## Impact of Bowel, Bladder, or Sexual Dysfunction Following SCI on Quality of Life

| Study Details | Article Type and Research parameters | Population and sample selection | Outcomes and methods of analysis | Results | Conclusions |
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| **Title:** Combining Adult Learning Theory with Occupational Therapy Intervention for Bladder and Bowel Management After Spinal Cord Injury: A Case Report[1]<br>**Year:** 2016<br>**Authors:** Gina Gallagher & Allison Bell | **Article Type**: Case Report | **N = 1**<br>27 y.o. male with traumatic SCI following a fall out of a tree.[1]<br>Underwent decompression surgery of spinal cord at T10 and posterior and lateral fusion of T7 though L1.[1]<br>Classified as T9 ASIA B injury (sensory but not motor function preservation below neurological level, including S4-S5)[1]<br>On evaluation, required total assistance with Bowel and Bladder management according to Functional Independence Measure (FIM).[1]<br>Had full range of motion and strength in bilateral arms and had intact cognition and willingness to learn.[1] | **Adult Learning theory Principals**[1]**:**<br>Adult learners:<br>1. Are independent and self-directing<br>2. Have accumulated a great deal of experiences<br>3. Value learning that integrates with demand of everyday life<br>4. Are more interested in immediate, problem centered approaches than in subject centered ones<br>5. Are more motivated to learn by internal drives than by external ones<br>Effective learning environments make learners feel safe expressing themselves and encourages learners to diagnose their own needs and learning strategies.[1] | Patient progressed to modified independent with bowel and bladder management measured by FIM.[1]<br>Completed self-catheterization every 6 hours and bowel program every other day.[1]<br>Able to identify two positions for self-catherization and utilized log sheets to initiate and complete bowel and bladder program without staff prompting.[1] | Adult learning theory can be an effective framework for addressing bowel and bladder management after SCI.[1] Placing patients into real life contexts can be an important step in bridging the gap between healthcare teaching and patient goals for injury management.[1] |

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| | | | **Intervention**[1]:<br>Nursing staff provided education on techniques for catheter insertion, typical catherization and bowel program schedules, bladder and bowel medication management and urinary tract infections.<br>Occupational therapists focused on process of these skills in real life context.<br>Participated in daily occupational therapy sessions, 5 – days a week, for 60 – 90 minutes.<br>**Application of Adult Learning Theory Principal 1**[1]:<br>Was given printed educational handouts that was later discussed in treatment sessions. Discussed best strategies to keep track of bladder and bowel program schedules and determined log sheets was most helpful for him. | | |

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| | | | **Application of Adult learning theory Principal 2[1]**: Utilized past experiences in computer and internet work to c complete homework assignments of locating self-catherization and bowel management supplies and determining techniques for transporting supplies in community.<br>**Application of Adult Learning Theory Principal 3[1]:** Co-treatment sessions with nursing addressed various positions for self-catheterization and bowel program routines.<br>**Application of Adult Learning Theory Principal 4[1]:** Review attempted self-catheterization positions and allowed patient to demonstrate his transfer techniques.<br>**Application of Adult Learning Theory Principal 5[1]:** Engaged in a variety of real-life problem solving activities (how to self-catheterize in the community) | | |

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| **Title:** Phenomenological Study of Neurogenic Bowel From the Perspective of Individuals Living with Spinal Cord Injury[2]<br><br>**Year:** 2015<br><br>**Authors:** Anthony S Burns, Daphney St-Germain, Maureen Connolly, Jude J. Delparte, Andréanne Guindon, Sander L. Hitzig, B. Catherine Craven | **Article Type**: Qualitative Interviews and Analysis<br><br>Conducted in Ontario and Quebec.<br><br>Phenomenological interviews performed for 45 minutes long and discussed the social, cultural, and relationship laden phenomena of bowel function and care.[2]<br><br>Interviewers participated in two-day training to ensure a consistent interview approach.[2] | Individuals with spinal cord injury (SCI) and neurogenic bowel dysfunction (NBD).[2]<br><br>**N= 19**<br><br>**Mean age**[2]**:** 42 ± 13.4 years<br><br>**Mean duration of injury**[2]**:** 10.4 ± 9.2 years<br><br>**Sex**[2]**:** 13 males, 6 females<br><br>**9 paraplegia**<br><br>**14 complete injuries**<br><br>**Inclusion Criteria**[2]**:**<br>- Adults 18 years or older<br>- Fluent in English or French<br>- History of discrete and identifiable injury to spinal cord<br>- Impaired or absent ability to volitionally defecate<br>- Discharged from inpatient | Concerns related to living with NBD after SCI.[2] | ICF Domains of Common Concerns/Challenges related to living with NBD after SCI[2]:<br><br>**Body Function/Structure**[2]**:**<br>- Lack of Predictability (Incontinence)<br>- Medical Complications<br>- Pain or Discomfort<br><br>**Activity**[2]**:**<br>- Impact on Diet<br>- Impact on Spontaneity & Daily Schedule<br>- Physical Effort of Bowel Routine<br>- Time Requirements<br>**Participation**[2]**:**<br>- Impact on Education & Employment<br>- Impact on Intimacy & Relationships<br>- Impact on Social Participation<br>- Impact on Travel<br>**Environmental**[2]**:**<br>- Cost & Requirements of Bowel Care | NBD can have a profound impact on individuals living with SCI.[2]<br><br>Providers need to understand the importance of these identified barriers within the ICF domain to appropriately address these barriers and improve the clinical management of those living with NBD after a SCI.[2] |

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| | | rehabilitation for at least 3 months<br><br>**Exclusion criteria**[2]:<br>- Presence of a cognitive or communication deficit<br>- Other medical condition that would confound bowel function or defecation | | - Lack of Appropriate & Consistent Assistance<br><br>**Personal**[2]:<br>- Emotional Impact<br>- Loss of Autonomy<br>- Perceived Physical Experience | |
| **Title:** Factors influencing bladder management in male patients with spinal cord injury: a qualitative study[3]<br><br>**Year:** 2014<br><br>**Authors:** JP Engkasan, CJ NG, WY Low | **Article Type**: Qualitative study with interviews | **17** patients with spinal cord injury (SCI)<br><br>7 in-patients with recent injury<br><br>10 community living<br><br>**Inclusion Criteria:**<br>- Patients with traumatic SCI<br>- Neurogenic bladder<br>- Malaysian<br>- Male<br>- Ability to speak English or Malay<br><br>**Exclusion Criteria:**<br>- Cognitive impairment | Sought to illustrate factors influencing the choice of bladder management for male patients with SCI.[3]<br><br>Semi- structured individual interviews that were audio-recorded and transcribed.[3]<br><br>**Interview Question Topics**[3]**:**<br>- Understanding of spinal cord injury and bladder problem<br>- Knowledge on bladder management options<br>- Perceptions of bladder management options | <u>**Emerged Themes:**</u><br>**Treatment Attributes:** [3]<br>- Convenient: frequent catheterization, care of urine bag, presence of tubing<br>- Treatment Harm: risk of urethral trauma, risk of UTI, penile discomfort, pain, risk of surgical complications, risk of renal disease<br>- Continence<br><br>Variable concept of convenience amongst patients. Most were concerned about renal disease, but varied reactions to other | The importance of a treatment option, patient attributes, health care professional attributes, and social factors will all impact the decision-making process of bladder management in patients with SCI.[3]<br><br>Patients trust the information they receive from health care professionals |

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| | | | - Preferred/current treatment and why he chose it<br>- Resources for changing methods of bladder drainage<br>- Sources of Information<br>- Information needs<br>- People involved in making this decision and their roles | complications.[3] Most felt that infrequent incontinence is manageable, but if it is consistent, they wanted to seek alternative bladder management options.[3]<br><br>**Health professionals' influences**[3]**:**<br>- Opinion on treatment option<br>- Support<br><br>Reported a general respect and agreement with health professionals' opinions on treatment recommendations, even if they were not fully informed on treatment options and associated risks.[3] Early stages of injury, patients felt overwhelmed with other concerns and bladder management often wasn't a priority.[3] Degree of support from health professionals influenced treatment choices.[3]<br><br>**Social influences**[3]**:**<br>- Family support: decisional role, supporting | and so it is important that providers are informed and provide sufficient education to patients so they can make informed decisions.[3]<br><br>There may be an opportunity to utilize peer-support networks to aid in the decision-making process for patients with SCI.[3] |

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| | | | | patient's choice, burden of care<br>- Peers' experiences and opinion: observation of peers' experiences, sharing of information, motivation<br>- Social activities<br>Peers with bladder problems' opinions at times overrode doctors' recommendations. Family support did not have direct influence on treatment decision.[3] Many felt uncomfortable discussing bladder management with family members because it felt private.[3] Participants wanted bladder management options that allowed for social engagement.[3]<br>Physical Attributes[3]:<br>- Physical ability: hand function, body balance, transfer skills<br>- Sexuality and fertility functions | |

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| | | | | Reported that impaired hand function, body imbalance, and impaired transfer skills were reasons to not use CIC.[3]<br>At earlier stages in injury, having kids and sex were not proprieties and did not influence bladder drainage management choices.[3]<br>Later stages showed increased perception of importance of these functions.[3]<br>**Psychological attributes**[3]**:**<br>- Embarrassment<br>- Confidence<br>- Satisfaction<br>Reported embarrassment with urine bag and concerned about stigma.[3] Choice to use CIC was based on confidence in their ability to catheterize as well as trust in caregiver.[3] | |
| **Title:** Who decides? A qualitative study on the decisional roles of patients, their caregivers and doctors on the method of bladder | **Article Type**: Qualitative Interviews and Analysis<br>Goal was to explore roles of patients, | **N = 31**<br>**17 male patients**<br>**4 caregivers** | Semi-structured interviews conducted by two researchers in-person.<br>Primarily consisted of open questioning. | Eight themes emerged:<br>**Patient as the decision maker**[4]:<br>- Patients' rights and responsibilities | Doctors seem to dominate the decision-making process around bladder management for male |

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| drainage after spinal cord injury[4]<br>**Year:** 2014<br>**Authors:** JP Engkasan, CJ NG, WY Low | their caregivers, and doctors when making decisions on bladder drainage after a spinal cord injury (SCI).[4]<br>Set in five public hospitals in Malaysia. | **10 rehabilitation professionals**<br>**Inclusion Criteria for SCI patients**[4]:<br>- Patients with traumatic SCI<br>- Neurogenic bladder<br>- Malaysian and ability to speak English or Malay<br>**Exclusion Criteria for SCI patients**[4]:<br>- Cognitive impairment<br>- Bladder management had not yet been discussed<br>Rehabilitation Professionals selected who had at least 6 months of experience in taking care of patients with SCI on a regular basis.[4] | **Examples of questions included**[4] **:**<br>1. Patients: Tell me how this decision is made? Who made the decision? Whom did he discuss with? What did they say? What are their concerns about the options?<br>2. Patients: In your opinion, who should make this decision? Roles of patient, caregivers, & doctors<br>3. Caregivers: Did he discuss with you or anyone else about which options should he take?<br>4. Caregivers: Did he discuss this decision to you or anyone else?<br>5. Caregivers: Who do you think should make this decision?<br>6. Professionals: In your setting, how is the method of bladder drainage decided for these patients? | - Patient as informed decision maker<br>- Forced to accept the decision<br>**Caregiver as decision maker**[4]:<br>- Surrogate decision maker: perception on whether patient should be decision maker influenced by age and severity of injury (younger/older and those with more complete injuries should allow caregiver to make decision given physical responsibilities)<br>- Silent partner: caregivers sometimes play passive roles and patients are frustrated at their lack of knowledge<br>**Doctor as the decision maker**[4]:<br>- Doctors know best: patients and caregivers consider doctor to be expert and always choose | patients with SCI and was received variably by patients themselves.[4] Although patients recognize their role in decision making, this was not always the case. Health professionals need to educate patients about disease and treatment options and give patients the opportunity to express their preferences and degree of comfort prior to selecting an option regardless of age, injury severity, and level of dependency.[4] |

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| | | | 7. Professionals: Do you recommend the method you think is best for them? | the best option for them<br>- Override patient's decision: some doctors refuse to accept patient's decision<br>- Reluctant decision maker: doctor's were frustrated when they were forced to make decisions for the patients and caregivers | |
| **Title:** Secondary health conditions and spinal cord injury: an uphill battle in the journey of care[5]<br>**Year:** 2013<br>**Authors:** Sara J.T. Guillcher, B. Cathy Craven, Louise Lemieux-Charles, Tiziana Casciaro, Mary Ann McColl, Susan B. Jaglal | **Article Type**: Case Study<br>Intends to understand the influence of informal and formal networks, health system, and policies on care for secondary health conditions (SHC) in patients with spinal cord injuries (SCI).[5] | Individuals interviewed included persons with SCI living in the community, formal and informal care providers, administration managers, case managers, policy-makers, and decision-makers.[5]<br>**N= 32**<br>**14 persons with SCI** (4 with traumatic SCI-motor vehicle related, 7 traumatic SCI-non motor vehicle related, 3 non-traumatic SCI)<br>**10 care providers** (9 formal, 1 informal) | Utilized conceptual guide of Network Episode Model (NEM).[5] NEM has four domains: social context (sociodemographic or organizational health constraints), social support system (informal network), treatment system (formal network), and illness career (journey of care).[5] The population characteristics and organizational constraints influences the informal networks, journey of care, and formal networks. Informal networks, journey of care, and formal networks interact with one another. [5] | Major over-arching theme that emerged was "fighting" amongst all stakeholders and were categorized into micro level (individual), meso level (care provider level), and macro level (health system level).[5]<br>**Micro Level[5]:**<br>**Individual experiences**<br>1. Social isolation and system abandonment: challenges transitioning from inpatient rehabilitation to community dealing with SHC. Participants | Journey of care is challenging for persons with SCI, their care providers, and community-based advocates.[5] Given the noted frustrations at the macro-level, interventions need to shift to be provided at a health system level as opposed to just the individual or health provider level.[5] |

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| | | **6 community advocacy organization representatives (**2 regional service coordinators, 2 senior administrators)<br><br>**2 system service delivery administrators (**1 public senior administrator/policy makers, 1 private senior administrator) | Performed semi-structured interviews. Interviews conducted in two phases, the first with individuals with SCI. The second phase involved formal and informal care providers, case managers, and policy makers. Questions were open-ended.<br><br>**Questions for participants with SCI**[5]**:**<br>1. What have been your experiences with your health care in the community? What made your health care experience easier? Harder?<br>2. What have been your experiences with care related to prevention and/or management of secondary complications? What made it easier? Harder?<br>3. What has been the role of your informed social networks related | highlighted feelings of social isolation and perception of system abandonment.[5] Many reported that recreational activities and community participant were important aspects to health and minimizing SHC.[5] Those with non-traumatic SCI reported that they felt resources and research was biased towards traumatic SCI.[5]<br>2. <u>Fight for funding and equitable care:</u> Suggested that inequities related to funding and insurance coverage were huge factors related to prevention and management of SHC.[5] Those with public insurance were not receiving services that addressed the minimization or | Therapists should be aware of these noted barriers and frustrations of the many stakeholders involved in a person with SCI's medical care as it has a significant impact on the development of secondary health conditions.[5] |

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| | | | to secondary conditions?<br>4. Is there anything else you would like to mention that we have not had an opportunity to discuss?<br>**Questions for care providers, managers, and policy makers[5]:**<br>1. Would you be able to tell me a little bit about your professional role?<br>2. What are some important barriers in preventing and/or managing secondary health conditions?<br>3. What are some facilitators in preventing and/or managing secondary health conditions?<br>4. What are some strategies and/or solutions that might help assist the prevention and/or management of secondary health | occurrence of SHC, while those with private insurance were able to receive physical therapy, occupational therapy, and massage therapy.[5] Those with public insurance noted the difficulties in accessing proper technology and assistive devises, home and vehicle modifications, medical expenses for equipment such as catheters.[5]<br>3. Fight for self-management: Participants expressed frustrations with care providers and health system in regards to self-management.[5] For example, many expressed frustration over not being able to initiate home care services without a practitioner referral | |

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| | | | conditions in the community? | in timely circumstances (wound management).[5]<br>**Meso level[5]:**<br>**Caregiving Tension**<br>**1.** Gender and informal caregiving strain: Informal caregiving was expressed as “filling in the gaps” of the formal health care system.[5] Females appeared to be reported most within the caretaker role which led to different experiences between male and female SCI patients.[5] The female SCI patients often did not report assistance from their significant others for intimate personal care.[5]<br>**2.** Help versus disempowerment: Participants reported a critical balance between | |

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| | | | | helping persons with SCI and over-prescription.<br>**3.** Holistic care and thinking outside the box: Expressed frustration with health care professionals who treated SHC without considering “whole person”.[5]<br>**4.** Poor communication and care coordination: Challenges with communication between persons who have SCI, informal care providers, and formal health care providers.[5] Many reported that a case coordinator made a significant difference in facilitating communication.[5] Informal care providers and community resources reported feeling a lack of respect and a | |

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| | | | | failure to be recognized as integral part of team.[5]<br>**Health system influences on journey of care** [5]<br>1. Fight for access and availability: Reported a common fight to get access to services especially specialists and rehabilitation professionals.[5] Many participants reported significant wait-times to see rehabilitation professionals which led to heightened risk for re-admission to acute care (ex: pressure sores from waiting for seating assessment).[5] Reported a need for a “one stop shop” where all needed services are in one location as traveling was a noted barrier.[5]<br>2. Models of care tensions: bio- | |

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| | | | | medical vs. social determinants, prevention vs. acute care, GPs vs specialists, informal vs formal care provision.<br>3. Public vs private tension: Significant tensions were noted regarding privately versus publicly funded care.[5] Those with private funding often face concern of over-prescription as opposed to struggles to receive basic services and equipment in public funding.[5]<br>4. Rigidity and inflexibility of policies: Noted frustrations over policies related to home care services.[5] Participants also shared frustrations over rules established to determine rehabilitation eligibility and felt it | |

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| | | | | highlighted the "reactive" nature of healthcare as opposed to a "preventative" approach.[5] | |
| **Title:** Women's experiences of living with neurogenic bladder and bowel after spinal cord injury; life controlled by bladder and bowel[6]<br>**Year:** 2015<br>**Authors:** Andrea Nevedal, Anna L. Kratz, Denise G. Tate | **Article Type:** Qualitative Study through semi-structured interviews<br>**Research Question**[6]: How do women with SCI describe the impact of experiencing and managing neurogenic bowel and bladder (NBB) on the quality of life (QOL)? [6] | **N = 50**<br>Community dwelling women with SCI from rehabilitation facilities in Michigan.<br>**Mean age**[6]: 45.6 years<br>**Ethnicity**[6]: 52% white, 48% black<br>**Method of Injury**[6]: 48% motor vehicle accident, 4% sporting injury, 26% violence, 16% fall, 6% other<br>**Level of Injury**[6]: 22% incomplete paraplegia, 20% complete paraplegia, 32% incomplete tetraplegia, 26% complete tetraplegia<br>**Average time since injury**[6]: 11.3 years | In-depth and semi-structured interviews that focus on stress and coping over life course among women with SCI.[6]<br>Interviews completed face-to-face or over the phone.[6]<br>Transcripts of interviews analyzed for keywords.[6]<br>Two investigators then utilized pile sorting techniques to identify themes and topic categories that characterized data.[6] | Six identified meta-themes[6]: life controlled by bladder and bowel, bladder and bowel accidents, women's specific challenges, life course disruption, bladder and bowel medical management, finding independence.[6]<br>**Life controlled by bladder and bowel**[6]**:**<br>- Negative consequences of NBB that require time, planning, preparation, and unpredictable management that hinders daily activities, responsibilities, and social relationships.[6]<br>- Major barriers to social activities outside of the home included finding accessible bathrooms[6] | Women with SCI identify NBB as a major source of stress, frustration, and disruption in their daily lives that differ from males with SCI's experiences and concerns regarding NBB. [6] Clinicians should not only consider physical health of patients in their bladder management strategies but the impact on the patient's independence and quality of life. They should also recognize that a females experience with SCI will differ |

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| | | **Marital status**[6]**:** 26% married, 24% single, 30% divorced, 10% widowed<br>**Education**[6]**:** 25% less than high school, 58% high school diploma or GED, 12% associates/junior college degree, 14% bachelor's degree, 10% masters degree<br>**Employment**[6]**:** 18% currently working for pay, 86% employed prior to injury, 42% employed after injury<br>**Family**[6]**:** 70% have children, 12% have children after injury, 22% live alone | | - Reported when away from home, many restricted fluid intake to reduce need for bladder care which increases risk for kidney damage or autonomic dysreflexia.[6]<br>- NBB is a burden, source of stress and suffering in daily life, and a barrier to engaging in desired life activities[6]<br>**Bladder and Bowel Accidents**[6].<br>- Reported needing to fully recline and remove clothing in order to access urethra for catheterization.[6]<br>- Limitations in hand, arm, and leg dexterity and strength made removing clothing difficulty and interfered with catheterization process.[6]<br>- Many reported challenges in | from a male's experience.[6] |

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| | | | | finding accessible bathrooms large enough for them to lie down.[6] Others reported an alternative of using a motor vehicle when accessibility to a restroom is not feasible.[6]<br>- Many reported feeling unprepared to address their needs and specific problems associated with bladder emptying.[6]<br>**Life course disruption**[6]:<br>- Women highlighted independence, career, and social/sexual relationships as important yet disrupted life course expectations.[6]<br>- Reported an abrupt loss of independence after SCI (especially difficult with adjusting to physical dependency on | |

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| | | | | others for basic needs)[6]<br>- Reported that managing NBB constrained career opportunities and social interactions.[6]<br>**Bladder and Bowel Medical Management**[6]:<br>- Some medical management options (diversion surgery, indwelling catheters, Foley catheters, leg bags, and colostomies) helped reduce burden of bowel and bladder program and caregiver dependency.[6]<br>- Felt torn between “gold standard” bladder programs that were burdensome and limited independence versus medical management programs with increased medical risks but with less burden on independence.[6] | |

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| | | | | - Reported limited input into their own management and how many programs were not covered by insurance.[6]<br>**Finding Independence**[6]:<br>- Many reported that mastering self-intermittent catheterization was required for independence.[6] | |
| **Title:** Patient Reported Bladder Related Symptoms and Quality of Life after Spinal Cord Injury with Different Bladder Management Strategies[7]<br>**Year:** 2019<br>**Authors:** Jeremy B Myers, Sara M Lenherr, John T. Stoffel, Sean P. Elliot, Angela P. Presson, Chong Zhang, Jeffrey Rosenbluth, Amitabh Jha, | **Article Type**: Prospective Observational Study<br>Measured neurogenic bladder related quality of life after spinal cord injury.[7]<br>Conducted in United States. | **1,479 participants**<br>**57% paraplegia**<br>**60% men**<br>**Median age**[7]**:** 44.9 years<br>**Median time since injury**[7]**:** 11 years<br>**Inclusion Criteria**[7]**:**<br>- 18 years or older<br>- Acquired spinal cord injury<br>- English speaking<br>**Exclusion Criteria**[7]:<br>- Congenital conditions<br>- Progressive SCI | Participated either remotely via phone interview or electronically via questionnaire.[7]<br>Bladder management categorized as[7]:<br>1. Clean intermittent catheterization<br>2. Indwelling catheter<br>3. Surgery<br>4. Voiding (Foley catheter, involuntary leaking, or volitional voiding)<br>**Primary Outcome Measures**[7]**:**<br>- Neurogenic Bladder Symptom Score (NBSS): | Analyzed groups separately based on injury level (tetraplegia (cervical level 1 – 8) or paraplegia (thoracic level 1 and below).[7]<br>Participants with paraplegia had a higher rate of CIC use compared to those with tetraplegia (62% vs. 36%)[7]<br>In those with paraplegia, NBSS scores were better for increasing age (p=.003) and male gender (p<.001) and worse for UTIs (p<.001).[7]<br>In those with tetraplegia, NBSS was better in men (p<.001) and worse in those with obesity (p<.001) and with UTIs (p<.001).[7] | Participants who manage bladder using IDC or surgery had fewer bladder symptoms than those who used voiding methods.[7]<br>Regardless of level, participants treated with surgery had better satisfaction with urinary function than those with CIC.[7] |

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| Darshan P. Patel, Blayne Welk | | | scores range from 0 – 74 with lower scores indicating better function[7]<br>- Spinal Cord Injury Quality of Life Measurement System Bladder Management Difficulties (SCI-QoL): mean score of 50 and range of 0 – 100 with lower scores indicated less bladder difficulty[7]<br><br>**Secondary Outcome measures**[7]**:**<br>- NBBS subdomains: incontinence (0 – 29 range), storage and voiding (0 – 23 range), consequences (0 – 23 range) [7]<br>- Satisfaction with urinary function (0-4 range)[7] | For paraplegia and tetraplegia, the IDC (p<.001) and surgery (paraplegia p<.001, tetraplegia p =.036) groups had improved NBSS scores while voiding group (p<.001) had worse scores than CIC group.[7]<br><br>SCI-QoL scores were best for paraplegia participants with surgery (p<.001).[7]<br><br>SCI-QoL scores were better for tetraplegia participants with ICD (p<.001) and surgery (p=.006), and worse for voiding (p=.004).[7] | Patient reported bladder systems and quality of life is variable and is influenced by the patient and their injury characteristics.[7]<br><br>It is important for health care professionals to include patients in the decision making and to counsel and educate on risks and benefits of various bladder management strategies.[7] |
| **Title:** Women's sexual functioning and sex life after spinal cord injury[8]<br><br>**Year:** 2011 | **Article Type**: Cross-sectional, qualitative (mail-back questionnaire) | **392 community-living women with spinal cord injury (SCI)** being treated at spinal cord centers in Sweden, Denmark, | **Sexual Functioning and Sexual Life**[8]**:** SCI Women Questionnaire (SCIWQ). Contains 104 items that assess various dimensions of sexuality. | **Changes in sex life after injury**[8]**:**<br>- Changes to physical, psychological, and practical nature[8] | Most women continue to be sexually active following a spinal cord injury and it is |

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| **Authors:** M Kreuter, C Taft, A Siosteen, F Biering-Sorensen | Conducted in Sweden, Denmark, Norway, Finland, and Iceland. | Norway, Finland, and Iceland<br>**Mean age**[8]: 42 years<br>**Mean time since injury**[8]: 11<br>**Inclusion Criteria**[8]**:**<br>- Age between 18 and 70 years<br>-<br>**Exclusion Criteria**[8]**:**<br>- Known recovery (ASIA Impairment Scale E)<br>- Injured less than 2 years<br>- Brain injuries and psychiatric diseases<br>- Inability to understand Nordic language | Researchers used 10 open ended questions from the SCIWQ.[8]<br>1. Describe in your own words how your sex life has changed after the SCI[8]<br>2. If you have impaired sensibility, can you then describe what you do to compensate for the decreased sensibility?[8]<br>3. If you have had an orgasm, or something like an orgasm after the injury, how would you describe that experience?[8]<br>4. What is the best thing your sexual partner can do to help you to relax and enjoy sex?[8]<br>5. How has your partner reacted if you had leakage during sex?[8]<br>6. How do you handle urostomy or | - 2% reported that it was better and of greater importance after injury.[8]<br>- 11% reported no major changes or that it functioned well.[8]<br>- 26% had sex less frequently after injury.[8]<br>- 13% claimed they no longer had sexual desire[8]<br>- 8% claimed they had difficulties with orgasm[8]<br>- 7% reported no previous sexual experience before injury[8]<br>**How to compensate for decreased sensibility**[8]<br>- 30% reported compensating with fantasy and thinking about how sex was before the injury.[8]<br>- 22% reported use of kissing, touching, and caressing of other erogenous zones.[8] | considered to be important part of their lives.[8]<br>Women following SCI experience a range of physical and psychological alterations to their sexual functioning. Various strategies can be employed for women following SCI in order to maintain safe, and consensual sexual lives.[8]<br>Successful SCI rehabilitation requires a holistic approach, that takes into account the patient's physical, psychological, and |

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| | | | colostomy during sexual togetherness?[8] | - 6% reported watching the act directly or with help of the mirror.[8]<br>- 5% reported longer foreplay and stronger stimulation of the clitoris.[8]<br>- 21% reported they did nothing, and did not know what to do, or could not do anything.[8]<br>**Experience of having an orgasm[8]:**<br>- 8% experienced orgasm in the same way as prior to injury.[8]<br>- 25% described it like being in heaven, flying, and unbelievable with strong feelings.[8]<br>- 16% felt they had fewer orgasms, and that it was more difficult to achieve an orgasm or that it was weaker than before injury [8]<br>- 13% mentioned they were satisfied with the quality of their orgasm.[8] | interpersonal circumstances.[8] |

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| | | | | - Many described orgasms positively, while others described negative sensations such as pain, cramps, spasticity, headaches and autonomic dysreflexia.[8]<br>**Best Thing for Sexual Partner to Do[8]:**<br>- 38% mentioned physical stimulation.[8]<br>- 14% mentioned long foreplay.[8]<br>- 7% reported massage.[8]<br>**Tips for Improving Sexual Pleasure[8]:**<br>- Open discussion with partner about what is pleasurable, what their partner can do to help them, and how they can experiment to compensate for physiological impairments.[8]<br>- Try to relax, explore thoughts and fantasy, work on body image, | |

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| | | | | experiment and explore, use external devises (dildo, massage apparatus, vibrator).[8]<br>**Partner response to leakage during sex[8]:**<br>- 25% partner had reacted with understanding, support, and positivity.[8]<br>- 19% reported that their partner had no reaction.[8]<br>- 5% reported that their partner tried to joke about it.[8]<br>- 5% reported that partners reacted by cleaning up, cleaning the sheets, etc.[8]<br>- 10% reported negative reactions such as becoming disgusted, frustrated, loosing interest, etc.[8]<br>- 30% reported never experiencing leakage during sex.[8]<br>**Ways to handle stomas[8]:** | |

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| | | | | - Most reported that they emptied the stoma bag before sexual activity.[8]<br>- Other solutions included putting on a new clean bag, attaching a stop-bag, empty and tape the bag.[8]<br>- Women with urethral or suprapubic catheters reported taping it to their stomach or thigh.[8]<br>**Birth control methods**[8]<br>- 47% used oral contraceptives, 32% IUD, 32% condoms, 7% sterilization, 6% p-syringe, 5% mini-pills.[8] 2% interrupted coitus.[8] | |

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