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

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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 will be generated 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.

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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 decision 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.

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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 proposes to examine neurogenic bowel and bladder decision making for both veterans and civilians with SCI. Accomplishments are described based on the submitted SOW with new dates inserted in italics for the no cost extension year August 2020 - August 2021.

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)

Subtask 2: Regulatory Documents and Research Protocol Maintenance

- 1.2a. Prepare IRB protocol submission for both sites – **completed** (Months 2-5)
- 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)

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)

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** (Month 6)

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**

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)

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) (Month 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 38-40)

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 – **on going**

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 and on-going** (Months 20-26) (Months 20-41)

Subtask 3: Analysis of Interview and Standardized Instrument Data (Months 16-32) (Months 25-43)

- 5.4 Upload standardized instrument data to SPSS and run analyses - **ongoing** (Months 16-22) (Months 25-43)

5.5. Analyze coded data for the identification of themes and patterns – **ongoing** (Months 20-28) (Months 30-41)

5.6 Identify and analyze cases; generate case reports - **to be completed** (Months 26-32) (Months 37-44)

5.7 Compare PVA clinical practice guidelines to participants' responses – **to be completed** (Months 26-32) (Months 39-42)

Subtask 4: Triangulate Data between Data Sets (Months 28-30) (Months 39-43)

5.8 Compare major themes and patterns to statistical analyses – **to be completed** (Months 40-43)

Major Task 6: Dissemination and Data Sharing

Subtask 1: Disseminate Findings to Lay Audience (Months 25-35) (Months 41-43)

6.1 Generate lay language reports for dissemination of findings – **to be completed** (Months 41-42)

6.2 Work with MPVA and PVA to identify venues for dissemination – **to be completed** (Months 42-43)

Subtask 2: Disseminate Findings to Professional Audience (Months 24-36) (Months 24-48)

6.3 Attend and present findings at professional meetings - **ongoing** (Months 24-48)

6.4 Prepare manuscripts for publication – **ongoing** (Months 30-48)

Subtask 3: Prepare final report to CDMRP – to be completed (Months 46-48)

Subtask 4: Discuss with PVA project findings related to current CPGs, submit brief report with suggestions – to be completed (Months 45-46)

What was accomplished under these goals?

Major Task 1: Administrative Tasks

As the project entered its third 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 48 times during the reporting period to discuss data collection, identify population sub-groups and cases, plan for qualitative coding and data analysis, training of new team members, data visualization options, and plan for focus

groups. The team also planned an Advisory Council meeting and dissemination of products. During the first three quarters of the reporting period the team was able to meet normally face-to-face, but after the enactment of the Michigan Governor COVID-19 stay at home order the team moved meetings to a virtual format. These continued on a weekly basis with structured agenda and data reporting and were conducted using BlueJeans and Zoom meetings platforms used by the University of Michigan.

Several changes have occurred with study team members. At the close of the last reporting period, two team members (Ms. Riedman and Ms. Scott) left the project for doctoral programs. Since data collection was close to completion, a quantitative specialist (Ms. Wolgat) joined the project to complete the remaining survey interviews, and a qualitative specialist (Ms. Markel) joined the project to review transcripts for quality control and assist with coding. Both the qualitative and quantitative specialists left the project during the second quarter as work was completed; one was re-assigned and one left to start a doctoral program. As the qualitative work evolved, a new qualitative specialist (Ms. Charara) joined the project in December of 2019. Her work was instrumental in assisting with the completion of interviews and NVivo coding. She was temporarily furloughed from May through July 2020 due to personal circumstances related to family illness. She has returned on a part-time basis and will remain with the project for the remainder of this year.

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 3/2/2020 and 2/4/2020 respectively. In addition, an amendment to the UM IRB was submitted July 24, 2020 to add the focus group protocol to the study. Approval is currently pending.

On June 2nd 2020, the study team met virtually with the Advisory Council and project consultant to discuss the current state of the project, to share preliminary data analysis and to elicit suggestions for enhancing data analysis as the team proceeds. The team shared analyses of 18 surgery cases in terms of decision making and outcomes. 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.

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 have not been completed.

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.

Table 1: Screening

Participants Screened	New Participants	From previous DoD study	Totals
Veterans with SCI	56	23	79
Civilians with SCI	39	17	56

Task 4: Data Collection and Processing

Data collection and processing was completed during the second quarter of the reporting period. 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. Completed transcripts were downloaded from the transcription services' secure website, checked for accuracy against the audio recording, de-identified so that transcripts were ready for data analysis, and stored securely until analysis began. Quantitative interviews were administered after the qualitative interviews were completed using REDCap to record and securely store responses. In total, the study team completed interviews with the 61 participants, each completing one qualitative and one quantitative interview.

During the third quarter of the reporting period, the study team developed 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. Additionally, work began on developing a focus group guide and question set. In April 2020, due to the impact of COVID-19, the University of Michigan suspended all in-person data collection until further notice. Recognizing the need to complete the focus group in a timely fashion, the study team devised a plan to use Zoom for Health and hold the focus group virtually. A UM IRB amendment, which included a virtual protocol, was submitted in July 2020 and is still in review. IRB change requests relate to the consent process using e-consent and virtual focus groups, requiring participants to be able to use Zoom for Health technology for these group activities.

Task 5: Data Analysis and Evaluation

The development of the coding manual began before data collection was completed, and was refined during the first and second quarters of the reporting period. The study team met multiple times to review the codes, discuss and clarify the intention of each code, and to identify the most salient topics related to the project aims. A study team member who was not involved in the development of the codebook practiced coding with a de-identified transcript. Feedback from the team member regarding code definitions and ease of use was incorporated into the final codebook. Inter-rater reliability of the codebook was then tested and confirmed. Ten (10) randomly selected interview transcripts were double coded, checked for overlap and verified between the two study team coders. Early in the coding process it was determined that the time needed to code every code in the codebook would delay completion and slow the analysis process. The team then developed 'super codes' directly addressing the study aims to more quickly work through the transcripts. A first round of coding was completed, followed by a second round of coding to ensure accuracy and thoroughness. Transcript coding was completed during the third quarter.

Analysis of the qualitative data has been the chief analytic task of the study team over the previous reporting period. During our initial attempts at coding, we determined the level of specificity and granularity was too high for the exploratory nature of our research questions. We revised the coding

scheme to a simpler model designed to capture information relevant to our three aims. Then, armed with this narrower subset of the data, we could better focus our coding and analysis towards the factors, mechanisms, and outcomes of decision-making. Following this new coding, the team then engaged in an intensive test run of “first cycle” coding work and data extraction to more-fully develop our analysis process. We used a subset of the full sample – 18 participants whose main NBB management decision for our study was to have surgery. These surgical cases were richly detailed, focusing on a clear 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. We are still finalizing our findings from this process, but it has allowed us to test and refine our approach, facilitating its expansion outward to the remaining 43 participants (non-surgical cases) of the total sample (n=61). By examining the challenges and time involved in producing this table for 18 cases, we have been able to identify clear means by which to more-quickly replicate this process for the remaining 43 cases. Specifically, this process allows us to pivot from an inductive (exploratory) approach to a more deductive approach (targeted searches) to analyzing the data. *Appendix Table 1* in Appendix B summarizes data by project aims for the surgery decision making cases. *Appendix Table 2* in Appendix C shows the type of surgery and role in decision making played by the participant and doctor.

Quantitative analyses have included importing the study data into SPSS and preparing it for analysis, conducting some preliminary analyses using the whole sample, with more extensive analyses being conducted on the cohort of subjects whose decision making was related to a surgical intervention. These were used for an abstract submitted and accepted for the annual meeting of the International Spinal Cord Society (ISCoS). Findings described surgery participants being on average 54.7 years old and 25 years’ post-injury. Participants were equally split between veterans and civilians. Most were diagnosed with complete paraplegia (39%). Their demographic characteristics are displayed below. 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.

Table 2: Demographic and Injury Characteristics for Surgery Cases (n=18)

	Civilian (n=7)	Civilian % of Cohort	Veteran (n=11)	Veteran % of Cohort	Total Sample (n=18)	% of Total Sample
Gender						
Male	5	27.8	10	55.6	15	83.3
Female	2	11.1	1	5.6	3	16.7
Etiology						
Vehicular	5	71.4	5	45.5	55.6	
Sports	0	0	1	9.0	5.6	
Fall	0	0	4	36.4	22.2	
Violence	1	14.3	0	0	5.6	
Other	0	0	1	9.0	5.6	
Medical	1	14.3	0	0	5.6	
Non-Traumatic	0	0	0	0	0	

Appendix Table 3 in Appendix C shows the scores across the quantitative measures for the entire sample.

Decision making style was not significantly associated with self-efficacy but trends were observed among those who used a shared decision making style towards higher self-efficacy. Results were presented at the virtual 59th annual meeting of the International Spinal Cord Society (ISCoS) during the first week of September.

The proposed quantitative analysis plan was revisited and Mr. Forchheimer expanded on this to more comprehensively address the various analyses that will need to be conducted, both focused on the quantitative data alone and using mixed methods. Quantitative measures have been classified in terms of whether they assess factors, mechanisms or outcomes. Quantitative analysis was also conducted in order to prepare an abstract, discussed below, that was submitted for the PVA Healthcare Summit.

Still to be completed during the no cost extension are the focus groups and the resulting analyses, case series analyses, as well as both comprehensive quantitative analysis and mixed-methods analyses. These last analyses will involve data triangulation, taking data from the qualitative interviews that can be readily categorized and using this in conjunction with quantitative data, as well as determining the extent to which findings from qualitative and quantitative analyses are supportive of one another. In addition, we will conduct longitudinal analyses. This is discussed in detail below.

Longitudinal Analyses: An additional step in analysis will involve 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 over 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 will also identify 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 begun, based on participants' stories that most challenge the normative procedures of decision-making as seen in the wider literature. These ideas include patients with repeated surgeries (e.g. multiple hemorrhoidectomies) which challenge the idea 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 could also effectively address the longitudinal analysis 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. A selection of dissemination products are included in Appendix D and described below.

In November 2019, the PI (Tate) made an oral presentation at the 58th International Spinal Cord Society (ISCoS) meeting in France on neurogenic bladder and bowel dysfunction from a patient's perspective.

She used qualitative data to substantiate how persons with SCI make decisions about their bladder and bowel dysfunction. In addition, Dr. Tate's abstract *Factors Related to Decision Making About Surgery after Neurogenic Bowel and Bladder (NBB) Following Spinal Cord Injury (SCI)* was accepted to the 59th ISCOS virtual meeting, which has moved to a virtual format and will take place in the first week of September 2020. These data will be shared virtually during this meeting. Plans are underway to develop a publication based on this data. Findings emphasize the role of physician's in the decision making process. Seeking social support and emotional support from peers and family seems to influence this process as well.

In April 2020, co-investigator Rohn's article *Narratives of Long-term Resilience: Two Case Studies of Women Aging with Spinal Cord Injury* was accepted for publication to *Spinal Cord Series and Cases*. Dr. Rohn submitted two conference abstracts on SCI and chronic pain, based in part on the work of this study. Both were accepted but were deferred due to cancelation of both conferences due to COVID-19.

Co-investigator Forchheimer's abstract entitled *Differences Between Veterans and Civilians with Spinal Cord Injury* was submitted to the 2020 PVA Healthcare Summit and was accepted for poster presentation. The PVA Healthcare Summit was cancelled due to COVID-19. However, a publication is also in the plans summarizing this data and it may be submitted for another conference in 2021.

Ms. Walsh also submitted an abstract to the 2020 PVA Healthcare Summit entitled *Women's Voices: Creating Better Neurogenic Bowel and Bladder Outcomes through Experimentation and Knowing One's Body* and was not selected. In May 2020, Ms. Walsh submitted an abstract entitled *The Truth of My Body: How Four Women Living with Traumatic Spinal Cord Injury (SCI) Create A New Sense of Personhood* to the American Anthropological Association's Annual Meeting, which was canceled due to COVID-19 before acceptance decisions were made.

In July of 2019, the PI (Tate) along with Mr. Forchheimer worked with a group of colleagues on an article about evaluation of neurogenic bowel and bladder after SCI. The article, entitled *Recommendations for Evaluation of Neurogenic Bladder and Bowel Dysfunction after Spinal Cord Injury/ Disease* and published in the *Journal of Spinal Cord Medicine*, resulted from collaborations with experts in this subject area. Dr. Tate focused her contribution on self-reported measures to assess bowel and bladder. Although not directly related to this project, this publication provides an extensive review of the literature on issues faced by persons with SCI and best ways of assessing these. Recommendations were issued based on findings. These are likely to also play a role into recommendations from this project to current clinical practice guidelines for neurogenic bowel and bladder after SCI.

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 will be presenting a course at the September 2020 annual meeting of ISCoS with colleague physicians and psychologists about ways to best assess dysfunctionality related to neurogenic bowel and bladder after SCI/D and their impact on quality of life. These recommendations in part due to information gained from these project narratives as well as analyses of assessment tools currently available to measure symptoms and complications are being included in the Common Data Elements for SCI from NINDS/NIH.

How were the results disseminated to communities of interest?

Preliminary results have been disseminated at professional meetings as listed in our dissemination activities. Furthermore, discussions have taken place about these preliminary findings with Ms. Cheryl Vines, Executive Director of Paralyzed Veterans of America (PVA), Mr. Michael Harris, Executive Director of the Michigan Paralyzed Veterans of America and member of our Advisory Council, 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 June 2020.

On June 12, 2020, the study team presented the project as a Work-In-Progress (WIP) at the Qualitative and Mixed Methods Learning Laboratory (QMMLL). QMMLL is designed for students and faculty at the University of Michigan interested in conducting mixed methods research and offers expert panel review and peer feedback. Plans to develop a consumer fact sheet are in progress and to have a person with a locomotor disability help with the development and further dissemination of study findings to non-professional community audiences.

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 continue to analyze both qualitative and quantitative transcripts and interviews. In addition, data triangulation will be conducted to assess some qualitative and quantitative data jointly, as described above.

During our 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 and the resulting analyses 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 as of yet

What was the impact on other disciplines?

Nothing to Report as of yet

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. In-person data collection includes, but is not limited to, any data collection that occurs through face-to-face contact.

Changes in approach and reasons for change

The focus group session, originally planned to be administered face-to-face, will be conducted using Zoom for Health, a HIPAA compliant conferencing cloud platform.

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

A no cost extension request was submitted as advised by our previous P.O. to address delays due to COVID 19, staff changes and extensive work required for qualitative analyses by aims as well as developing the resultant publications. The award has been made and the extension was approved. The purpose of this request is to extend the period of performance by 12 months (through August 2021) at no additional cost to the government.

The team has begun implementing the nine activities listed in the previous section focusing on IRB amendments required for implementing a virtual focus group. This amendment has been submitted and the IRB has requested some additional modifications to the consent process. These are currently being worked on and we expect to resubmit by the first week in September. Once approved, this amendment will be sent to the HRPO for approval. A final technical report will be due no later than December 2021. 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. G., Cameron, A. P., Rodriguez, G., DiPonio, L., Forchheimer, M., Rohn, E., Walsh, S.** (2019). *Pee or Poop: Battling Neurogenic Bladder and Bowel Dysfunction from a Spinal Cord Injury Patient's Perspective*, November 5th Plenary Session, 58th International Spinal Cord Society (ISCoS) Meeting, Nice, France.
- **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.
 - o *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.

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

Nothing to Report

Other publications, conference papers, and presentations.

The feature article on the Department of Physical Medicine and Rehabilitation SCI website for February 2020 was an update on the *Neurogenic Bowel and Bladder Management After Spinal Cord Injury* study with a video interview discussing incontinence and its effect on quality of life.

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 has provided guidance to the project team and will ensure that all activities are being implemented as proposed. She has reviewed the proposed measures, interview guides, literature so far, and recruitment plans. She will begin the process of reviewing clinical practice guidelines to ensure its inclusion in the project, coordinate meetings with consultants and Advisory Council as needed. Dr. Tate has led regular team meetings, reviewed transcripts, presented on project findings so far, reviewed project budget and assisted on the preparation of reports.
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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 data collection and analysis, as the project unfolds. Currently, 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.

Name:	Martin Forchheimer, MPP
Project Role:	Co-Investigator

Researcher Identifier (e.g. ORCID ID):	0000-0002-7709-9622
Nearest person month worked:	1.2
Contribution to Project:	Mr. Forchheimer has provided guidance on the application and the selection of standardized measures. He is also 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..

Name:	Suzanne Walsh, MBA/MA
Project Role:	Study Coordinator
Researcher Identifier (e.g. ORCID ID):	0000-0001-5210-3704
Nearest person month worked:	9.4
Contribution to Project:	Ms. Walsh has worked the recruitment of participants, including screening, enrolling and scheduling eligible participants. Ms. Walsh has also worked to build community relationships, provide oversight to study staff, and ensure study procedures and guidelines are followed.

Name:	Lynn Charara, MA
Project Role:	Research Assistant

Researcher Identifier (e.g. ORCID ID):	0000-0003-4978-606X
Nearest person month worked:	2.4
Contribution to Project:	Ms. Charara has worked on coding qualitative interviews and ensuring transcript accuracy. She participates in weekly team meetings.

Name:	Stacy Markel
Project Role:	Research Assistant
Researcher Identifier (e.g. ORCID ID):	0000-0002-9198-3668
Nearest person month worked:	2.4
Contribution to Project:	Ms. Markel worked on participant recruitment, including screening, enrolling and scheduling eligible participants. She also worked on cleaning data and preparing transcripts for coding/analysis.

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 has assisted in scheduling and interviewing participants for the quantitative interviews.

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: *Attach all appendices that contain information that supplements, clarifies or supports the text. Examples include original copies of journal articles, reprints of manuscripts and abstracts, a curriculum vitae, patent applications, study questionnaires, and surveys, etc. Reminder: Pages shall be consecutively numbered throughout the report. **DO NOT RENUMBER PAGES IN THE APPENDICES.***

***** **ADDITIONAL NOTES:**

MARKING OF PROPRIETARY INFORMATION: Data that was developed partially or exclusively at private expense shall be marked as "Proprietary Data" and Distribution Statement B included on the cover page of the report. Federal government approval is required before including Distribution Statement B. The recipient/PI shall coordinate with the COR/GOR to obtain approval. **REPORTS NOT PROPERLY MARKED FOR LIMITATION WILL BE DISTRIBUTED AS APPROVED FOR PUBLIC RELEASE.** It is the responsibility of the Principal Investigator to advise the COR/GOR when restricted limitation assigned to a document can be downgraded to "Approved for Public Release." **DO NOT USE THE WORD "CONFIDENTIAL" WHEN MARKING DOCUMENTS. DO NOT USE WATERMARKS WHEN MARKING DOCUMENTS.**

Summary of Appendices

Appendix A – Q4 Quad Chart

Appendix B – *Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision Making (DM) Related to Bladder and Bowel Surgery Following SCI (N=18)*

Appendix C –*Appendix Table 2: Bladder and Bowel Surgeries Following Neurogenic Bladder and Bowel After SCI*

Appendix C – *Appendix Table 3: Quantitative Scores for the Entire Sample*

Appendix D – Poster presentations, publications and abstracts

Appendix A: Q4 Quad Chart

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

SC160219

W81XWH-17-1-0484

PI: Denise Tate, PhD

Org: Regents of the University of Michigan

Award Amount: \$774,994

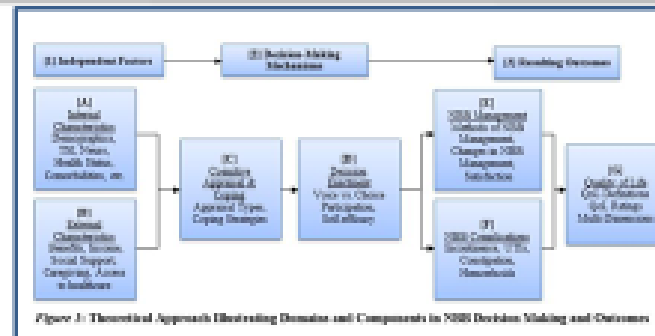


Study/Product Aim(s)

- **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, HRPD approved data collection for UM site and VA site. Data collection is completed at UM and VA sites. Transcript coding is in process. Cases are being identified.

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: August 15, 2020

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

- Nothing to report

Budget Expenditure to Date through Y3Q4 (Total Costs)

Y3Q4 Projected Expenditure: \$71,239

Y3Q4 Actual Expenditure: \$47,310.83

Appendix B

Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Distribution Limited

Appendix Table 1. Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Each column contains a redacted summary of the relevant information for each participant. Column 1 includes demographics, surgery type, and important dates. Columns 2-4 include thematic keywords as headers, one or two key quotes, and bullet points of relevant elements for each aim that contributed to the decision in question. **Keywords** are summative, the *quote* is demonstrative, and the bullet points are exhaustive.

Participant Information	Factors	Mechanisms	Outcomes
1. CIV-005 Bladder augmentation Surgery: 09/2018 Interviewed: 11/13/2018 Participant: 40-year-old female, single, incomplete paraplegia, vehicular injury, unemployed, auto No Fault insurance, Bachelors' degree. 24 years post injury. Current method of bladder management: Intermittent self-catheterization (IC)	Multiple UTIs, incontinence, meds ineffective, trust in doctor, gathered information <i>I was having a lot of UTIs and I was having a lot of urinary incontinence. So I was cathing a lot, like a lot more than normal. So that's why my doctor decided that I needed to have surgery. I was having, you know, kidney reflux and things like that.</i> -increased UTIs every 2-3 months -increased urinary incontinence -increased need to cath -kidney reflux/long term damage -high trust in doctor -meds not working -talked to peers, nurses, doctor	Doctor-led DM; exhausted every option, listened to doctor, 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, exhausted all other avenues, I would think that most people should have a surgery, right? So I mean that's the gist of it. There was really nothing else that went into the decision-making process. -managed UTIs with antibiotics -surgery was last resort; tried everything else -doctor said she needed surgery; doesn't see much else involved -very clear cut choice; admits she wasn't getting better -either surgery or risk of kidney damage (weighed options) -normalized concerns "like anyone who has surgery" -talked with peer -didn't feel rushed -felt that sometimes you need to do	Problems mostly resolved, takes meds for lingering issues, would do the same again if need be <i>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.</i> -had the sling put in -felt the problem was resolved -takes meds for proctitis -would make the same choice again if necessary -(very brief)

Appendix B

Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

		something that's hard to have a better QOL -still asserts the patient makes the final decision -doesn't jump into things-normalized her worry, convinced there were no other options	
2. CIV-012 Hemorrhoidectomy Surgery: 06/2018 Interviewed: 7/25/2018 Participant: 61-year-old male, married, complete tetraplegia, vehicular injury, retired, auto No Fault, Bachelors' degree, 17 years since injury. Bowel management: digital stimulation	Bleeding hemorrhoids, pain, trust in doctor, auto insurance <i>...I make 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. And then the doctor knowing that I've been down this road already, me coming in just to see him that he knows that, you know, it could be one hemorrhoid, but okay, we got to do something about it, because it's just bleeding way too much.</i> -lives on a busy schedule -physical therapy 3x week -bleeding hemorrhoids; monitors how long they take to stop -lengthening bleed time suggests surgery is needed -difficult bowel program -pain; takes pain meds; can feel the pain in hemorrhoids -prior hemorrhoid surgeries (banding did not work)	Participant led DM; preventative changes to bowel program, avoiding surgery, keeps log of all medical information <i>I'll say, "Okay, I'm not going to do a program, so this way you're not getting the digital stimulation, and so you may take a day off," knowing that you're going to feel miserable, or can feel miserable. So I'll say well, it's worth that maybe the hemorrhoid will start to subside some. This is just logical bullshit that I put through my head to try to tell myself, "Do everything you can before you get to go in and get the surgery."</i> -exercise helps pain -changed dig stim approach; to be less rough -suppositories, laxatives, gravity commode over toilet -bleeding rate had urged him to get the surgery -doesn't need prior authorization from PCP for surgery -works closely with doctors -maintains a computer file with all his medical information/notes -tracks his hemorrhoids	Longer healing time, anticipates needing surgery again, major positive QOL impact <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 where it'll be a, you know, a few years, three or four years before you have to um, have the next surgery.</i> <i>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> -resolved the hemorrhoids -longer healing time than prior surgeries (more intensive) -discomfort as he healed -trust in surgeon was well-founded, in his opinion -already anticipates another surgery in the future -hopes for three years relief -anticipates bleeding still from time to time -surgery had major positive impact on QOL

Appendix B

Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	-knows he needs another surgery because bleeding won't stop -knows the longer he waits, the longer it'll take to recover -still reluctant -auto insurance covers procedure	-always tried to make the best decisions to feel the best he can	
3. CIV-050 Suprapubic catheter procedure Surgery: Spring 2017 Interviewed: 7/26/2018 Participant: 68- year-old female, married, complete paraplegia, fall injury, retired, Medicare, Bachelors' degree; 51 years post injury Bladder management: suprapubic catheterization	Incontinence; wounds; did not have knowledge about contemporary methods <i>The decision was made because my spinal cord injury resulted in – after all these years - huge, um, bed sores, 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.</i> -crede method for years; incontinence grew worse over time -wounds; aggravated by incontinence -experienced sepsis and other complications from wounds -bladder hardening -began cathing and using Ditropan when crede method	Participant led DM; wound healing greatly influenced decision; doctor recommended but took time to decide. <i>Keeping the catheter in, drinking lots, and on days when I'm out and can't drink a lot, when I get home I always have two cups by my bedside at night so I can always drink. Um, I've got to admit, there are some days I don't do as good as others, but I try. And I'm also taking all the medicines I should.</i> <i>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> -fought against supra pubic initially -wounds continued to worsen although was cathing properly; developed osteomyelitis -admits to being "bullheaded" and not taking care of herself properly -drinks water -doctor encouraged reducing toileting time; resisted the advice	Positive experience with surgery, doctors, and the supra pubic itself. <i>I got the super pubic, and that really helped. And it didn't have any incontinence – well, you know how every now and then catheters get clogged up every now and then, but in general very good results. I've had a couple of infections, but I was always having infections.</i> -resolved leakage -wounds are better but not completely healed -feels like the decision was a good one

Appendix B

Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	stopped working & incontinence increased -felt like didn't know much; injury occurred in the 1970's "when we left the hospital you're on your own" -doctor suggested suprapubic to help with incontinence and keeping wounds dry; "I fought it for a while and then thought, well okay" -history of UTI's; continued experiencing them with the suprapubic -long toileting times aggravated wounds	-questions the doctor; questions the process -had to develop confidence in the technique -talked with husband, sisters, and cousins about decision -worried surgery would cause another wound -worried about a new 'normalcy'	
4. CIV-051 Mitrofanoff procedure Surgery: 09/2017 Interviewed: 8/15/2018 Participant: 49-year-old female, married, incomplete tetraplegia, vehicular injury, unemployed, private insurance, Bachelors' degree; 2 years post injury. Bladder management: IC with caregiver	Leveraged professional knowledge; UTI's that led to sepsis <i>At the time of the accident, we were doing intermittent cathing and I ended up with a couple of really nasty UTIs. One of which caused me to be septic. One of the questions that I was asking was, "Are you planning to do something to get rid of this Foley, which is causing these infections?"</i> -RN by profession -had Foley indwelling catheter 5 months' post-injury; "as a nurse I knew this was too long" -rehab doc did not think a suprapubic was appropriate "he didn't believe that that was safe for women"	Participant led DM; learned of technique and pushed for it to be done as soon as possible during rehab <i>I can wear pretty much whatever I want to and nobody knows that, you know, that I have this little stoma in my belly that that's how I drain my bladder. And I like it a lot better.</i> -uses straight cath to drain so can 'eyeball' the volume and color -schedules cathing; tries not to go more than 6 hours without cathing -caregivers are trained so not worried about their ability to perform cathing technique -talked with husband about procedure -was excited about Mitrofanoff because 'felt disgusted' about having a drainage bag	Was persistent in pursuit of the procedure; very happy with the results <i>Unless, there was something miraculous that could restore my bladder function to previously especially being able to actually know when I need to empty my bladder and when it's actually all the way empty, I think that having this stoma is so much better than having, 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.</i> -has had 1-2 minor UTI; pushed fluids and takes cranberry if thinks it is happening

Appendix B

Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	- had suprapubic placed because of issues with indwelling but was not happy with it; pushed for Mitrofanoff after hearing about it from OT -wanted to stop having UTI's -did not want to have a urine bag; doctor has said to just "deal with it"; was upset by this comment -learned about Mitrofanoff from OT during inpatient rehab -covered by auto no-fault	-felt self-conscious about the Foley -experienced some distress during the first three months because was not sure when to empty bladder or if it was fully empty	
5. CIV-053 Colostomy Surgery: 2012 Interviewed: 10/29/2018 Participant: 44-year-old male, single, complete paraplegia, medical injury, unemployed, Medicare, HS/GED degree; 27 years post SCI. Bowel management: colostomy	Felt pain medications contributed directly to situation; felt that doctors could have been more helpful or perhaps known better the impact <i>So like for six months I took like pain medication and I definitely know that that helped with my pain but that did not help with my what? My bowels.</i> -bad hemorrhoids -autonomic dyseflexia -high blood pressure -long bathroom times -pain medications caused constipation -developed high blood pressure -did not drink water/keep self hydrated -resisted doctor's suggestion of getting	Doctor-led DM; medical issues necessitated the surgery <i>I started having problems. Like I had problems before, but that didn't even help it. I mean, it made my hemorrhoids even worse, and then the one day I had like uh, I was using the bathroom on both sides I was throwing up and had diarrhea. And then uh, that just like inflamed my hemorrhoids to the point where my blood pressure was like 290. I was literally gonna die so they had to go in and they gave me uh, a colostomy bag.</i> -visited surgeon who indicated would not perform colostomy because of hemorrhoids (2 mos prior to episode)	Angry about colostomy; not pleased with outcome <i>They should've given me a warning about all that, let alone, like, they should tell people, like, like I was telling my doctor, like I started the other day, I'm like you know what? I got a word of advice for you. Like what's that? I go to her, do you have a patient that, that anus mucus, just tell 'em to wear a freakin' diaper. Seriously.</i> -experiences mucus drainage -frustrated that can still experience backups or blockages with a colostomy (none reported)

Appendix B

Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	a colostomy before the side effects began	-was happy had avoided surgery -at time of high blood pressure episode, he agreed to surgery but felt like the doctors 'turned their back on me'	
6. CIV-055 Ileovesicostomy Surgery: Not available Interviewed: 12/20/2018 Participant: 41-year-old Male, single, incomplete tetraplegia, violence injury, work-school, Medicaid, Bachelors' degree; 24 years post SCI. Bladder management: ileovesicostomy with indwelling catheter	UTI's would have led to kidney failure <i>I have an ileovesicostomy with an indwelling catheter, so when I'm at home I basically just use a large draining—drainage bag, uh, which gets emptied, uh, twice a day, uh, usually per shift, uh, with my nurses. And, uh, when I'm out and about, I use a, um, night bag—night drainage bag attached to my leg and try to empty it, uh, as needed or as we, uh, get the opportunity to.</i> -persistent UTI's; doctor suggested ileovesicostomy because of potential future kidney failure	Shared DM; potential for kidney failure spurred the decision <i>I don't like surgeries, so, uh, I did—I was being catheterized, uh, three—three, maybe four times a day. And, um, I kept getting UTIs</i> -wanted 2nd opinion but urologist who proposed the procedure had invented it -does not like surgeries and will typically avoid them	Pleased with outcome; good QoL <i>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.</i> -he made the right choice
7. CIV-073 Ostomy Surgery: 2016 Interviewed: 7/19/2019 Participant: 50-year-old male, single, complete paraplegia, violence, retired, HS/GED degree, 48 years post SCI Bowel management: Colostomy	Ruptured bowel; septic on arrival at hospital <i>If I'm gonna go in for a doctor's appointment or something I do follow-up to find out about the results. And I just, uh, if I'm ever curious about anything any of my doctors are just a phone call away</i>	Doctor-led DM; sepsis <i>I was going septic...had he not performed (surgery) right away I would have died...he saved my life.</i> - participant was not in the position to make a decision; emergency due to ruptured bowel	Decision due to emergency situation <i>I would have never opted for this if I had a choice, but even if I'd been awake, there really wasn't a choice.</i> -participant agreed with doctor but felt had no choice in order to survive -suffered a bit of body dysmorphic disorder post-surgery; sees a therapist to deal with the emotional and cognitive aspects

Appendix B

Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	<i>basically most of the time.</i> -bleeding; cousin took him to the hospital -nonresponsive shortly after arrival -was not able to discuss the surgery with doctor until 2-3 days post -injured at age 2; mother died (primary caretaker) when he was age 16; has been own advocate most of life. -does his own research; has experience with medical issues -used suppositories and enemas without results -close with sister who helps him make decisions and deal with life; emergency contact.	-participant was non-responsive after X-ray in ER	
8. VET-002 Nephrectomy Surgery:2014 Interviewed: 8/29/2019 Participant: 51-year-old male, married, incomplete tetraplegia, vehicular injury, work/school, VA insurance, Bachelors' degree.; 26 years post SCI. Bladder management: IC	Almost no kidney function, UTIs, incontinence, family support, decisiveness, time to choose <i>My right kidney had stones and it didn't function properly so it was causing repeated UTIs and what not so it was better to remove it than keep fighting UTIs.</i> -10% kidney function; full of stones	Shared DM; wife support, doctor gave space to decide, weighed pros and cons, researched online <i>The doctor recommended what could be, what our options were... here's your choice. You can have it removed and probably solve all these issues or you can leave it in there and keep having UTIs...</i> <i>My wife asked all the pertinent questions</i>	Very positive outcome, UTIs greatly reduced, no noticeable problems only having 1 kidney, high contribution to QOL <i>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.</i> <i>If I knew, shoot, if I had known earlier I would have had it done earlier.</i>

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	-added to work stress and led to his retirement (went back to work later) -increased urinary incontinence -meds & Botox for incontinence -Trackchair for hunting -reduced UTIs following surgery -other kidney strong; no stones -blood in urine led to bladder study & kidney function test -loss of bladder elasticity -wife's support; worries a lot, helps him ask the right questions -children worried too -later hospital for high BP; anxiety – brought issue to head -doctor urged surgery for his “long term health” but left choice to him -VA insurance covered everything -says he has “lots of resources” to meet his medical needs -injured while in service -credits military background in being decisive – goal focused	<i>about where, what, whys, and all of that for us, and then I made the final decision, basically.</i> -considered options -wife helped him ask the right questions; she an OT -surgery would have to be invasive because of his scarring -doctor gave him space to decide -went home after hospital and weighed options -explored the topic on WedMD, YouTube (normal approach for anything medical – meds, etc.) -took a couple months to schedule surgery -wife fretted the whole time; he didn't worry; wife main support -feels his doctor guided him well; weighed pros and cons together -deciders: me, my wife, and my doctor -sees doctors as less paternalistic than in the past -apprehensive, but confident it was the right choice; pragmatic	<i>Instead of going through all the lithotripsies and ultrasounds and whatnot to breakup the stones.</i> -now uses online SCI groups to ask questions (didn't know about them before his kidney decision) -wasn't a bad recovery; felt normal the next day -told to anticipate blood in urine, but there was none -significantly fewer UTIs -“another scar” but that's it -very significant contribution to his current QOL (9 vs. 2, in his words)
9. VET-004 Hemorrhoidectomy Surgery: 01/2019 Interviewed: 8/22/2019 Participant: 48-year-old male, divorced, complete paraplegia, sports injury, retired, VA insurance, Associates	Hemorrhoids, possible colitis, VA let him travel to where he could stay in-patient longer to recover, prior surgeries were successful <i>It (the decision) was actually something I initiated and talked to the doctors and</i>	<u>Participant led DM;</u> changed bowel regimen, talked to doctor during annual visit, pushed to get surgery, <i>I talked to the doctors in [city] about it at my annual physician and told them that I thought that the hemorrhoids were causing pre-</i>	Longer recovery than anticipated, able to avoid colostomy, improved his diet, more successful bowel program <i>... changing of my diet and changing frequency of the bowel program, I'm doing it daily now. I also had a hemorrhoidectomy done when I was in [city]</i>

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

degree; 15 years post SCI. Bowel management: digital stimulation, suppository, laxatives, diet	<i>told them I thought the hemorrhoids were causing pre-autonomic dysreflexia.</i> <i>So basically I think I would have been dead if it wasn't for the VA.</i> -bowel always a struggle -wanted to avoid colostomy -dig stim added to "trauma" -suspected colitis -change in diet -change to daily bowel routine -dysreflexia symptoms -VA let him stay for three weeks -previous surgery were good -surgeon was excellent	<i>autonomic dysreflexia when I was doing my bowel program.</i> <i>I, I, I really pushed for getting the hemorrhoidectomy done.</i> -looked online for other's experiences -family did not play a role -changes in diet/bowel regimen to once a day -talked to doctor -advocated for the surgery -traveled to a VA out of town that allowed him to stay in-patient for some of his recovery -resists reflected on emotional coping or appraisals	<i>in January. That had a lot to do with helping out.</i> -surgery impact on QOL (9 of 10) -still making diet and bowel regimen adjustments to maximize improvements -different diet to avoid colitis -shorter bowel program -successfully avoided colostomy -resists reflecting on emotional outcomes -supplements bowel program with suppository to avoid hemorrhoids coming back
10. VET-013 Suprapubic catheter procedure Surgery: ~1994-1999 (unsure, 20-25 years ago) Interviewed: 5/22/2019 Participant: 61-year-old male, married, complete tetraplegia, fall injury, retired, VA benefits, Bachelors' degree; 42 years post SCI. Bladder management: suprapubic catheterization	Exhausted other options; talked to others; faith in doctor; very decisive personality <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.</i> -bladder infections -went through every option first -couldn't IC because too busy; too expensive to have home care	Participant led DM; talked to friend's doctor; went outside VA <i>You know, let's, let's do it. Let's do it, and if we're going to do it let's get it over with, or let's not do it and move on.</i> -went non-VA, because he "knew the VA wasn't going to do it". -had bad prior experiences with surgeries at the VA, too -a friend same procedure; talked to friend's doctor who agreed to do procedure for him	Easy choice, good results, still gets infections, but fewer <i>Everything's working fine, except for the infections I've been getting. But they have, I've gotten fewer the last couple years.</i> -easy decision; turned out as he'd hoped -helped with intimacy -still has bladder infections but not as many -maintained lifestyle; more convenient -feels relief that he's fully emptying/has fewer infections [Does not reflect much on emotional/cognitive results]

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	-not voiding as easily (bladder wall thickening); -sweating while voiding -condom cath leaked a lot -indwelling cath backup a lot -suprapubic for convenience -faith in doctor's knowledge/skill -talked to neighbor (who has an SCI) and mother (concerned but supportive) -reversibility of procedure was key factor (wants to remain as close to his pre-injured body as possible) -wants to avoid ileostomy; scary surgery, but may be necessary; he connects this to UTIs (mean something else?) -working, always on the go, thought procedure would help maintain / improve lifestyle -very assertive personality – enact decision and move on -good VA benefits for lifestyle	-mother didn't want him to -he made the decision; sought information and procedure -friend's doctor agreed and he had the surgery done [Does not reflect much on emotional/cognitive process]	
11. VET-055 Colostomy Surgery: 4/2019 Interviewed: 9/23/2019 Participant: 67-year-old male, married, complete paraplegia, vehicular accident, was a paramedic, retired, VA benefits, Associates degree, 37 yrs post SCI	Lost bowel sensation; collapsing spine; accidents; gathered info; prior experience as EMT <i>It just made me feel that it's what I needed to do, number one, and that, you know, no matter what other people think, you're</i>	Shared DM; talked with social network; took 2 weeks to decide <i>I've taken care of people with colostomies in the past, years ago [was EMT]. They said, "If you want to get these wounds healed, that's the way to go." I still took two weeks to</i>	Satisfied with results; wounds healing somewhat <i>I'm not absolutely 100% happy, but – I'm happier than I would be, I think, the other way.</i> -doing fairly well with colostomy -positive progress on wounds (though getting

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Bowel management: Colostomy	<i>going to have the thing, and, you know, if they can't live with you, then the heck with them.</i> -lost sensation that he needed to have a bowel movement -doctor ordered MRI, found lower spine was collapsing; osteoporosis -repeated pressure sores -started having bowel accidents -tried daily bowel program to prevent accidents; didn't help -unhappy that spouse had to help with accidents -concerned about maintaining independence -understood colostomies because he was an EMT (early years of injury was still ambulatory) -active lifestyle to maintain -possibility to reserve the procedure was a factor -had some concerns that the bag would smell	<i>finally say yes [to the colostomy].</i> -talked to friends about their colostomy experiences/concerns -talked to doctors, wound care specialists, spouse, peers, kids -took these people's ideas into consideration -peers with colostomy said it was the best thing they'd ever done [Not much captured here]	worse again at time of interview) -happy with new bowel regimen [Not much captured here]
12. VET-057 Ileal Conduit Urostomy Surgery: 2002 Interviewed: 10/21/2019 Participant: 71-year-old male, widowed, incomplete paraplegia, fall injury, retired, VA benefits, Bachelors' degree; 50 years post SCI. Bladder management: ileal conduit urostomy (drainage)	Unable to void; threat to kidneys <i>My Urologist told me I better start checking with my relatives for a kidney transplant...We tried all medications...I was having UTIs but it was the (high) pressure was killing the kidneys.</i> -intense spasms	Shared DM; took enough time to prepare; talked with social network; internet research <i>I don't believe in leaving anything to chance. I'm like, "Okay, let's think this thing out." It was like how I chose an ileal conduit; it was like, I looked at all the various different forms of surgery and things they could do, uh, and it finally came down to</i>	Satisfied with outcome; has not experienced any issues <i>The only regret I have with my bladder is I didn't do it 20 years' sooner.</i> -no complications or issues

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	-urine backing up to kidneys; creating lots of pressure -unable to void; could not cath -tried all medications without results -not interested in suprapubic because likes to swim -leveraged experience as Army medic in his treatment/health care	<i>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 any trouble with? Which one do you not have to mess with?" Oh, he said, "That's an ileal conduit." And I spent some time researching and, you know, apparently it's right.</i> -discussed issues with doctor at length; discussed with aides; friend provided support and role model; did his own research and decided considering all input received. -conducted own website research -was able to prepare for surgery because it was urgent but not an emergency -talked to friend with ileostomy who helped him understand the procedure; really informed his decision -requested ostomy supplies to test them; very methodical in approach	
13. VET-062 Ileal Conduit Surgery: 09/20/2019 Interviewed:10/15/2019 Participant: 55-year-old male, married, incomplete tetraplegia, other type of injury, retired, VA benefits, HS/GED degree; 37 years post injury.	Renal failure; dialysis; medication stopped working <i>I really didn't want to get this ileal conduit done but, uh, you know, I was really skeptical about it, but, uh, you know, I – I – if that's what's going to – you know, the – the physicians – the whole – the</i>	<u>Doctor-led DM</u>; He thought about it for a long time to come to grips with it, but his doctors really pushed it as the only choice. <i>Yeah, I wanted, uh – I want to do the right thing, you know? And if they're saying that this is what we got to do to make the transplant successful, then, yeah,</i>	Was readmitted to hospital right after surgery because not producing urine; continues to have leakages post-surgery <i>I got sick the following day, I – I just didn't feel good, I couldn't breathe. I was delirious then, and I called my wife, and I said, "Hey, I don't feel good," I said, "Why don't you just</i>

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Bladder management: ileal conduit urostomy (drainage)	<i>whole transplant team told me about if we put a new kidney in here, the number one problem that's going to make it all go bad is going to be the UTIs.</i> -constant UTIs removed bladder; End stage renal failure/dialysis; on kidney transplant list -running out of medications for treating UTIs; hospitalizations from UTIs at VA. -leakage is biggest issue; drains into a bag. -cannot self-catheterize; has to rely on mother for catheterization -passed out at Home Depot; was septic and almost died -talked with wife, who has medical background, and she agreed that a kidney ideal conduit was in order. -didn't really want to get surgery; even with a kidney transplant, the ileal conduit needed to be done to prevent UTIs. -reservations about a seven-hour surgery.	<i>definitely, let's just go ahead and do it, you know? I mean, it's – they're – there's no other way around it, you know?</i> - the urgency of needing a transplant was the real motivator in getting the surgery.	<i>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.</i> -unable to urinate when discharged -catheter reinserted at second hospital admission -bag adhesive doesn't last causing leakage around the wafer (unresolved at time of interview)
14. VET-064	Stoma bulge; prior reconstruction in 2013; experiencing	Shared DM; talked with caretakers and doctor	Waiting to see what the next step should be

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Modified Indiana pouch: re-do stoma Surgery: 1988 Interviewed: 7/12/2019 Participant: 56-year-old female, divorced, complete tetraplegia, vehicular injury, work-school, VA benefits, Bachelors' degree; 34 years post SCI. Bladder management: IC through stoma	anxiety about cathing because stoma bulge reoccurred <i>Because I was starting to be more active...able to transfer independently...I would start to dislodge the catheter...he (urologist) suggested the modified Indiana pouch.</i> - indwelling catheter dislodged when transferring and during activities: led to MIP - trouble cathing through stoma (belly button) due to bulge developed in stoma - VA doc performed stoma surgery at non-VA facility (2013) - stoma bulge issue has reoccurred, causing cathing issues - experiences autonomic dysreflexia if can't cath	<i>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 the trouble in 2013.</i> -in a holding pattern (wait and see) -received emotional support from caretakers -not many know about MIP; finding technical guidance a problem -reached out to VA doc when first happened; was apprehensive but doc was very supportive -less worried at this point in her life about things going wrong; less pessimistic -has not talked to VA doc about recent problem but will if something changes	<i>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.</i> -original surgery for MIP was "awesome" -has grown in terms of self-care and knowledge about her body -has learned to deal with things if they go wrong -has more confidence that things will work out "this too can be conquered" "taking care of yourself is something you need to do and not just blow off cause you can claw your way through it" "be willing to be vulnerable and talk about problems objectively" -no resolution to the current stoma issue (yet)
15. VET-065 Suprapubic procedure Surgery: Late 2015 Interviewed: 9/24/2019 Participant: 49 year old male, married, complete tetraplegia, fall injury, work/school, private insurance, HS/GED degree; 5 years post SCI.	Home experience between injury and rehab informed decision; limited motor function and need for independence <i>Independence was a very key issue to it (decision), yes. We did not want either of our parents in their 70s...trying to cath me. That's when I contacted the</i>	Participant led DM; requested suprapubic as soon as learned of procedure <i>I discussed it with my wife, and at that point, she knew me, she said, "This is 100% your decision," she would support me either way. And she, you know, said she will cath me every four hours the rest of my</i>	Satisfied with outcome; gained independence <i>I'm going to say there was, you know, no – no surprises along the way. I knew it was going to get me about a five-hour independence, and that – you know, I have no embarrassment or discomfort with, you know, having someone empty the bag that's hooked to the bottom of my leg. I would have to</i>

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Bladder Management: suprapubic catheterization.	<i>Cleveland VA, and they recommended that there is an option of getting a suprapubic catheter, so once they explained that to me, it sound like a huge win and my kind of thing, and I knew it would gain me some independence.</i> -limited to no motor skills in hands -limited finances but would need 24 care for cathing per CPG - learned through VA about suprapubic; doctor suggested -wanted independence -latex allergy impacts adhesive choices -was home for 2 weeks between hospital and rehab; participant and wife found it would be impossible to be on a regular cathing program -nurses were not reliable; had to lean on wife and relatives for help. Hated being catheterized. -tried a Foley but caused complications; leaking, penis getting raw. Wife was supportive of his decision. VA support group also offered emotional and social support.	<i>life, that's not an issue. she basically left it up to me, and it was my decision and the only – the only input I would've accepted into it was between, uh, risks from a doctor or something from my wife.</i> -actively pursued favor because it would give him independence -spouse supported whatever decision he would make	<i>strongly recommend it to anyone who would ask.</i> -occasional accident if hose gets pinched -has to be careful about latex adhesives; allergic
16. VET-069 Colostomy/emergency ileostomy Surgery: 2012	Temporary colostomy performed due to sacral wound; but intestine collapsed	Doctor-led DM; decision followed doctor advice based on medical emergency	Management is easier; subject is still angry about what happened <i>I heard 'reversible' and I'm thinking okay, cool, I</i>

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Interviewed: 7/2/2019 Participant: 57-year-old male, divorced, complete paraplegia, vehicular injury, unemployed, VA insurance, Associates degree; 36 years post SCI. Bladder management: ileostomy	and had emergency ileostomy <i>Well, at that time they messed up the colonoscopy and they wouldn't do anything about it even though I was sitting there hollering in pain and everything for like over three days. And by the time they rushed me into emergency surgery to find out that the colonoscopy had collapsed or not working, which forced them to do the permanent ileostomy, which I currently have to live with to this day.</i> -developed bad sacral wound; had flap surgery and temporary colostomy -was supposed to be in bed for six months after flap surgery; lives alone; couldn't do it. -developed abdominal pain, couldn't eat; went to hospital	<i>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 permanent ileostomy</i> -intestine had collapsed -doctors explained procedure; participant had little choice but to agree -had emergency surgery repair and then a permanent ileostomy.	<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> -ileostomy performs as it should -subject is experiencing negative body image
17. VET-070 Colostomy Surgery: 2013 Interviewed: 9/9/2019 Participant: 68-year-old male, married, complete paraplegia, fall injury, retired, Medicare, Bachelors' degree; 4 years post-SCI.	Wounds and discomfort with caretaking for bowel management <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</i>	<u>Participant led DM;</u> his career background made him a strong decision maker <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</i>	Successful surgery; very happy with colostomy <i>I've had it for almost four years now, and it is the best thing since sliced bread.</i> -improved lifestyle -is able to go out more

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

Bowel Management: colostomy, laxatives and diet	<i>was my wife. Second – secondly, was, uh, trying to get my wound to heal. And then, uh, third would be embarrassment on my part.</i> -inconsistent bowel regimen led to accidents and aggravation of wounds -spouse managed bowel regimen -long history of surgeries (even unrelated to NBB) so was not overly concerned about colostomy -talked to a couple different doctors about their opinions -spirituality/religious beliefs; has faith based support group	<i>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."</i> -didn't like having spouse manage bowel routine -accidents made him embarrassed	-able to independently manage bowel
18. VET-072 Ostomy Surgery: June 2011 Interviewed: 10/18/2019 Participant: 70-year- old Male, married, complete paraplegia, vehicular injury, retired, VA insurance, Bachelors' degree; 8 years post injury. Bowel management: colostomy, ileostomy, laxatives, medications	Wounds and accidents precipitated both a colostomy and ileostomy <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 couple of hours (to) avoid a caregiver. It was always embarrassing, you know, having the suppository and then... having...somebody clean me up afterwards.</i>	Participant led DM; participant sought out consultation on ostomy. <i>[While in hospital] Also, I was concerned about, you know, control of my bowels and I talked to my primary care doctor about it and she had somebody from colorectal come up and interview me about having an ostomy.</i> -nurses provided good information about the procedure -bowel management source of embarrassment	Ostomy successful but experiencing unexpected outcomes -pleased with ostomy -unexplained anal discharge -doctor is uncertain what is causing discharge, even after exploratory procedures -participant currently using pads and frustrated by situation

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Appendix Table 1: Factors, Mechanisms, and Outcomes for Decision-Making (DM) Related to Bladder or Bowel Surgery Following SCI (N=18)

	-flap surgery; had indwelling catheter put in -did not have control of bladder; was concerned about impact on sores; slept in urine at night so as not to disturb spouse -occasional bowel accidents -did not like being helped with bowel program -discussed ostomy with nurse; developed friendship with the ostomy nurse, who helped support and inform him -concerns about impact on body image – appearance, cleanliness	Surgeon discussed results; -spouse was very supportive	
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Appendix C

Appendix Table 2: Bladder and Bowel Surgeries Following Neurogenic Bladder and Bowel after SCI (grey color= Veterans)

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Appendix Table 2. Bladder and Bowel Surgeries Following Neurogenic Bladder and Bowel after SCI (grey color= Veterans)

Bladder Surgery Type	Participant Characteristics	Symptoms/Complications	Decision Making Agent/Role
Bladder augmentation	40 year old male, incomplete paraplegia; 24 years post injury SCI	>UTIs >incontinence Kidney reflux	Doctor led DM Participant went along
Suprapubic (SP) stoma	68 year old female, complete paraplegia; 51 year post SCI	Leakage, incontinence Did not want IC	Participant DM Followed doctor recommendation
Mitrofanoff valve	49 year old male incomplete tetraplegia; 2 years post SCI	Septicemia, UTIs Foley catheter Did not like SP Less flexibility	Participant led, did research, got support and doctor recommended
Ileovesicostomy	41 year old male incomplete tetraplegia; 24 years post SCI	>UTIs Bowel incontinence	Shared DM Doctor suggested; participant researched; agreed
Nephrectomy	51 year old male Incomplete tetraplegia 26 years post SCI	> bladder pressure >UTIs incontinence	Shared DM Participant ponder the options and agreed with doctor
Suprapubic stoma	61 year old male complete tetraplegia 42 years post SCI	>UTIs Residual voiding Had condom catheter, leakage	Participant led DM Doctor provided information Family and peers involved
Ileal Conduit Urostomy	71 year old male Incomplete paraplegia 50 years post SCI	> UTIs, threat of kidney failure, bladder pressure	Shared DM Emergency surgery Discussed issues with doctor and others
Ileal Conduit	55 year old male Incomplete tetraplegia 37 years post SCI	> UTIs, removed bladder, end stage renal failure, dialysis	Doctor led given emergency of situation, participant agreed
Modified Indiana Pouch; re-do stoma	56 year old female complete tetraplegia 34 years post SCI	Difficulties catheterizing, >UTIs, dysreflexia	Doctor led DM Participant agreed Discussed with peers
Suprapubic stoma	49 year old male Complete tetraplegia 5 years post SCI	Poor hand function requires 24 care Foley before leaking	Doctor led DM Participant agreed Wife supportive

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Appendix Table 2: Bladder and Bowel Surgeries Following Neurogenic Bladder and Bowel after SCI (grey color= Veterans)
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Appendix Table 2. Bowel Surgeries Following Neurogenic Bowel and Bladder after SCI (grey color = Veterans)

Bowel Surgery Type	Participant Characteristics	Symptoms/Complications	Decision Making Agent/Role
Hemorrhoidectomy	61 year old male, complete tetraplegia; 17 years post injury SCI	>Bleeding from hemorrhoids, pain, soreness, burning Multiple minor surgeries to stop bleeding	Participant led DM Doctor recommended; trust; Wife supportive
Colostomy	44 year old male, complete paraplegia; 27 year post SCI	BP took very long Constipation due to pain meds High blood pressure	Doctor led DM Debate between doctors; participant reluctant at first but then agreed
Ostomy	29 year old male complete tetraplegia; 8 years post SCI	Bowel ruptured due to impaction Septic upon arrival Bleeding	Doctor led DM due to emergency of situation ; participant agreed
Hemorrhoidectomy	48 year old make complete paraplegia; 15 years post SCI	BP difficult – digit stim caused bleeding Autonomic dysreflexia, poor diet	Participant led DM Doctor agreed Participant did research; changed diet
Colostomy	67 year old male complete paraplegia 37 years post SCI	Lost sensation due to spine collapse >Pressure sores Bowel accidents	Doctor led DM Participant agreed discussed with providers, family and peers
Colostomy	68 year old male complete paraplegia 4 years post SCI	Inconsistent BP; incontinence Wound/anus Long history of surgeries	Participant led DM
Ostomy	70 year old male complete paraplegia 8 years post SCI	Sacral sores from lying on urine Bowel leakage and accidents	Shared DM Emergency surgery Discussed issues with doctor and others

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Appendix Table 3: Quantitative Scored for the Entire Sample

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Appendix Table 3. Quantitative Scores for the Entire Sample

Measure	Minimum Score	Maximum Score	Mean Score	Standard Deviation
International SCI Quality of Life Basic Data Set				
1. Life as whole	3	10	7.30	1.78
2. Physical health	0	10	6.34	2.07
3. Psychological health	0	10	7.31	2.21
4. Social life	0	10	6.64	2.53
PROMIS Global Scale				
1. Physical Health	29.6	61.9	45.68	7.15
2. Mental Health	28.4	62.5	48.55	7.64
3. Cognitive Abilities	25.0	61.1	47.23	7.81
SCI Quality of Life (SCI-QOL)				
1. Bowel Management	39.2	67.0	51.89	7.07
2. Bladder Management	40.9	67.0	51.07	8.20
3. Bladder Complications	39.7	66.2	46.44	7.37
4. Ability to Participate in Social Roles and Activities	25.1	61.1	47.97	7.68
Moorong Self Efficacy Scale				
Daily Activity Scale	31	63	47.21	7.75
Social Function Scale	25	49	40.90	5.14
Total score	57	112	88.11	12.06
Melbourne Decision Making Questionnaire				
Vigilance	2	12	9.57	2.22
Hypervigilance	0	10	2.64	2.11
Buck Passing	0	7	2.16	2.01
Procrastination	0	10	2.41	1.95
COMRADE				
Satisfaction with Communication Scale	12.5	100	73.65	17.85
Confidence in the Decision Scale	5.0	100	75.12	17.86
Measure of the Quality of the Environment (MQE-II)				
Score	2.65	5.69	4.03	.67
MOS Social Support Survey				
Emotional/Informational	15.6	100	66.39	21.59
Tangible	6.3	100	80.73	20.54
Affectionate	0	100	75.82	26.16
Positive Interactions	0	100	70.90	23.65
Total score	7.9	100	71.52	19.34
Ways of Coping Questionnaire				
Seeking Social Support	0	83.3	33.15	21.15
Escape Avoidance	0	58.3	19.87	13.00
Positive Reappraisal	0	85.7	30.52	21.05
Accepting Responsibility	0	100	25.41	22.22
Planful Problem Solving	0	56.7	26.80	12.35

Appendix C

Appendix Table 3: Quantitative Scored for the Entire Sample

Confrontive Coping	0	50.0	16.65	11.20
Distancing	3.3	46.7	18.57	8.74
Self-Controlling	3.3	50.0	22.46	12.03

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Factors Related to Decision Making (DM) About Surgery After Neurogenic Bowel and Bladder (NBB) Following Spinal Cord Injury (SCI)

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Introduction

Neurogenic bladder and bowel (NBB) is one of the most challenging aspects of life after spinal cord injury (SCI). Bladder and bowel managements can often lead to complications such as incontinence and leakage, kidney disease, haemorrhoids and others. These complications can have devastating effects to people's health, psychological well being and quality of life (QOL) and many require surgery. Making decisions about surgery require access to information, resources including financial and insurance coverage, trust on health providers, good communications and cognitive skills.

Findings presented here are part of a larger study which examines DM related to NBB in veterans and civilians with SCI. We examined the factors that relate to DM with respect to surgery recommended to address NBB complications.

Methods

We used a mixed method design with 18 participants who underwent surgery for various complications. Qualitative methods included a semi-structured interview tool designed to elicit detailed, narrative responses. Audio was transcribed and data coded using NVivo software. Narratives were coded in terms of DM style (vigilant and others), to identify factors influencing decisions, and their preference of participation in decision-making (his or her voice in the process). Quantitative methods included a bank of survey measures: PROMIS Global Health and Cognition, the Moorong Self-Efficacy (S-E), and the Melbourne DM and COMRADE DM. Descriptive statistics, ANOVA, correlations were computed for relevant variables. Style of DM was reflected by participants' scores on the Melbourne as compared to their narrative responses. We examined factors influencing DM and mechanisms (i.e. cognition, health appraisal, coping and self-efficacy) in facilitating this process. The SCI-QOL (bladder and bowel) was used to capture satisfaction with methods and complications.

Factors identified in the qualitative interviews clustered into 7 thematic categories: a) symptoms; b) methods of management; c) QOL impact; d) barriers to access/resources; e) treatments; f) emotional, social, and/or physical support; g) health provider-related factors (knowledge, relationship); h) participant's unique personal skills. **Voice in decision participation** was classified as: participant led (participant active engagement and leadership); shared DM (collaborative between doctor/provider and participant); doctor led (participant followed provider recommendation)

Results

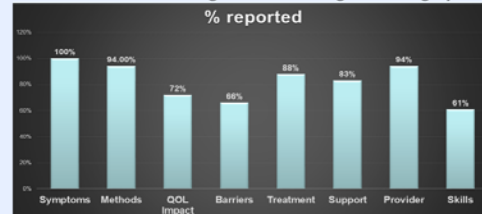
Participants Characteristics, Bladder Surgeries, Voice Participation

Surgery Type	Participant Characteristics	Symptoms/Complications	Decision Making Agent/Role
Bladder augmentation	40 year old male, incomplete paraplegia, 24 years post-injury SCI	UTI's, incontinence, kidney reflux	Doctor led DM Participant went along
Suprapubic (SP) stoma	68 year old female, complete paraplegia, 51 years post SCI	Leakage, incontinence Did not want IC	Participant DM Followed doctor recommendation
Microsurgical valve	48 year old male, incomplete tetraplegia, 3 years post SCI	Sepsis, UTIs Foley catheter Did not like SP Less flexibility	Participant led, did research, got support and doctor recommended
Neovesicostomy	41 year old male, incomplete paraplegia, 24 years post SCI	UTI's Bowel incontinence	Shared DM Doctor suggested, participant researched, agreed
Nephrostomy	61 year old male, incomplete tetraplegia, 28 years post SCI	> bladder pressure UTI's incontinence	Shared DM Participant ponder the options and agreed with doctor
Suprapubic stoma	61 year old male, complete tetraplegia, 42 years post SCI	UTI's Residual voiding Hard condom catheter, leakage	Participant led DM Doctor provided information Family and peers involved
Real Conduit Uroostomy	71 year old male, incomplete paraplegia, 50 years post SCI	> UTIs, threat of kidney failure, bladder pressure	Shared DM Emergency surgery Discussed factors with doctor and others
Real Conduit	58 year old male, incomplete tetraplegia, 37 years post SCI	> UTIs, removed bladder, end stage renal failure, dialysis	Doctor led given emergency of situation, participant agreed
Modified Indiana Pouch; redo stoma	58 year old female, complete tetraplegia, 34 years post SCI	Difficulties catheterizing, UTIs, dysreflexia	Doctor led DM Participant agreed Discussed with peers
Suprapubic stoma	49 year old male, complete tetraplegia, 5 years post SCI	Floundering function requires 24 care Foley before leaking	Doctor led DM Participant agreed Wife supportive

Participants Characteristics, Bowel Surgeries, Voice Participation

Surgery Type	Participant Characteristics	Symptoms/Complications	Decision Making Agent/Role
Hemorrhoidectomy	61 year old male, complete tetraplegia, 17 years post injury SCI	Bleeding from hemorrhoids, pain, soreness, burning Multiple minor surgeries to stop bleeding	Participant led DM Doctor recommended, but, wife supportive
Colostomy	44 year old male, complete paraplegia, 27 years post SCI	BP took very long Constipation due to pain meds High blood pressure	Doctor led DM Debate between doctors, participant reluctant at first but then agreed
Ostomy	29 year old male, complete tetraplegia, 8 years post SCI	Bowel ruptured due to impaction Sepsis upon arrival Bleeding	Doctor led DM due to emergency of situation ; participant agreed
Hemorrhoidectomy	48 year old male, complete paraplegia, 15 years post SCI	SP difficult - digit stim caused bleeding Autonomic dysreflexia, poor diet	Participant led DM Doctor agreed Participant did research, changed diet
Colostomy	67 year old male, complete paraplegia, 37 years post SCI	Lost sensation due to spine collapse Pressure sores Bowel accidents	Doctor led DM Participant agreed discussed with providers, family and peers
Colostomy	68 year old male, complete paraplegia, 4 years post SCI	Incontinent BP, incontinence Wound sinus Long history of surgeries	Participant led DM
Ostomy	70 year old male, complete paraplegia, 8 years post SCI	Sacral sores from lying on urine Bowel leakage and accidents	Shared DM Emergency surgery Discussed issues with doctor and others

Factors Influencing Decision Making about Surgery



Demographic and Quantitative Scores

Measures	Average Score; SD	Range of Scores
PROMIS Physical Health	46.5;6.9	35-62
PROMIS Cognitive Skills	49.2;7.9	37-61
Moorong S-E	89.3;11.5	60-103
WOC Seeking Self Support	34;23	0-83
Melbourne DM - Vigilance	10;2.3	4-12
COMRADE- Communication	75.5; 19.6	12.5-100
COMRADE-Decision.	8.2;2.4	0-10

Participants were on average 54.7 years old and 25 years post-injury; most were male; married; 11% incomplete paraplegia; 39% complete paraplegia; 22% incomplete tetraplegia and 28% complete tetraplegia. All scores were within normal range and most used seeking social support as a coping strategy and vigilance as a DM style. There were no association between self-efficacy and DM style but trends were observed in those that used a shared DM for S-E in daily activities and S-E total scores ($p < .10$; .19). COMRADE satisfaction with communication was associated with the Melbourne DM Style of hypervigilance ($p < .43$); procrastination ($p < .33$) and with satisfaction in DM ($p < .0001$). The latter was also inversely associated with procrastination ($p < .015$) and positively with hypervigilance ($p < .024$).

Conclusions

Participants' symptoms and problems with methods of bowel and bladder management as well as unsuccessful treatments are main factors influencing DM. Equally important in making decisions about surgery are patient doctor relationships. Trends in the data suggest that shared DM is associated with higher self-efficacy scores. Seeking self-support seems to be a preferred way of coping with surgical DM related to NBB complications.

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Denise G. Tate, Tracey Wheeler, Giulia I. Lane, Martin Forchheimer, Kim D. Anderson, Fin Biering-Sorensen, Anne P. Cameron, Bruno Gallo Santacruz, Lyn B. Jakeman, Michael J. Kennelly, Steve Kirshblum, Andrei Krassioukov, Klaus Krogh, M. J. Mulcahey, Vanessa K. Noonan, Gianna M. Rodriguez, Ann M. Spungen, David Tulskey & Marcel W. Post

(2020) *Recommendations for evaluation of neurogenic bladder and bowel dysfunction after spinal cord injury and/or disease*, The Journal of Spinal Cord Medicine, 43:2, 141-164

To link to this article: <https://doi.org/10.1080/10790268.2019.1706033>

Abstract

Objective: To provide an overview of clinical assessments and diagnostic tools, self-report measures (SRMs) and data sets used in neurogenic bladder and bowel (NBB) dysfunction and recommendations for their use with persons with spinal cord injury /disease (SCI/D).

Methods: Experts in SCI/D conducted literature reviews, compiled a list of NBB related assessments and measures, reviewed their psychometric properties, discussed their use in SCI/D and issued recommendations for the National Institutes of Health (NIH), National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements (CDEs) guidelines.

Results: Clinical assessments included 15 objective tests and diagnostic tools for neurogenic bladder and 12 for neurogenic bowel. Following a two-phase evaluation, eight SRMs were selected for final review with the Qualiveen and Short-Form (SF) Qualiveen and the Neurogenic Bowel Dysfunction Score (NBDS) being recommended as supplemental, highly-recommended due to their strong psychometrics and extensive use in SCI/D. Two datasets and other SRM measures were recommended as supplemental.

Conclusion: There is no one single measure that can be used to assess NBB dysfunction across all clinical research studies. Clinical and diagnostic tools are here recommended based on specific medical needs of the person with SCI/D. Following the CDE for SCI studies guidelines, we recommend both the SF-Qualiveen for bladder and the NBDS for bowel as relatively short measures with strong psychometrics. Other measures are also recommended. A combination of assessment tools (objective and subjective) to be used jointly across the spectrum of care seems critical to best capture changes related to NBB and develop better treatments.

Edward J. Rohn, Andrea L. Nevedal, Denise G. Tate (2020) *Narratives of long-term resilience: two cases of women aging with spinal cord injury*, Spinal Cord Series and Cases, 6:23

To link to this article: <https://doi.org/10.1038/s41394-020-0267-8>

Abstract

Introduction Spinal cord injury (SCI) is a life-changing event that drastically affects a person's sense of identity, ability to participate, and quality of life (QOL). Researchers studying the coping process have often focused on identifying maladaptive behaviors and barriers, and less on positive psychology approaches emphasizing individual strengths. More recently, positive psychology constructs, such as resilience, have received greater attention from SCI researchers. Early and ongoing recognition of resilience in patients with SCI may provide important information to clinicians about adjustment and longterm management. Our purpose is to document patterns and indicators of resilience, using a narrative approach, during various stages of adjustment following SCI.

Case presentations Narrative case presentations are deriving from in-depth qualitative interviews with two women aged 63 and 52, living with SCI. Both had complete motor

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neurological injuries that incurred at 27 and 35 years, respectively. Each woman was interviewed twice, approximately 10 years apart (age 63 and 52, and age 54 and 42). Each demonstrated high levels of resilience through evolving roles of family and caregivers, inner personal strength, and participation in their respective communities. We highlight differences, similarities, and evolution of resilience factors in and between each case.

Discussion These cases illustrate examples of long-term resilience, adding richness to the resilience construct. Results provide knowledge that can be used to target rehabilitation interventions toward successful coping styles. In sharing these cases, we hope to assist clinicians and researchers to better recognize patterns of resilience in their own patients and study participants.