sample. This sampling strategy allows for intentional screening of potential participants based on the research question, assuring those included have experienced the issue under investigation. This approach allowed for the intentional selection of 18 participants with SCI (7 civilians and 11 veterans) who underwent surgery for various NBB complications or related emergency conditions. The choice of surgical treatments reflects the intention to examine cases for which no other solutions were deemed satisfactory. Eligibility criteria included being at least one-year post-SCI, 18 years of age or older, having NBB dysfunction, and involvement in a decision related to NBB that lead to a surgical treatment. Recruitment occurred through a major Midwestern hospital and associated clinics, a University-managed SCI patient research registry, a nearby VA center, and assistance from the Paralyzed Veterans of America (PVA). The final sample was a mix of civilian (38.8%) and veteran (61.2%) participants who underwent surgeries from 2000 to 2019.

Qualitative methods included using an in-depth semi-structured interview tool designed to elicit detailed, narrative responses of participants' decision making, while allowing participant-driven responses to emerge freely. Interviews lasted 45-90 min and were conducted over the phone or in person with an interviewer trained in qualitative data collection. The interviews were audio recorded, transcribed, and then coded using NVivo12.¹¹ The coding scheme targeted decision factors, enactment steps, and resulting outcomes, including QOL reflections.

Quantitative methods involved a number of Patient Reported Measures (PROMs) selected to compliment the narrative data and describe the participants' psychosocial characteristics (*i.e.* coping, global health and

wellbeing, cognitive abilities, self-efficacy, social support, and decision enactment). Surveys were administered by phone within two weeks of the qualitative interview. We used the Bowel and Bladder Treatment Index (BBTI)⁴ to provide an overview of current NBB management methods and satisfaction. We assessed QOL with the SCI-QOL Bladder and Bowel scales,¹² and SCI-QOL Ability to Participate and Satisfaction with Social Roles and Activities short forms.¹³ The Combined Outcome Measure for Risk Communication and Treatment Decision Making Effectiveness (COMRADE) assessed confidence in DM and satisfaction with communication with providers.¹⁴ PROMIS measures were used to assess global health and cognition.^{15,16} A full list of the PROMs used to assess psychosocial factors are shown in Table 1.

Analyses

Qualitative data was analyzed using content analysis to identify individual topics, shared themes, and broad patterns in the interview transcripts.^{17,18} Topics were identified using a deductive coding scheme designed to identify text that addressed the type of surgery, factors used in the decision to seek and carry through with surgery, the participants' steps in enacting their decision, and the resulting outcomes of their decision to have surgery. Data were assembled into a matrix, which displayed the demographics, surgery type, factors, enactment steps, and outcomes for each participant, including example quotes.

Each participant's narrative was independently rated by three investigators to determine the style of DM enactment used in each case. These fell into three broad categories: (1) participant-led decisions (when active engagement and leadership for the final decision stemmed primarily from the participant); (2) shared DM (when decisions were based on clear collaborative relationships of equitable roles); or (3) doctor-led decisions (when the participant left the decision primarily to their doctor). Each decision was placed exclusively into one of these three categories.

Using the data matrix, pile sorting was used to generate themes that represented patterned responses across multiple participants that characterized the factors, enactments, and outcomes of surgical DM. Quotes from participants were used to illustrate these themes and preserve individual voices on these issues. Surgeries were roughly grouped by purpose and similar procedural steps for comparison purposes. These surgeries appear in Table 2. Throughout all

qualitative analysis steps, authors discussed any discrepancies until consensus was reached.¹⁹

Statistical analyses were conducted to describe all quantitative variables. To test for sample differences and relationships among variables, Chi square, t-tests, ANOVAs, and Pearson correlations were computed, depending on the nature of the variables involved. Significance was set at $P < .05$ to detect differences. While significance testing was conducted, analyses were limited by the small sample size, and the purpose of this qualitative analysis was primarily to highlight trends in the data, which could help us contextualize thematic findings, and not to test established hypotheses. Throughout both qualitative and statistical analyses, differences between civilians and veterans were investigated.

Results

Demographic, neurological, and surgery characteristics

Table 1 shows key demographic and neurological attributes of the participants, along with scores on the study's psychosocial measures. Our exploratory analyses suggested some potentially important differences in spite of the small sample sizes. Veterans were older ($P < .033$); more likely to be married or divorced ($P < .027$); and receiving VA insurance ($P < .011$). Civilians reported lower mental global health as measured by the PROMIS ($P < .033$); greater dissatisfaction with their bowel management ($P < .048$); and less satisfaction with their ability to participate in social activities ($P < .004$). Other trends in the data are indicated in Table 1.

Half of bladder surgeries performed involved stomas or suprapubic tube insertion, followed by ileal conduits (30%). For bowel, colostomy (42.8%) followed by ileostomy (28.5%) and hemorrhoidectomy (28.5%) were the main surgeries. Bladder surgeries were performed mostly on those with incomplete tetraplegia (40%), followed by those with complete tetraplegia (30%) while bowel surgeries were performed mainly on those with complete paraplegia (87.5% compared to only 10% for those with bladder surgeries, $P < .01$). There were no differences in terms of bladder and bowel surgeries and participants' psychosocial characteristics based on their survey scores, with the exception of their cognitive abilities. Those who underwent bowel surgeries reported higher cognitive abilities than did those with bladder surgeries: 53.76 (SD 7.26) versus 46.54 (SD 6.62); $P < .040$.

Table 1 Differences in participant characteristics by civilian and veteran status and total sample characteristics.

	Characteristics	Civilians (n = 7)	Veterans (n = 11)	Total Sample (n = 18)	P*
315	Age: Mean (SD)	47.43 (13.28)	59.36 (8.52)	54.72 (11.87)	.033
	Time Since Injury: Mean (SD)	21.86 (15.78)	26.73 (16.13)	27.06 (16.02)	
	Neuro Classification (%)				370
	Incomplete Tetraplegia	28.6	18.2	22.2	
	Complete Tetraplegia	28.6	27.3	27.8	
320	Incomplete Paraplegia	14.2	9.1	11.1	
	Complete Paraplegia	28.6	45.5	38.9	
	Sex (%)				.093
	Male	57.1	90.9	77.8	
	Female	42.9	9.1	22.2	375
	Marital Status (%)				.027
	Single	57.2	0	22.2	
325	Married	42.9	63.6	55.6	
	Divorced	0	27.3	16.7	
	Widowed	0	9.1	5.6	
	Education (%)				
	Bachelors	71.4	54.5	61.1	380
	Associate	0	27.3	16.7	
330	HS/GED	28.6	18.2	22.2	
	Income (%)				
	<25K	14.3	18.2	16.7	
	25–39K	28.6	9.1	16.7	
	40–59K	28.6	18.2	22.2	
	60–79K	0	18.2	11.1	385
	>80K	14.3	27.3	22.2	
335	Unknown	14.3	9.1	11.1	
	Insurance (%)				.011
	VA	0	81.8	50.0	
	Auto No Fault	28.6	0	11.1	
	Private	14.3	9.1	11.1	390
	Medicare	28.6	9.1	16.7	
	Medicaid	28.6	0	11.1	
340	PROMIS Global Health				.033
	Physical: Mean (SD)	45.10 (10.00)	47.42 (4.24)	46.52 (6.88)	
	Mental: Mean (SD)	46.36 (6.14)	52.89 (5.60)	50.35 (6.52)	
	PROMIS Cognitive Abilities	47.01 (9.89)	50.57 (6.62)	49.19 (7.97)	
	MOS Social Support				395
	Tangible	84.82 (17.99)	88.64 (15.26)	87.15 (15.97)	
	Affectionate	75.00 (15.21)	81.06 (28.16)	78.70 (23.61)	
345	Positive Social Interactions	61.90 (19.16)	79.55 (25.92)	72.69 (24.56)	
	Emotional/Informational	65.63 (18.22)	77.28 (21.52)	72.75 (20.58)	
	SCI-QOL Bowel Management.	52.16 (6.17)	48.33 (6.29)	50.07 (6.76)	.004
	SCI-QOL Bladder Management.	47.13 (6.63)	48.67 (6.75)	48.07 (6.55)	
	SCI-QOL Bladder Complications	48.49 (6.96)	46.00 (6.98)	46.97 (6.88)	400
	SCI-QOL Ability Participate	43.39 (3.63)	52.66 (6.62)	48.40 (7.22)	
	In Social Activities				
350	WOC				
	Seeking Social Support	30.16 (19.73)	35.86 (25.50)	33.64 (22.98)	
	Escape Avoidance	7.14 (6.88)	17.43 (12.89)	13.43 (11.83)	.071
	Positive Reappraisal	30.61 (16.00)	28.57 (17.04)	29.37 (16.19)	
	Accept Responsibility	16.67 (13.61)	20.45 (23.08)	18.98 (19.56)	405
	Planful Problem Solving	22.76 (6.27)	26.67 (12.74)	25.15 (10.64)	
355	Confrontive Coping	10.47 (8.26)	11.82 (9.11)	11.30 (8.57)	
	Distancing	18.09 (3.25)	18.78 (10.57)	18.52 (8.34)	
	Self-Control	15.24 (13.03)	26.97 (14.02)	22.41 (14.50)	.095
	Moorong Self-Efficacy				
	Daily Activities	46.57 (6.37)	48.82 (9.27)	47.94 (8.14)	
	Social Functioning	41.29 (2.14)	41.36 (5.75)	41.33 (4.59)	410
	Total Score	87.86 (8.05)	90.18 (13.57)	89.28 (11.51)	
360	COMRADE				
	Satisfaction w/Communication	73.93 (28.35)	76.59 (13.15)	75.56 (19.68)	
	Confidence in Decision	72.50 (31.39)	78.86 (17.44)	76.39 (23.17)	

Continued

Table 1 Continued

Characteristics	Civilians (n = 7)	Veterans (n = 11)	Total Sample (n = 18)	P*
BBTI Satisfaction w/Bowel Management				.048
Very Dissatisfied	14.3%	0.0%	5.6%	
Dissatisfied	28.6%	0.0%	11.1%	
Satisfied	57.1%	54.5%	55.6%	
Very Satisfied	0.0%	45.5%	27.8%	
BBTI Satisfaction w/Bladder Management				
Very Dissatisfied	0.0%	0.0%	0.0%	
Dissatisfied	0.0%	9.1%	5.6%	
Satisfied	57.1%	54.5%	55.6%	
Very Satisfied	42.9%	36.4%	38.9%	

Note: p values are included for differences that approached significance, $P < .10$ showing trends in the data; statistical significance was set at $P < .05$, and these p values are in bold.

Table 2 Categories of factors referenced by each participants as influencing decisions related to NBB surgery^a.

Surgery Type and Participant's Characteristics: age, sex, and neuro classification, year of interview and surgery	Complications Symptoms	Prior Methods of Management	Impact on QOL	Barriers/ Access to Resources	Treatment Approaches	Social Support	Doctor Factors	Participant Skills, Traits
<i>Bladder Augmentation</i> 40, female, incomplete Paraplegia Interviewed: 2018 Surgery: 2018	UTIs, kidney reflux	IC			Medications did not work		Trust	
<i>SP Catheter</i> 68, female, complete Paraplegia Interviewed: 2018 Surgery: 2017	Leakage, bed sores	IC	Burden to others	Caregiver	Unsuccessful method of management	SCI family member	Trust	Self-awareness
<i>SP Catheter</i> 61, male, complete Tetraplegia Interviewed: 2019 Surgery: 2000	UTIs, autonomic dysreflexia	Indwelling Foley	Changes in lifestyle	VA insurance	Unsuccessful method of management	Mother, neighbor	Trust	Self-directed
<i>SP Catheter</i> 49, male, complete Tetraplegia Interviewed: 2019 Surgery: 2015	Leakage, urine incontinence	Indwelling Foley	Changes in lifestyle Autonomy	Caregiver Limited hand function	Unsuccessful method of management	Wife	Trust	
<i>Mitrofanoff Valve</i> 48, male, incomplete Tetraplegia Interviewed: 2018 Surgery: 2017	UTIs, spasticity	Indwelling Foley, SP, IC	Changes in lifestyle	Caregiver	Unsuccessful methods of management	Husband, others	Trust	Nursing background, did own research
<i>Modified Indiana Pouch/stoma</i> 56, female, complete Tetraplegia Interviewed: 2019 Surgery: 2013	UTIs, autonomic dysreflexia	Tapping, indwelling catheter	Changes in lifestyle Autonomy	Caregiver Limited hand function	Unsuccessful methods of management	Sister, peers, friends	Trust	Inquisitive, resourceful, self-directed
<i>Ileo Vesicostomy</i> 41, male, incomplete Tetraplegia Interviewed: 2018 Surgery: Not available	UTIs	IC	Changes in lifestyle	Insurance coverage	Unsuccessful method of management	Nurse, peers, family	Trust	Driven style self-directed

Continued

Table 2 Continued

	Surgery Type and Participant's Characteristics: age, sex, sex, and neuro classification, year of interview and surgery	Complications Symptoms	Prior Methods of Management	Impact on QOL	Barriers/ Access to Resources	Treatment Approaches	Social Support	Doctor Factors	Participant Skills, Traits	
525	<i>Ileal Conduit</i> 71, male, incomplete paraplegia Interviewed: 2019 Surgery: 2002	Unable to void, UTIs, bladder pressure	IC	Changes in lifestyle	VA insurance	Medications did not work	Wife	Trust	Seeks information, free spirit	575
530	<i>Ileal Conduit</i> 55, male, incomplete tetraplegia Interviewed: 2019 Surgery: 2019	UTIs, renal failure	IC	Changes in lifestyle	Caregiver	Medications did not work	Wife	Trust	Positive disposition, spiritual	580
535	<i>Nephrectomy</i> 51, male, incomplete Tetraplegia Interviewed: 2019 Surgery: 2014	UTIs, leakage, kidney stones	IC	Urine odor	VA insurance	Medications did not work	Wife	Trust		585
540	<i>Hemorrhoidectomy</i> 61, male, complete, tetraplegia Interviewed: 2018 Surgery: 2018	Bleeding, pain, soreness	Digital stimulation	Changes in lifestyle		Unsuccessful minor surgeries	Wife	Trust	Self-awareness	590
545	<i>Hemorrhoidectomy</i> 48, male, complete paraplegia Interviewed: 2019 Surgery: 2019	Bleeding, autonomic dysreflexia	Digital stimulation		Insurance coverage	Unsuccessful method of management		Trust		595
550	<i>Colostomy</i> 44, male, complete paraplegia Interviewed: 2018 Surgery: 2012	Hemorrhoids, autonomic dysreflexia, diarrhea constipation	Digital stimulation		Cost of surgery	Medications did not work	Family	Trust		600
555	<i>Colostomy</i> 67, male, complete paraplegia Interviewed: 2019 Surgery: 2019	Bowel incontinence, wounds	Digital stimulation	Changes in lifestyle, intimacy		Unsuccessful method of management	Friends	Trust	Self-directed	605
560	<i>Colostomy</i> 68, male complete paraplegia Interviewed: 2019 Surgery: 2013	Bowel incontinence, wounds	Digital stimulation, laxatives, diet	Changes in lifestyle	Insurance coverage	Unsuccessful method of management	Family, friends	Trust	Religious, strong willed	610
565	<i>Colostomy, Ileostomy</i> 57, male, complete paraplegia Interviewed: 2019 Surgery: 2012	Abdominal pain, wounds	Digital stimulation	Body image, intimacy	VA insurance	Unsuccessful method of management		Trust		615
570	<i>Ileostomy</i> 50, male, complete paraplegia Interviewed: 2019 Surgery: 2016	Ruptured bowel	Digital stimulation, suppositories enemas	Changes in lifestyle	Caregiver	Unsuccessful methods of management	Sister, family	Trust	Self-directed	620
575	<i>Ileostomy, Colostomy</i> 70, male, complete paraplegia Interviewed: 2019 Surgery: 2011	Incontinence, bowel accidents, wounds	Digital stimulation	Body image	Caregiver, nurse	Unsuccessful Method of management	Wife, nurse, caregiver	Trust		625

^aBlank cells reflect lack of information provided by the participant about this category of factors.

Factors influencing surgery decisions

Table 2 illustrates the factors influencing DM related to NBB surgeries for each participant. Across eight broad categories of factors, all participants endorsed increased frequency and/or severity of symptoms, and trust in their doctor. Testimonials ranged from clear satisfaction to great disappointment in how their providers communicated. Other factors included problems with current methods of bladder or bowel management (94.4%), and ineffective treatments, including issues with medications and supplies such as catheters (94.4%).

Recurrent UTIs, incontinence, wounds, renal complications, and ineffective bladder medications were the major reasons given for seeking bladder surgeries, and intermittent catheterization was the most common management method prior to surgery. Bleeding hemorrhoids, bowel incontinence, wounds, and ineffective management methods were the primary reasons given for seeking bowel surgeries, with digital stimulation the most common pre-surgery management method used.

A number of factors influenced both bladder and bowel DM without being explicitly tied to either. Independent lifestyle, autonomy and body image concerns were all important factors, with some reference to possible impact (positive or negative) on QOL as a factor in DM for 13 of the participants (72.2%). Access to or barriers to resources enabling or limiting DM was mentioned by 12 (66.6%) participants. Emotional and social support, coming from family members, peers and friends, along with providers, was a DM factor for 14 (77.7%) participants. Eleven participants (61.1%) espoused self-awareness, self-direction, spiritual strength, and/or high motivation to find their own solutions for problems, directly informing DM.

In summary, surgery decisions were shown to be influenced by the perceived risk of more serious complications, the benefits of having a more effective or easier method of management, need for independence, physical and financial access to hospitals and experienced doctors, concerns about body image and sexuality, embarrassment due to accidents, and past experiences with surgeries. The interplay of these factors contributed to the potential enactment and outcomes of a surgical decision.

Common themes illustrating factors in DM

Table 3 illustrates six related themes that contextualizing the experiences of the above factors influencing NBB surgery DM. In each case, examples from the

narrative text are provided, endorsing a multitude of factors within these themes. Themes include: (1) recurrent symptoms and complications; (2) balancing dissatisfaction with NBB management/treatment against surgery risk; (3) achieving independence, avoiding dependence, and life style adjustments; (4) behavior- or personality-driven solutions (*i.e.* doing their own research, talking to others, seeking guidance from professionals); (5) support and guidance, including communication with providers; and (6) access to resources and/or barriers influencing DM (*i.e.* appropriate healthcare facilities, knowledgeable providers, and caregivers help).

Recurrent symptoms and complications were mentioned by every participant as factors critical in DM. Participants recalled the lengthy efforts to overcome or manage stubborn NBB-related symptoms, including the ineffective approaches leading to surgical options, suggestive by theme *balancing dissatisfaction with NBB management/treatment against surgery risk*. Evaluating the pros and cons of surgery was a challenge. Most relied on trust in doctors, emotional support and clear communication. Reluctance or fear of surgical procedures led many to delay the surgical decision, only accepting surgery as a last resort. In numerous instances, these decisions were associated with last minute serious complications and life threatening situations. Mixed feelings of fear, anger, and gratitude indicate the emotions of participants in these life-threatening decisions.

Achieving independence, avoiding dependence, and life-style adjustments guided many surgery decisions. These participants accepted surgical risks for the possibility of achieving a better sense of control over their lives and greater social participation. These decisions were often associated with participants' engagement and involvement in the DM process resulting in satisfactory outcomes. Powerful emotions such as being a burden to others, feelings of guilt, embarrassment, and shame appeared in this theme. An example of these factors can be found for colostomy under row 3 of Table 3, where the participant clearly stated that the burden on his wife and his self-image guided his DM. Addressing uncertainty related to treatment effectiveness explain *participant behavior- or personality-driven solutions* towards DM. The same sorts of psychosocial characteristics that led to awareness of the impact of NBB on others motivated some to take action. These characteristics influenced participants' self-confidence in DM through gathering information, being the kind of people who decide things for themselves, and seeking out support in their DM process.

Table 3 Themes reflected in narratives of participants related to factors influencing NBB surgery.

Themes	Factors Cited Leading to Surgery	Narrative Quotes Illustrating DM Process
1. Recurrent symptoms and complications	Decision about suprapubic surgery <i>Cited factors:</i> bladder incontinence, wounds, did not have knowledge about contemporary methods, life threatening. Decision about hemorrhoidectomy <i>Cited factors:</i> hemorrhoids, bleedings, VA let him travel to where he could stay in-patient longer to recover, prior surgeries were not successful, concerns about re-injuring with digital stimulation.	<i>The decision was made because my spinal cord injury resulted in ... after all these years – huge, um, bedsores, called decubiti wounds. I didn't realize how bad it was. I let it go because I was just- I went to see a wound care doctor; he was treating them. Well, it turns out he wasn't treating them enough. I ended up going into the hospital septic and very, very sick. I mean I was on – close to death by that time. (68-year-old civilian woman with complete paraplegia)</i> <i>So basically I think I would be dead if it wasn't for the VA. I'll say, Okay, I am not going to do a program, so this way you are not getting the digital stimulation ... knowing that you will feel miserable. So, I'll say well, it's worth it that maybe the hemorrhoids will start subside some. Do everything you can before you get to go and get the surgery. (48-year-old male veteran with complete paraplegia)</i> <i>My urologist told me I better start checking with my relatives for a kidney transplant ... we tried all medications ... I don't like surgeries ... I was being catheterized ... maybe four times a day. And ... kept getting UTIs ... he (doctor) invented the procedure ... It's like there is no second opinion ... (41-year-old civilian male with incomplete tetraplegia)</i> <i>I could not put my wife nor myself through that anymore, and quite frankly, uh, it was more, uh, the decision I made for my wife's part, and not mine. My priority was my wife. Second ... was trying to get my wound to heal. And then, third would be embarrassment on my part. (68-year-old male veteran with complete paraplegia)</i> <i>I can wear pretty much whatever I want to and nobody knows that, I have this little stoma in my belly that that's how I drain my bladder. And I like it a lot better. (49-year-old civilian woman with incomplete tetraplegia)</i> <i>Doctor did not think a SP was appropriate "he did not believe it was safe for women". Participant did not want to have urine bag –had a Foley in place- doctor said to just "deal with it"; she was upset by his comments</i> <i>The walls were getting thicker ... and the bladder was not emptying it completely ... I kept getting these bladder infections ... that's to find out why I went and did some research to find out what I needed to do. (61-year-old male veteran with complete tetraplegia)</i> <i>Participant went to non-VA facility; he "knew" the VA wasn't going to do it, talked to friend's doctor who agreed about surgery, talked to neighbor with SCI, trust in doctor's skills and knowledge</i>
2. Balancing dissatisfaction with NBB management/ treatment against surgery risk	Ileovesicostomy <i>Cited factors:</i> recurrent UTIs leading to kidney failure, ineffective medications, reluctant about surgery at first.	
3. Achieving independence, avoiding dependence, and life style adjustments	Colostomy <i>Cited factors:</i> wounds, discomfort with wife caretaking for bowel management Mitrofanoff catheterizable channel <i>Cited factors:</i> recurrent UTIs, learned about Mitrofanoff from OT during inpatient rehabilitation, bad communication with doctor.	
4. Participant behavior- or personality-driven solutions	Suprapubic catheter <i>Cited factors:</i> urinary retention, spastic bladder, bladder infections, decisive personality, talked to others, trust in doctor.	

Continued

Table 3 Continued

885

Themes	Factors Cited Leading to Surgery	Narrative Quotes Illustrating DM Process
5. Support and guidance, including communication with providers	Colostomy <i>Cited factors:</i> life threatening situation with autonomic dysreflexia (AD), bad hemorrhoids, high blood pressure, pain medications caused constipation, dehydrated. Miscommunications with doctors.	<i>... I was literally 'gonna' die so they had to go in and they gave me a bag (Surgeon first refused colostomy but agreed after BP episode). They (doctors) should've given me a warning about all that let alone like, they should tell people ... (44-year-old civilian male with complete paraplegia)</i>
	Modified Indiana pouch <i>Cited factors:</i> anxiety about cathing, could not catheterize due to stoma bulge, trust and emotional support from doctor and caregivers.	<i>Participant not pleased with surgery outcomes, worried about mucus drainage, blockages, felt uninformed going into this surgery, forced into agreeing with decision, angry with doctor. ... I could not get the catheter in ... so my bladder gets full ... my body reacts with AD. I was very apprehensive to do that (surgery) initially. My doctor was very concerned about me ... she was willing to do whatever needed ... I feel more comfortable about reaching out to help through the VA doctors. I was very apprehensive to do that initially, um, um, when I was starting to have trouble in 2013. (56-year-old woman, veteran with complete tetraplegia)</i>
6. Access to resources and barriers influencing DM	Colostomy/ileostomy <i>Cited factors:</i> complications leading to surgery, bowel accidents, bladder incontinence, reluctant about caregiver help, shame and guilt; burden to wife; informed by nurse about surgeries.	<i>I was concerned that I'd have feces around the sores and as a result, cause further infection ... I'd sleep in the urine for a couple of hours (to) avoid a caregiver. It was always embarrassing, you know, having suppository and then ... having someone clean me up afterwards. (70-year-old male veteran with complete paraplegia)</i>
	Emergency ileostomy/temporary colostomy <i>Cited factors:</i> life threatening complications from surgery, pain, wounds, lack of choice due to severity of condition, lack of caregiver help.	<i>Participant slept in urine at night not to disturb spouse; did not like being helped with bowel program; ostomy nurse provided support and information. I was sitting there hollering in pain ... they rushed me into emergency surgery to find out that colonoscopy (colostomy) had collapsed or not working, which force them to do a permanent ileostomy.</i>
		<i>Participant developed bad sacral wounds; had flap surgery and temporary colostomy; was supposed to be in bed rest for 6 months but lives alone; could not do it.</i>

Support and guidance, including communication with providers was a clear theme that illustrated the broad range of social experiences that influenced DM. Chief among these was trust in providers' recommendations and guidance, their willingness to share information and degree of emotional support towards their patients. Individual experiences varied widely, with some experiencing effective, comfortable interactions with their doctors while others feeling angry about or neglected by their lack of clear communication. Emotional support for DM from family and caregivers was also frequently expressed. This social support feeds into the access to resources and barriers influencing DM, in that lack of caregiver assistance couple with limited physical functioning was a critical barrier for many that made the choice of surgery an essential step. For others, the idea of needing caregiving was associated

with embarrassment, dependence, and lack of privacy, linking back to the earlier theme of independence. The impact of differences in insurance benefits varied across the sample. Some veterans, for example, sought care outside the VA healthcare system when met with resistance; others were very happy with services and surgery benefits coverage received from the VA.

Enactment of surgery decisions

The actual acting out of NBB-related decisions takes into consideration the process described above. Table 4 illustrates the three broad DM enactment styles observed in the sample. For DM regarding bladder surgeries, 40% were participant-led; 40% involved shared DM; and 20% doctor-led. For bowel surgeries, 50% were participant-led; 37.5% were doctor led and 12.5% were shared DM. Across all

Table 4 Examples of categories of neurogenic bladder and bowel decision making enactment preferences after SCI.

Category of DM Enactment for Bladder Surgery	Process of Decision Enactment: Factors Leading to Acting	Narrative Quotes
Participant-led decision: SP catheter	Incontinence increased, developed sores, recurrent UTIs. Doctor suggested SP catheter instead to help with incontinence and keep wounds dry. Participant was reluctant about surgery but considered problems and doctor's recommendation making the final decision to undergo surgery; she expresses guilt about not doing it sooner	<i>She (doctor) suggested getting a SP. We fought for a while then I thought ok ... and it really helped. I'm dealing with the feeling that I caused part of it myself by not listening to my head, or whatever you listen to that tells you to go take care of it.</i> (68-year-old woman with complete paraplegia)
Shared Decision-Making: Ileal conduit	Unable to void; could not catheterize due to intense spasms; urine was backing up to kidneys; was not interested in SP catheter as he likes to swim. Participant talked to doctor, consider all options, did research, leveraged experience and knowledge as Army medic in making decision about surgery.	<i>I don't leave anything to chance. I'm like, "Okay, let's think this thing out." It was like how I chose an ileal conduit ... I look at all the various forms of surgery and things they could do, uh, and finally came down to the point where I asked the doctor. I say, "Okay, which one do you never have to go back and touch? Which one do you never have any trouble with? Which one do you not have to mess up with?" Oh, he said, "That's an ileal conduit." And I spent some time researching it and, you know, apparently it's right.</i> (71-year-old male with incomplete paraplegia)
Doctor-led Decision: Bladder augmentation	Recurrent UTIs with renal complications, kidney reflux; incontinence; increased need for catheterizations; ineffective medications. Participant had complete trust in doctor; good insurance coverage.	<i>I mean it's really simple. If you have a serious condition and your doctor tells you, you need surgery and, you know, you've tried other avenue, all other, I would think that most people should have a surgery, right? There was really nothing else that went into the decision-making process. Things were not clearing up. The medication was not working</i> (40-year-old woman with incomplete paraplegia).
Participant-led Decision: Hemorrhoidectomy	Bleeding hemorrhoids; takes pain medication; difficult bowel program; prior hemorrhoids surgeries (banding did not work); busy life style; considered persistent symptoms; trust in doctor; wife support; good insurance coverage.	<i>... I made the decision, because I know I've been having – bleeding too many days, too many weeks, or whatever. My wife just saying, okay you've made the decision. Let's go.</i> (61-year-old male with complete tetraplegia)
Shared Decision-Making: Colostomy	Wounds and discomfort with caretaking for bowel management; inconsistent bowel regimen led to accidents and aggravation of wounds; spouse managed bowel regimen; long history of surgeries so was not too concerned about colostomy; talked to a couple of doctors about their opinions; wife support.	<i>When I came home from the hospital, we had to put pads down, and I kept defecating into the pad, my wife would have to clean me and so, one thing led to another, and finally, um, the – the doctor said, "Well, would you want us to do a colostomy?" And it was the third time it had been suggested to me, and I looked at my wife, and I looked at the doctor, and I said, "Let's do it, and do it soon." (68-year-old with complete paraplegia)</i>
Doctor-led Decision: Emergency ileostomy	Rupture bowel; septic on arrival at hospital; non-responsive after X-Ray in ER; was not able to discuss the surgery with doctor until 2–3 days after surgery. Participant agreed with doctor but felt had no choice in order to survive.	<i>I was going septic ... had he not performed (surgery) right away I would have died ... he saved my life.</i> (50-year-old male with complete paraplegia)

surgery cases, 44.6% of DM was participant led with 27.7% being shared and 27.7%, doctor lead.

Shared DM (SDM) is a process of matching choices to patients' values and preferences with the goal of promoting individual autonomy.²⁰ SDM was used mostly by veterans (36.36%) compared to civilians (14.28%). Our examples in Table 4 show it being used in situations requiring more complex decisions (e.g. ileal conduit, nephrectomy, ileovesicostomy and Modified Indiana

Pouch bladder surgeries) as well as those requiring trust with no better options in view of persistent problems (e.g. colostomy).

The degree to which decisions were participant-led or shared decreased as the complexity or risk of the considered surgery increased. For example, DM enactment was less complex and more participant-led for straightforward bladder surgeries such as insertion of suprapubic catheters, hemorrhoidectomies, and some

colostomies. With increased surgery complexity, came the need for greater reliance on medical expertise, where DM enactment required greater doctor involvement, either through shared DM or through doctor-led DM, in which participants followed doctors' recommendations with little or no questioning. Trust in the doctor became a critical factor for at least one other participant, who had a bladder augmentation surgery and who commented, "my doctor was very concerned about me ... she was willing to do whatever was needed". Finally, the most complex surgical decisions, with more severe systemic issues, possibly related to survival, were all doctor-led (see last row of Table 4).

DM enactment was not clearly associated with demographic and injury characteristics with exception of work status ($P < .04$). Participant-led DM was more likely to be made by retired participants (85.7%) of which 54.5% were veterans. There were no statistically significant associations between most survey measures and DM enactment. Trends were observed: those who used SDM were more likely to have higher self-efficacy scores ($P < .10$) but less likely to use planful problem solving as a coping strategy ($P < .09$).

Outcomes from surgery decisions

Table 5 describes narratives reflecting level of satisfaction with the surgical decisions, and ratings about these decisions and overall QOL (both rated on a 10-point scale). Most participants were satisfied with their surgeries. Satisfaction ratings for bladder surgeries were high averaging 8.75. All of those who had SP catheter surgery were happy with the results. Two female participants reported high satisfaction with the Mitrofanoff and Modified Indiana pouch procedures, which provided independence, decreased the number of UTIs and restored dignity and self-confidence. Other factors considered included body image and ease of catheterization, as well as personal and spiritual growth.

Satisfaction ratings for bowel were slightly lower, averaging 7.50. Two participants expressed dissatisfaction related to lack of choice, emergency situations, and lack of information on what to expect from the surgery. Another felt there was no choice nor decision but seemed satisfied with results. Both colostomies and ileostomies received mixed reviews with dissatisfaction with respect to lack of informed choices and unexpected complications. Participants felt they had no choice on the matter. In contrast, two participants with colostomies were happy with results, citing healing from wounds and improved lifestyle and independence as benefits. Among those with ileostomies,

satisfaction varied. While the first person rated satisfaction with this decision as a 5, the second although unhappy and experiencing feelings of negative body image, rated the decision outcome a 9. Participants who underwent hemorrhoidectomies were satisfied, preferring surgeries to the symptoms they had experienced previously.

Overall QOL ratings were lower (7.65) than ratings of satisfaction with decisions (8.75). Decision outcomes about SP surgeries and overall QOL were rated very similarly (averaging 8.50 versus 8.16) as were decision regarding bladder augmentation and nephrectomy surgeries and related QOL ratings (9.75; 9). Greater disparity in satisfaction ratings were noted for those who underwent ileal conduits, Mitrofanoff catheterizable channel and Indiana pouch procedures. These were rated higher (8.50) than respective QOL ratings (6.80). For decisions about colostomies, satisfaction ratings averaged 5.50 while QOL ratings averaged 5.62. Those with ileostomies rated satisfaction with decisions higher (9.75) and QOL (8.25) accordingly. Those who had hemorrhoidectomies reported the highest satisfaction, with both providing ratings of 10 for satisfaction and 9 for QOL.

Civilians rated their satisfaction with bowel surgeries lower than veterans (6.33; 8.33) QOL ratings were lower but similar for civilians and veterans: bladder (7.25; 7.91) and bowel (7; 7.2). With respect to satisfaction with methods of bowel management, 42.9% of civilians were dissatisfied with their management while no veterans were dissatisfied. This difference was significant, $P < .04$.

Discussion

Decisions about NBB after SCI can be particularly complex, involving a web of diagnostic options and treatment uncertainties, patients' health characteristics, preferences and values, and costs. In this study, we examined the factors influencing DM to address NBB dysfunction for those with SCI who had NBB-related surgeries. Unlike many daily decisions, these decisions have substantial consequences for one's QOL and involve important uncertainties and trade-offs. We also assessed how these factors influenced the DM enactment, and the outcomes of surgeries, both satisfaction with the decisions and overall QOL. Six identified themes suggested common patterns across participants. In many cases, they focused on problems (recurring complications) without clear solutions (evidence-based treatments).

Many persons with SCI make decisions to have surgeries to improve NBB dysfunction, leveraging their

1145 **Table 5 Satisfaction with neurogenic bladder and bowel surgery decisions and overall quality of life ratings^a.**

	Type of Surgery	Narrative Quotes about Satisfaction	Decision Satisfaction Ratings	QOL Ratings	
1150	Suprapubic catheters	Positive experience with surgery, doctors, and the SP catheter itself. ... got the super pubic, and that really helped ... well, you know how every now and then catheters get clogged up ... but in general very good results. I've had a couple of infections, but I was always having infections.	8	7	1200
		Everything's working fine, except for the infections I've gotten fewer the last couple years.	8	9	1205
1155		I knew it was going to get me about a five-hour independence. I ... strongly recommend it to anyone who would ask.	9	9	
	Ileovesicostomy Ileal conduits	Mixed outcomes: 2 were pleased with outcomes; 1 experienced surgical complications I had ... I had the choice between getting the surgery and my kidneys most likely failing in four or five years. I elected to have the surgery. The only regret I have with my bladder is I didn't do it 20 years' sooner.	7	6	1210
1160		I got sick the following day (after surgery), I- I just didn't feel good, I couldn't breathe. I was delirious. I called my wife, and I said, "Hey, I don't feel good," I said, "Why don't you just take me back to the emergency room at the Mayo Clinic. And sure enough, I went back in, and, uh, they re-admitted me for about another week and uh, they put another catheter back in me. (Participant did not want to have the surgery but felt he had no choice but to agree as doctors explained that he need the surgery to avoid future UTIs which could affect his new kidney transplant).	9 8	7 7	Q2 1215
1165	Mitrofanoff catheterizable channel Modified Indiana pouch	Positive experiences with both procedures; very happy with results I can wear pretty much whatever I want to and nobody knows ... that I have this little stoma in my belly that that's how I drain my bladder. And I like it a lot better. Unless, there was something miraculous that could restore my bladder function ... I think that having this stoma is so much better than ... doing the intermittent urethral catheterization or having the indwelling Foley or the suprapubic catheter. Because of, you know, the fewer - much fewer - basically, no UTIs and not having it be visible to the outside world.	10	7	1220
1170		I have gone through amazing growth ... more faith, more confidence in myself, in my decision making ... I would have done it sooner ... it's the apprehension and the lack of professionals ... that ... had experience with Indiana pouch.	8.5	10	1225
1175	Bladder augmentation	Problem mostly resolved, takes medication for lingering issues. Satisfied with results so far. Well, God, I would hope and pray that I don't have to do that again. But, yeah, if I was in an urgent situation I would.	10	9	1230
1180		Not, not that I didn't want the surgery. I mean no one gets excited about having surgery whether you have a spinal cord injury or not, but, you know, there are times in your life where you have to do something hard to have a better quality of life, right?			
	Nephrectomy	Very positive outcome, UTIs greatly reduced, no noticeable problems only having 1 kidney, high contribution to QOL It actually turned out better than I expected. Like I said, the UTIs are way down. I haven't had any, haven't noticed any issues as far as, you know, I don't know what issues you would have with, only have one kidney but seems fine. If I knew, shoot, if I had known earlier I would have had it done earlier.	9.5	9	1235
1185					
	Colostomies	Mixed results- 1 participant very unhappy; 1 somewhat happy and 2 happy with surgery results. They should've given me a warning about all that, let alone like, they should tell people ... (worried about mucus drainage, blockages) ... I wished you (they) would 've told me all this before you (they) told me to do it. I would've never done it ... (they) should be more specific.	0	3	1240
1190		I'm not absolutely 100% happy (with colostomy), but- I'm happier than I would be, I think, the other way. Well, I think it has simplified my life ... made it much easier on my wife ... and it enabled me to heal.	8 9	8.5 7	1245

Continued

1195

Table 5 Continued

Type of Surgery	Narrative Quotes about Satisfaction	Decision Satisfaction Ratings	QOL Ratings
Ileostomies	Mixed Results – both participants expressed dismay about lack of choice and unhappiness about it. <i>There really wasn't any decision. I didn't really have a choice to say no to any of it. (emergency ileostomy) I would have never opted for this (ileostomy) if I had a choice, but even if I'd been awake, there really wasn't a choice.</i> <i>I heard 'reversible' and I'm thinking okay, cool, I can live with a scar ... There really wasn't any decision. I didn't really have a choice to say no to any of it.</i>	5	4
	<i>I'm extremely happy, yep, extremely happy with care and I have been very happy with the support I've gotten from the VA. I've had it (colostomy) for almost four years now, and it is the best thing since sliced bread.</i>	9	9
	Participant had both ileostomy and felt colostomy improved his lifestyle, able to manage his bowels, but is frustrated about unexplained anal discharge.	9.5	7.5
Hemorrhoidectomies	Positive impact on quality of life but concerns about lasting results and long duration of healing time <i>It's just a matter when. Like he says, it can be a year, it can be a couple of years. Hopefully we did enough this time, it will give you enough time ... before you have to um, have the next surgery. I have a period of time and I'll enjoy that period of time, how long it will ever be to know that I just overall will feel better.</i>	10	9
	Interviewer: Overall are you satisfied with the results of the surgery? <i>Yeah – ... I'd say overall right now everything's going great. I really like the past two months I haven't had any issues ... changing of my diet and changing frequency of the bowel program, I'm doing it daily now. I also had a hemorrhoidectomy done ... That had a lot to do with helping out.</i>	10	9
	Interviewer: So overall you're satisfied with the way things went? <i>Yeah absolutely _</i>		

^aNote: Ratings varied from 0 (totally dissatisfied) to 10 (totally satisfied).

sense of autonomy and QOL concerns, balancing the costs and benefits associated with all options. As seen by the narratives depicted here, study participants often considered their problems (symptoms, complications, ineffective methods of management and treatments) and potential solutions (surgeries) in relation to their personal goals and objectives (*i.e.* survivability, independence, participation). Throughout these 18 cases, surgery was seen as the best option requiring careful consideration of consequences and considerable trust in doctors and providers. For example, and similar to Boucher *et al.*²¹, participants in our study chose colostomies for different reasons ranging from solving bowel care problems to reducing reliance on caregivers and improving independence. Overall, the level of participants' decisional involvement varied based on their degree of comfort with their own skills, level of trust on providers, support and communication with doctors, and relative importance of family involvement.

The few studies that have explicitly explored the complexities of NBB management DM in SCI have found that the best outcomes occurred when patient

engagement in the process was high, as was providers' willingness to explore and incorporate patients' concerns in treatment recommendations. Locatelli *et al.*²² found that the benefits of shared DM (between patient and provider) produced more-effective solutions to health problems, while promoting both patient autonomy and adherence to management plans. Engkasan *et al.*²³ found a paternalistic model (doctor-led) is prevalent in DM for NBB management after SCI, wherein patients felt their autonomy in DM was overridden.

Our findings concur with these findings in that dissatisfaction occurred mostly due to unexpected negative outcomes, lack of trust or clear communications with providers. In our study, decisions on the more complex surgeries such as ileal conduits, nephrectomy, involving greater risks required greater trust in doctors and were primarily enacted by the doctor or involved a shared decision making (SDM) process. Hence, the value of clear lines of communication to establish successful DM and satisfaction with outcomes. In absence of such, participants felt neglected

and angry about outcomes. Overall, however, most participants viewed their surgery outcomes with high satisfaction and QOL post-surgery, except in extreme circumstances (*i.e.* an emergency or urgent surgery), suggesting a negative psychological outcome as patients lost control in the DM process. QOL ratings were in general lower than surgery decision satisfaction ratings, possibly attributed to the many other aspects of one's life that are affected by these decisions, such as relationships, employment, etc. To this point, ileal conduit procedures received high ratings of DM satisfaction, suggesting that participants were happy with outcomes of their care while impact on QOL was reflected by slightly lower ratings.

Not surprisingly due to the small sample size, only a few differences were observed among participants and surgeries. Civilians tended to report lower mental health and greater dissatisfaction overall with bowel management than did veterans. Civilians were less able to participate in social activities, which adversely affected their QOL. Interestingly, those who underwent bowel surgeries tended to report higher cognitive abilities than did those who underwent bladder surgeries. These differences deserve further exploration. It is possible that bowel problems require creative solutions relying on participants' cognitive abilities and problem-solving skills (trend observed) since bowel care is less standardized and mostly tailored to one's needs.

It is unclear why for veterans there was a smaller impact on QOL and mental health related to bowel management, though this may be related to the older age and longer times since injury among veterans, which may have helped them to adapt to NBB prior to DM regarding surgeries. Further, the higher rate of marriage among veterans along with the normative social expectations of them may have provided them with more support and resilience. Further, DM enactment was not significantly associated with personal characteristics other than employment status. Retired participants were more likely than others to make their own final decisions. Most retirees were older veterans and thus perhaps exhibited greater sense of direction and self-confidence in accessing the resources needed to enact their decisions.

Herein, we found a tension between the needs of providers and those of participants, thus influencing the DM process and participants' needs for recognition and autonomy. While participants tended to concur with their doctors' expert opinions on treatment recommendations, it is interesting to note that these recommendations were at times faced with reluctance,

and in some cases, participants sought out advice and guidance from others. Engkasan *et al.*²² found that persons with SCI with bladder problems had substantial influence on the decision of others with SCI and could, at times, override physicians' recommendations. We found some support for these findings across themes identified in relation to factors that summarized DM enactment. Taken together, seeking congruence between patient concerns, the opinions of the patient's social support network, and the clinicians involved seems critical for effective NBB related DM. Adequate time and space in clinical encounters would improve this consensus-building.

Limitations

The narratives of the DM process for surgery following NBB dysfunction in this sample may not be representative of veterans and civilians with SCI more broadly, due to the study's small sample size and the fact that most study participants were from one geographic area. These DM processes may be particular to the type of surgeries described here in terms of common practices at healthcare facilities, socioeconomic structures, or geography. There is also the possibility of bias in the selection of quotes or categorizations of DM enactment styles based on the narrative provided. Individual interviews can only present part of a person's larger life narrative. Also, quantitative comparisons were based on a relatively small sample size and need to be interpreted with caution. These analyses were conducted to highlight trends in the data rather than to draw hypotheses-driven conclusions. Since these were exploratory in nature, correction for the conduct of multiple tests, was deemed unnecessary. While Type I and Type II errors may have occurred, since null hypotheses testing was not a primary study purpose, this does not affect the primary findings. Our findings are based only on participants who decided to have surgery and thus findings do not address decisions not to have surgery. Finally, the time between these surgeries and the data collection varied greatly. Those with a longer time since surgery may have had less ability to recall details, emotions, and feelings associated with DM. Longer times since surgery may have also allowed some participants to be more detached in their assessments.

Conclusion

Above all, we have attempted to illustrate the complexity of NBB DM, as individuals move from broad factors to enactment, and then to outcomes. While every decision is unique, the patterns we have uncovered

demonstrate the multiple, complex ways people consider and weigh a range of pertinent concerns and circumstances. These considerations include the nature of one's healthcare system, providers' professional style of healthcare delivery, the circumstances of NBB dysfunction, and the social ramifications of various choices in DM towards the best outcomes. With greater evidence for treatment effectiveness, especially for bowel, we can decrease the complexity of these decisions for participants with SCI, thus increasing the likelihood of successful outcomes.

Clear patterns emerged in terms of factors influencing DM enactment and attendant outcomes of each decision. Satisfaction with surgery outcomes was associated with resolution of problems, clear communications, as well as a focus on personal goals and expectations. Attending to the complexity of the DM process through careful listening and clear communication, will allow clinicians to better assist patients in making the best decisions for NBB management including surgical options, which will in turn foster greater satisfaction and improved QOL. Because shared DM promotes autonomy and self-confidence, interventions to increase engagement in DM can be beneficial to persons with SCI facing NBB related surgeries.²² Lastly, clinical practice guidelines around surgery as treatment for NBB dysfunction after SCI should highlight the importance of a patient-provider alliance in treatment DM, discussing risks and consequences of each option.

Acknowledgements

This work has been made possible with a grant from USARMY Award Number W81XWH-17-1-0494, US Department of Defense.

Disclaimer statements

Contributors None.

Funding This work was supported by Award Number W81XWH-17-1-0494 (UNCLASSIFIED) of the USARMY, Department of Defense, Congressionally Directed Medical Research Program (CDMRP), Spinal Cord Injury Research Program (SCIRP); Proposal Log Number SC160219 (IRB Number HUM00129856).

Declaration of interest None.

Conflicts of interest Authors have no conflict of interests to declare.

ORCID

Denise G. Tate  <http://orcid.org/0000-0001-5210-3704>

Edward J. Rohn  <http://orcid.org/0000-0002-6092-2301>

Martin Forchheimer  <http://orcid.org/0000-0002-7709-9622>

Anne P. Cameron  <http://orcid.org/0000-0001-8414-3065>

References

- Fried TR, McGraw S, Agostini JV, Tinetti ME. Views of older persons with multiple morbidities on competing outcomes and clinical decision-making. *Am Geriatr Soc* 2008;56(10):1839–1844.
- Tate DG, Forchheimer M, Rodriguez G, Chiodo A, Cameron AP, Meade M, et al. Risk factors associated with neurogenic bowel complications and dysfunction in spinal cord injury. *Arch Phys Med Rehabil* 2016;97(10):1679–1686.
- Tate DG, Wheeler T, Lane GI, Forchheimer M, Anderson KD, Biering-Sorensen F, et al. Recommendations for evaluation of neurogenic bladder and bowel dysfunction after spinal cord injury and/or disease. *Spinal Cord Med* 2020;43(2):141–164.
- Tate DG, Forchheimer M, Hartwig R, Kalpakjian C. The bowel and bladder treatment index (BBTI): a new tool to assess bowel and bladder management in SCI. *Arch Phys Med Rehabil* 2015;96(10):e24–e25.
- Coggrave M, Norton C, Wilson-Barnett J. Management of neurogenic bowel dysfunction in the community after spinal cord injury: a postal survey in the United Kingdom. *Spinal Cord* 2009;47(4):323–333.
- Johansen ML, O'Brien JL. Decision making in nursing practice: a concept analysis. Paper presented at: Nursing forum 2016.
- Rohn EJ, Tate DG, Forchheimer M, DiPonio L. Contextualizing the lived experience of quality of life for persons with spinal cord injury: a mixed-methods application of the response shift model. *Spinal Cord Med* 2019;42(4):469–477.
- Entwistle VA, Sowden AJ, Watt IS. Evaluating interventions to promote patient involvement in decision-making: by what criteria should effectiveness be judged? *Health Serv Res Policy* 1998;3(2):100–107.
- Hawley ST, Lantz PM, Janz NK, Salem B, Morrow M, Schwartz K, et al. Factors associated with patient involvement in surgical treatment decision making for breast cancer. *Patient Educ Couns* 2007;65(3):387–395.
- Welk B, McGarry P, Kennelly M, Myers J, Group NBR. Bladder management experiences among people living with neurologic disease: a systematic review and meta-synthesis of qualitative research. *Neurorehabil Urodyn* 2019;38(2):668–676.
- NVivo 12 [computer program] [computer program]. Version 11. Doncaster, Victoria, Australia: QSR International; 2017.
- Tulsky DS, Kisala PA, Tate DG, Spungen AM, Kirshblum SC. Development and psychometric characteristics of the SCI-QOL bladder management difficulties and bowel management difficulties item banks and short forms and the SCI-QOL bladder complications scale. *Spinal Cord Med* 2015;38(3):288–302.
- Heinemann AW, Kisala PA, Hahn EA, Tulsky DS. Development and psychometric characteristics of the SCI-QOL ability to participate and satisfaction with social roles and activities item banks and short forms. *Spinal Cord Med* 2015;38(3):397–408.
- Edwards A, Elwyn G, Hood K, Robling M, Atwell C, Holmes-Rovner M, et al. The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. *Patient Educ Couns* 2003;50(3):311–322.
- Hays RD, Bjorner JB, Revicki DA, Spritzer KL, Cella D. Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Qual Life Res* 2009;18(7):873–880.
- Saffer BY, Lanting SC, Koehle MS, Klonsky ED, Iverson GL. Assessing cognitive impairment using PROMIS® applied cognition-abilities scales in a medical outpatient sample. *Psychiatry Res* 2015;226(1):169–172.

- 17 Luborsky MR. The identification and analysis of themes and patterns. In: Gubrium JF, Sankar A, (eds.) *Qualitative methods in aging research*. Vol 168. Newbury Park, CA: Sage focus edition; 1994. p. 189–210.
- 18 Ryan GW, Bernard HR. Techniques to identify themes. *Field Methods* 2003;15(1):85–109.
- 19 Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. *Educ Inf* 2004;22(2):63–75.
- 20 Epstein RM, Street RL. Shared mind: communication, decision making, and autonomy in serious illness. *Annals Fam Med* 2011;9(5):454–461.
- 21 Boucher M, Dukes S, Bryan S, Branagan G. Early colostomy formation can improve independence following spinal cord injury and increase acceptability of bowel management. *Top Spinal Cord Inj Rehabil* 2019;25(1):23–30.
- 22 Locatelli SM, Etingen B, Heinemann A, Neumann HD, Miskovic A, Chen D, et al. Perceptions of shared decision making among patients with spinal cord injuries/disorders. *Top Spinal Cord Inj Rehabil* 2016;22(3):192–202.
- 23 Engkasan JP, Ng CJ, Low WY. Who decides? A qualitative study on the decisional roles of patients, their caregivers and doctors on the method of bladder drainage after spinal cord injury. *Spinal Cord* 2015;53(2):130–134.

PROOF ONLY