



Social Ecology of Neurogenic Lower Urinary Tract Dysfunction

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Abstract

Purpose of Review. To review the literature on the social ecology of neurogenic lower urinary tract dysfunction through a multi-level framework.

Recent Findings. Neurogenic lower urinary tract dysfunction is a complex collection of symptoms, which significantly affects and is affected by various levels of the social experience across all levels, including individual, interpersonal, community, and societal. Individual factors include the profound effects on both overall and bladder-specific QOL, the significant psychosocial comorbidity, and the burden of unmet social needs. Interpersonal relationships—including social, romantic and sexual, and caregiver—are complex and have unique considerations. In the community, experiences in the workplace, schools, and healthcare settings, and interactions with public restrooms can be challenging for those with NLUTD, and special considerations are often overlooked by more able-bodied people. Finally, the economic burden and overall healthcare utilization of those with NLUTD is vast and likely greater than other non-neurogenic bladder conditions.

Summary There is a growing body of literature on the social ecology of NLUTD, however the literature to date remains sparse, and there is much room for further investigation. A better understanding of factors at each level may allow for better overall understanding of the lived experience of those with NLUTD.

Keywords Neurogenic bladder · Neurogenic lower urinary tract dysfunction · Spinal cord injury · Social determinants of health · Social ecology · Social-ecological framework

Introduction

Neurogenic lower urinary tract dysfunction (NLUTD) describes a constellation of urinary symptoms and chronic bladder conditions that result from neurologic conditions of the central and peripheral nervous system, both acquired and congenital. It refers to the “abnormal function of either the bladder, bladder neck, and/or sphincters” related to a known neurologic disorder [1•]. Healthcare providers often focus on the urologic management of NLUTD, including catheterization, surgical interventions, pharmacologic therapy, or a combination of all the above. However, living with NLUTD has profound impacts on patient’s quality of life (QOL) and psychosocial functioning. Additionally, social determinants/

drivers of health (SDOH) and unmet social needs may disproportionately impact people with NLUTD. Despite the growing appreciation in healthcare that SDOH and other non-medical factors may negatively impact health outcomes, there remains a paucity of literature focusing on the psychological and social experiences of people living with NLUTD. However, furthering our understanding of these factors will allow for the most comprehensive and thoughtful medical care for those living with NLUTD.

Therefore, the purpose of this review is to focus on these non-medical aspects of NLUTD. We aim to examine NLUTD through a multi-level social ecological framework, to consider how sociocultural environment, individual social needs, psychosocial burden, interpersonal relationships, community context, and the healthcare system may impact NLUTD and a person’s experience living this condition. We will review the available literature on these matters to help better understand the social ecology of these complex patients.

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Social Ecology of Noncancerous Genitourinary Conditions

Social ecology broadly refers to relationships between individual people and their environment. Social-ecological frameworks are often used in healthcare to help understand a health problem or condition across various levels, which can then be used to identify potential areas for intervention and/or prevention to improve health outcomes. These levels include intrapersonal or individual factors (including knowledge, attitudes, beliefs, biological factors, and personal history), interpersonal factors (such as personal relationships and social supports), community and institutional factors (which includes the physical and social environments in which people live, work, and learn—workplaces, schools, and neighborhoods), and finally societal factors (including social/cultural norms, healthcare utilization, economic burden, and social policies). [2•]

In the healthcare community, there is a growing appreciation and interest in how social ecology helps us understand disparities in healthcare and health outcomes of chronic conditions, including noncancerous genitourinary conditions and bladder health. A recent National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) interdisciplinary workshop aimed to conceptualize the “hidden burdens” of noncancerous genitourinary conditions across all levels of social ecology, including both upstream and downstream effects, which may vary across the life course and interact with other sociodemographic characteristics including gender and race or ethnicity [2•]. There is a small, but growing, body of literature considering some of these “burdens” and interactions between social factors and various urologic conditions. Multiple noncancerous genitourinary conditions and more severe lower urinary tract symptoms (LUTS) have been associated with a greater number of unmet social needs in a cumulative fashion [3]. Lower socioeconomic status and food insecurity have both been associated with more severe urgency urinary incontinence (UUI) [4, 5]. Likewise, overactive bladder (OAB) has been associated with multiple individual unmet social needs, including housing insecurity/stability, food insecurity, utilities insecurity, lack of transportation, skipping medical appointments, legal issues, interpersonal relationship stress, toilet and plumbing insecurity, and poor social supports, with interpersonal stress and violence specifically being associated with OAB with UUI (OAB “wet”) as opposed to OAB without UUI (OAB “dry”) [6]. Additionally, due to workplace or school limitations on number and access to toilets, OAB has been associated with decreased work productivity, difficulty finding and keeping employment, and difficulty concentrating in a work or school setting [7,

8]. While these studies clearly suggest associations exist between urinary conditions and LUTS and various levels of SDOH, even this limited literature focuses mostly on non-neurogenic bladder conditions. Therefore, there is a need to continue to focus efforts on understanding the social ecology of NLUTD. Herein, we will review the social ecology of NLUTD, across the individual, interpersonal, community/institutional, and societal levels.

Social Ecology of Neurogenic Lower Urinary Tract Dysfunction

Individual Factors—Knowledge, Attitudes/Beliefs, Quality of Life, Psychosocial Burden, Personal History, and Unmet Social Needs

Quality of Life

The impacts of NLUTD on overall individual QOL are significant. Urinary function is among one of the top priorities for functional recovery in the literature on spinal cord injury (SCI) patients, such that when asked, SCI patients did not have a preference between improvement in bladder function versus obtaining the ability to walk following their injury [9, 10]. The ways in which NLUTD affects individual QOL can be quite vast, as the morbidity experienced by the patient is variable and includes LUTS (frequency, urgency, and nocturia), urinary incontinence and the need to use incontinence products, urinary tract infections (UTIs), urologic management strategies including the need for catheterization or invasive surgical procedures, autonomic dysreflexia (AD), and the long-term risk of renal dysfunction.

For people with NLUTD, both overall and bladder-specific QOL are important considerations, however, each can be difficult to define given the complexity inherent to any neurologic condition. There are numerous questionnaires or patient-reported outcome assessment tools that can be used for people with NLUTD to assess and track QOL. A systematic review included 18 questionnaires that have been validated for patients with NLUTD due to various neurologic conditions, in both men and women [11]. The majority of questionnaires, however, are actually disease specific and therefore not broadly generalizable to any person with NLUTD. Additionally, they mainly assess overall QOL, which is incredibly complex. Additionally, while most measures include bladder-specific questions, they may poorly assess bladder-specific QOL, because urinary changes may or may not result in a change in overall QOL, which is multifactorial. There are a few specific tools of note. The Qualiveen is an older validated instrument which has been well-studied and assesses QOL in SCI and multiple sclerosis (MS) patients [12]. It comes in both long and

short forms and is divided into 4 domains of QOL: bother with limitations, frequency of limitations, fears, and feeling. The Neurogenic Bladder Symptom Score (NBSS) is a newer measure of both the symptoms and effects of NLUTD [13]. While the questionnaire mainly focuses on quantifying bladder symptoms, it also assessed bladder-specific QOL with a single, easy-to-use question. There are a few others, including Incontinence QOL (IQOL) instrument which is not NLUTD-specific but has been validated in NLUTD patients, specifically those with SCI and MS, and considers the disease-specific QOL of incontinence in NLUTD. [14]

Just as there are limited validated tools for assessing QOL in patients with NLUTD, there are limited studies assessing NLUTD impacts on QOL. A systematic review looked at 14 studies assessing the impact of NLUTD or incontinence from NLUTD on QOL [15]. Authors found, when compared to controls, QOL was significantly worse in patients with NLUTD from a variety of neurologic conditions. Domains affected included mental health, socialization, and physical functioning. The majority of these studies used generic QOL measures not actually designed or validated for NLUTD, which highlights the limitations in the existing literature on the matter. One study included in this review assessed the impact of health-related QOL domains (including pain, independence, and well-being) on patient-reported urinary symptoms in SCI patients [16]. Authors found a strong association between the two. People with increased pain reported worse urinary symptoms, while conversely increased independence and increased well-being is associated with less urinary symptoms. Objective urinary symptoms, therefore, may be differently perceived by different patients, and are greatly dependent on other domains of QOL, and optimizing aspects of overall QOL actually may help to improve bladder-specific QOL in those with NLUTD. Further understanding and assessments of the complexities of QOL, both overall and bladder-specific, in patients with NLUTD can help to improve the overall care for these patients.

Psychosocial Burden

The psychological distress and comorbidity associated with chronic medical conditions, including urologic conditions, are a growing area of interest. We have previously reviewed the psychological comorbidity associated with NLUTD at length and the opportunity for interdisciplinary care for these complex patients [17•]. Studies suggest that patients with NLUTD experience increased psychosocial distress, with increased social isolation and reductions in self-esteem, which can lead to poorer rehabilitation and long-term health outcomes due to poorer patient perceptions of their own health [18]. There is also extensive overlap with increased levels of anxiety (related to bladder symptoms—incontinence, lack of access to bathrooms when in

public, and fear of worsening symptoms) which leads to increased social isolation, feelings of shame, loss of dignity, and again, poorer self-esteem and confidence [19, 20]. The prevalence of major depression ranges in patients with SCI from 10 to nearly 40% in the literature [21] and is often comorbid with anxiety [22]. Depression has been associated with increased urinary symptom severity in patients with NLUTD, a relationship that is likely multifactorial and bidirectional. Increased psychosocial burden in patients with NLUTD is associated with poor outcomes, including increased hospitalization, [23] substance use disorders [24], decreased functional status [25], decreased life expectancy [26], and increase in all-cause mortality, including, specifically increased suicide rates. [27, 28]

Psychosocial burden likewise impacts coping in patients with chronic conditions, including NLUTD. As stated previously, common coping includes social isolation, due to fear, embarrassment, and worry that certain behaviors could actually intensify or worsen their urinary symptoms [29]. These coping strategies actually increase depression, anxiety, and negative self-perception, which in turn goes on to exacerbate pain perception and even urinary symptoms, which becomes a self-perceptualizing cycle. While there is limited data on this type of “catastrophizing” in NLUTD, it is intuitive to imagine this type of cyclical reinforcement that can occur with negative self-talk and self-perception, which exacerbates psychological distress and urinary conditions. These data suggest that supporting efforts towards psychosocial screening and interventions for patients with NLUTD is critical in the comprehensive care for these complex patients.

Unmet Social Needs

Just as we are considering the multi-level social-ecological framework of NLUTD, we can likewise understand social drivers of health in a similar multi-level framework, which is particularly useful when considering health system interventions to address healthcare disparities. While the term SDOH tends to be used quite ubiquitously, strictly speaking SDOH are a community’s underlying social and economic conditions, a more upstream concept, whereas many interventions target the downstream social risk factors, which are adverse social conditions associated with poor health outcomes, or, even more specifically, unmet social needs, which are the social risk factors self-identified as needs that are pressing at the moment to an individual person or group of people. In our own investigation of how unmet social needs differentially affect those with NLUTD, we surveyed a community-based sample of over 4000 adults in the USA, of whom 302 (7%) self-identified as having NLUTD [30]. We found that those with NLUTD more often reported individual unmet social needs including housing instability and safety, food insecurity, lack of transportation, healthcare

costs, needing child or elder care, legal issues, interpersonal violence and stress, and home toilet and sanitation insecurity as compared to people without NLUTD. These associations remained true even on multivariable analysis when adjusting for other sociodemographics (age, gender, race/ethnicity, living community, educational attainment, employment, and insurance). While this study is the first of its kind, it suggests that people with NLUTD have unmet social needs spanning multiple domains, which ultimately undoubtedly affect their overall healthcare and their medical condition(s). Further understanding the impact of these unmet needs on patients is critical to help address the healthcare disparities and inequities in this vulnerable population.

While the individual level factors affecting those living with NLUTD are important and interesting and tend to be the best studied, the broader levels of social ecology, which include the people and environment surrounding individuals living with NLUTD, are equally as important to consider. While the literature becomes more scarce, each of the following levels has significant impact on and is impacted by NLUTD and is important to consider when understanding the overall experience of a person living with this condition.

Interpersonal Factors—Relationships and Social Supports

Interpersonal Relationships

For people living with NLUTD, interpersonal relationships and social supports can be incredibly complex. As stated above, often social relationships are affected by patients' perceived embarrassment about catheters, incontinence, or urinary symptoms, a perceived loss of control, and the need to extensively plan social engagements around bathroom access or bladder management [31]. This leads to social isolation and disengagement. In fact, the less severe the urinary dysfunction in a person with NLUTD, the less social isolation and the more social engagement occurs [32]. While limited, studies suggest that social engagement can improve with good urologic management strategies and treatment of NLUTD, such that patients with successful urologic interventions to increase autonomy have increased confidence, independence, and reengagement in social activities and social relationships. [33•]. [34]

Sexual and Intimate Relationships

Sexual, intimate, and romantic relationships can also be affected in NLUTD. There is, of course, concomitant sexual dysfunction that occurs with NLTUD. But despite this, urologic management strategies can also affect sexual function, with the use of catheters and/or fear of incontinence during

sexual activity, which again leads to avoidance of intimate relationships, fear, embarrassment, and isolation, with the perception that sexual partners will have a lack of understanding [33•]. It can be stressful for people with NLUTD to date, with the fear of divulging urologic management or sexual dysfunction in new relationships. Additionally, this is an aspect of NLUTD that healthcare providers tend to ignore, with studies showing patients desire more information, discussion, and assistance on maintaining or starting sexual relationships. [35]

Caregiver Relationships

In people with disabilities and chronic medical conditions, including NLUTD, there is a special interpersonal relationship to consider, which is the caregiver relationship. There is the concept of “role changing” that occurs when considering people who have acquired NLTUD, such that family and friends assume caregiver roles as the patient develops new or worsening urinary symptoms requiring increasing care, which in turn creates strain on the former relationship [33•]. In a quantitative assessment of people with NLTUD due to spina bifida, barriers to performing intermittent catheterization included that they felt their caregivers had negative feelings about the need to assist with catheterization, and that this may hinder overall performance [36]. These perceptions can lead to feelings of shame, and significantly change interpersonal relationships.

Community and Institutional Factors—Workplace, School, Healthcare Settings, Neighborhood, Living Community, and Restroom Infrastructure

Workplace

The traditional office workplace setting may be ill-equipped to adapt to workers dealing with urinary symptoms, and especially NLTUD. Studies have demonstrated that increased urinary symptoms, and particularly urinary incontinence, may lead to decreased work productivity, greater loss of work time, and increased medical-related absenteeism [37, 38]. Additionally, a common barrier to restroom access in the workplace is the concept of “gatekeepers,” which may be people (including managers or supervisors) or time (restricted time to use for bathroom breaks) [39, 40]. People with NLUTD require frequent, unrestricted bathroom access and may additionally benefit from private bathrooms due to need for catheterization or even areas for storage of supplies. Finally, restroom infrastructure with physical proximity of bathrooms certainly affects job choice in these patients. Jobs without access to constant and close restrooms (bus drivers, production lines, construction, etc.) are just not suitable for those with NLUTD.

School

Considering many neurologic conditions resulting in bladder dysfunction are congenital, NLUTD may impact children's school environment and educational needs. While there is legislation that guarantees children with disabilities negatively impacting their education must be supported or accommodated through schooling, this can become quite complex, as this type of legislation most often focuses on learning disabilities. A child with NLUTD may have no clear special educational needs but still may require accommodation for urologic management, including frequent bathroom breaks, may need for assistance with catheterizations, and may have time away for other medical sequelae—procedures or UTIs. In a survey of parents of children with NLUTD conducted by the Mississippi Department of Education, the most common accommodation parents felt that was needed at school was unrestricted bathroom access, including changing and cleaning when necessary, possibly private restroom access with areas for supply storage, and/or accessible restrooms [41]. Additional considerations noted for children with chronic medical conditions being away from home and their normal caregivers when at school is the need for open communication, meaning parents being able to readily communicate with the school/teacher/nurses and vice versa. Finally, accommodations for breaks during testing, unrestricted access to fluids, and just an overall awareness of the conditions have also been identified as areas lacking in conventional education settings.

Public Restroom Infrastructure

Workplace and school restrooms are, by definition, public restrooms, and while there is limited information about those with NLUTD accessing public restrooms, we know that people with urinary symptoms often limit restroom use while at work and/or public [42, 43]. There are barriers in terms of lack of availability overall of wheelchair-accessible public restrooms and stalls that provide enough space for someone who needs to perform catheterization or needs caregiver assistance [44]. There are rarely clean shelves or surfaces to place supplies while in public restrooms. When traveling to avoid these difficulties, people with NLUTD may opt to place an indwelling catheter [45]. Aside from some of the structural difficulties in public restroom infrastructure, there is a general lack of understanding which leads to perceived or actual negative attitudes towards those with NLUTD when using public restrooms [33•]. The general, able-bodied, public may be unfamiliar with catheterization and not understand how using a handicap-accessible stall may adversely affect someone with NLUTD when the appropriate accommodations are not available [44]. Additionally, if there is no handicapped or larger stall available, people

with NLUTD may be forced to catheterize in the main bathroom area, which is embarrassing and results in a complete lack of privacy. Overall, public restroom infrastructure is not designed to accommodate those with NLUTD and undoubtedly contributes to negative experiences when in public spaces, again contributing to the social isolation that may accompany NLUTD.

Healthcare

The experiences of people with NLUTD even in healthcare settings can be very formative and affect their willingness to seek and continue with care. Patients with NLUTD, as they often have other physical disabilities, can experience difficulties in medical office settings, such as wheelchair-inaccessible buildings, lack of equipment to assist with transfers, difficulty with transportation to and from appointments, and a lack of knowledge and sensitivity by office staff in dealing with people with disabilities [46]. Likewise, patients with NLUTD may exhibit avoidance behaviors when seeking medical care for their urinary symptoms, due to fear, lack of knowledge of treatment options, feeling their symptoms are not severe enough to warrant medical care, and concerns about healthcare costs. [47]

Societal Factors—Healthcare System and Economic Burden

Healthcare Utilization and Economic Burden

The overall healthcare utilization and economic burden of NLUTD are difficult to assess, as it encompasses many aspects (work-up, pharmacologic, surgical, devices, hospitalizations, etc.) and the care is often long-term and requires surveillance. Renal failure was historically the leading cause of death among patients with NLUTD, although complications from NLUTD remain one of the leading causes of hospitalization in those with SCI [48, 49]. One study using United States Medicare claims database found that over a one-year period, 40% of patients with NLUTD saw a urologist and 30% saw a neurologist, with an average number of 15 office visits per year [50•]. Additionally, 33% of patients were hospitalized at least once during the year, most often for UTIs, 23% had at least one visit to an emergency room, and 15% lived in a nursing home. Utilization was the highest among those with NLUTD due to SCI. While there has not been a direct comparison between the healthcare utilization due to idiopathic OAB and NLUTD, the high rate of comorbid conditions, complications of treatment, and need for specialist consultation in NLUTD can lead us to hypothesize that the healthcare utilization of NLUTD would be greater than the estimated \$82.6 billion spent on the diagnosis and treatment of OAB in 2020. [51]

As stated above, UTIs are the most common reason for admission and emergency room visits among those with NLUTD and therefore contribute significantly to the overall healthcare burden. In the above study from the Medicare claims database, 21% of all hospitalizations over the 1-year study period were due to lower UTIs, with 8% of these resulting in sepsis [50•]. Likewise, due to the abnormal bladder function that defines NLUTD, the progression of lower UTIs to upper tract involvement is a special concern and means a much higher hospitalization rate than the average person without NLUTD, which is evidenced by the 46% of patients with upper tract infections requiring hospitalization in this study. [50•]

Another significant aspect of healthcare costs is equipment, the costliest of which is single-use catheters. In the USA, reimbursement for single-use catheters ranges from 2 to \$8 and depends on design [45]. The financial burden for single-use catheters for an individual may be significant and may not be completely covered by an individual's insurance. An estimated 56% of those in the USA with NLUTD report reusing their catheters, which, although likely mostly safe, could also increase the risk of UTIs or other sequelae.

Health Insurance

Insurance status is also something that can greatly affect the care and experiences of those with NLUTD. In our own previously described study of unmet social needs in those with NLUTD, we found that people with NLUTD were more likely to use Medicaid or Medicare over private insurance, as opposed to those without NLUTD [30]. Insurance status has also been found to affect the urologic management of NLUTD. Patients with NLUTD due to SCI who are publicly insured are more likely to be treated with indwelling catheters or be spontaneously voiding as opposed to intermittent catheterization and are less likely to be on any urologic medications, as compared to those who are privately insured [52]. Insurance status did not appear to be associated with differences in urologic symptom severity, however. While the relationships here are likely multifactorial and complex, due to patient preferences, care access, and other SDOH, it highlights the role the overall healthcare system may play in urologic management for these patients.

Conclusions

Neurogenic lower urinary tract dysfunction is a complex collection of urinary sequelae in people with neurologic conditions. The experience of living with NLUTD is affected by and affects all levels of social ecology, including the individual, interpersonal, community, and societal. The literature examined herein remains quite limited. We highlight the need

for continued understanding of the overall social ecology of NLUTD, with the goals of improving urologic and overall care, QOL, and social and societal functioning.

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Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

References

Papers of particular interest, published recently, have been highlighted as:

• Of importance

1. DA Ginsberg TB Boone AP Cameron et al 2021 The AUA/SUFU guideline on adult neurogenic lower urinary tract dysfunction: treatment and follow-up *J Urol.* 206 5 1106–1113 <https://doi.org/10.1097/JU.0000000000002239>. **Comprehensive AUA/SUFU Guidelines on the evaluation, management, and surveillance of neurogenic lower urinary tract dysfunction.**
2. Brady SS, Bavendam TG, Bradway CK, et al. Noncancerous genitourinary conditions as a public health priority: conceptualizing the hidden burden. *Urology.* 2021;doi:<https://doi.org/10.1016/j.urology.2021.08.040>. **Framework for understanding the social ecology of urinary conditions.**
3. Anne Zwaschka T, Sebesta EM, Gleicher S, Kaufman MR, Dmochowski RR, Reynolds WS. The cumulative effect of unmet social needs on noncancerous genitourinary conditions and severity of lower urinary tract symptoms. *Neuro-urol Urodyn.* 2022;41(8):1862–71. <https://doi.org/10.1002/nau.25038>.
4. Lee JA, Johns TS, Melamed ML, Tellechea L, Laudano M, Stern JM, Abraham NE. Associations between socioeconomic status and urge urinary incontinence: an analysis of NHANES 2005 to 2016. *J Urol.* 2020;203(2):379–84.
5. Okada C, Kim JI, Roselli N, Kadam Halani P, Melamed ML, Abraham N. Food insecurity is associated with urge urinary incontinence: an analysis of the 2005–2010 National Health and Nutrition Examination Survey. *J Urol.* 2023;210(3):481–91. <https://doi.org/10.1097/JU.0000000000003545>.
6. Sebesta EM, Gleicher S, Kaufman MR, Dmochowski RR, Reynolds WS. Associations between unmet social needs and overactive bladder. *J Urol.* 2022;208(5):1106–15. <https://doi.org/10.1097/JU.0000000000002841>.

7. Tellechea L, Zuo S, Kohn JR, et al. The effect of social determinants of health on overactive bladder symptom severity. *J Urol*. 2021;205(5):1415–20.
8. Sexton CC, Coyne KS, Vats V, Kopp ZS, Irwin DE, Wagner TH. Impact of overactive bladder on work productivity in the United States: results from EpiLUTS. *Am J Manag Care*. 2009;15(4 Suppl):S98–107.
9. Lo C, Tran Y, Anderson K, Craig A, Middleton J. Functional priorities in persons with spinal cord injury: using discrete choice experiments to determine preferences. *J Neurotrauma*. 2016;33(21):1958–68. <https://doi.org/10.1089/neu.2016.4423>.
10. Simpson LA, Eng JJ, Hsieh JT, Wolfe and the spinal cord injury rehabilitation evidence research Team DL. The health and life priorities of individuals with spinal cord injury: a systematic review. *J Neuro*. 2012;29(8):1548–55.
11. Tsang B, Stothers L, Macnab A, Lazare D, Nigro M. A systematic review and comparison of questionnaires in the management of spinal cord injury, multiple sclerosis and the neurogenic bladder. *NeuroUrol Urodyn*. 2016;35(3):354–64.
12. Costa P, Perrouin-Verbe B, Colvez A, et al. Quality of life in spinal cord injury patients with urinary difficulties. Development and validation of qualiveen. *Eur Urol*. 2001;39(1):107–13. <https://doi.org/10.1159/000052421>.
13. Welk B, Morrow S, Madarasz W, Baverstock R, Macnab J, Sequeira K. The validity and reliability of the neurogenic bladder symptom score. *J Urol*. 2014;192(2):452–7. <https://doi.org/10.1016/j.juro.2014.01.027>.
14. Schurch B, Denys P, Kozma CM, Reese PR, Slaton T, Barron R. Reliability and validity of the Incontinence Quality of Life questionnaire in patients with neurogenic urinary incontinence. *Arch Phys Med Rehabil*. 2007;88(5):646–52. <https://doi.org/10.1016/j.apmr.2007.02.009>.
15. Patel DP, Elliott SP, Stoffel JT, Brant WO, Hotaling JM, Myers JB. Patient reported outcomes measures in neurogenic bladder and bowel: a systematic review of the current literature. *NeuroUrol Urodyn*. 2016;35(1):8–14.
16. Myers JB, Lenherr SM, Stoffel JT, et al. Patient reported bladder related symptoms and quality of life after spinal cord injury with different bladder management strategies. *J Urol*. 2019;202(3):574–84.
17. Sebesta E, Connors E, Rourke E, Reynolds W, McKernan LC. Psychosocial factors in neurogenic lower urinary tract dysfunction: implications for multidisciplinary care. *Curr Blad Dysfunct Rep*. 2022;17(1):30–7 (**Review of psychosocial comorbidity in neurogenic lower urinary tract dysfunction.**).
18. Nseyo U, Santiago-Lastra Y. Long-term complications of the neurogenic bladder. *Urol Clin*. 2017;44(3):355–66.
19. Nevedal A, Kratz AL, Tate DG. Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel. *Disabil Rehabil*. 2016;38(6):573–81.
20. Al Dandan HB, Galvin R, McClurg D, Coote S, Robinson K. Management strategies for neurogenic lower urinary tract dysfunction: a qualitative study of the experiences of people with multiple sclerosis and healthcare professionals. *Disab Rehab*. 2021:1–11.
21. Bombardier CH, Richards JS, Krause JS, Tulsy D, Tate DG. Symptoms of major depression in people with spinal cord injury: implications for screening. *Arch Phys Med Rehabil*. 2004;85(11):1749–56.
22. Showen A, Copp HL, Allen IE, Baradaran N, Liaw A, Hampson LA. Characteristics associated with depression, anxiety, and social isolation in adults with spina bifida. *Urology*. 2021;149:255–62.
23. January A, Zebracki K, Chlan K, Vogel L. Mental health and risk of secondary medical complications in adults with pediatric-onset spinal cord injury. *Topics Spin Cord Injury Rehab*. 2014;20(1):1–12.
24. Williams RT, Wilson CS, Heinemann AW, Lazowski LE, Fann JR, Bombardier CH. Identifying depression severity risk factors in persons with traumatic spinal cord injury. *Rehabil Psychol*. 2014;59(1):50.
25. Arango-Lasprilla JC, Ketchum JM, Starkweather A, Nicholls E, Wilk AR. Factors predicting depression among persons with spinal cord injury 1 to 5 years post injury. *NeuroRehab*. 2011;29(1):9–21.
26. Hartoonian N, Hoffman JM, Kalpakjian CZ, Taylor HB, Krause JK, Bombardier CH. Evaluating a spinal cord injury-specific model of depression and quality of life. *Arch Phys Med Rehabil*. 2014;95(3):455–65.
27. DeVivo MJ, Black K, Richards JS, Stover S. Suicide following spinal cord injury. *Spinal Cord*. 1991;29(9):620–7.
28. Judd F, Brown DJ. Suicide following acute traumatic spinal cord injury. *Spinal Cord*. 1992;30(3):173–7.
29. McKernan LC, Bonnet KR, Finn MT, et al. Qualitative analysis of treatment needs in interstitial cystitis/bladder pain syndrome: implications for intervention. *Canad J Pain*. 2020;4(1):181–98.
30. Ellis T, Gleicher S, Park R, Kaufman M, Dmochowski R, Reynolds WS, Sebesta E. OM37 Neurogenic lower urinary tract dysfunction is associated with negative social determinants of health in a broad sample of U.S. adults. *NeuroUrol Urodyn*. 2023;42(1):7–309. <https://doi.org/10.1002/nau.25154>.
31. Welk B, Myers JB, Kennelly M, McKibbin M, Watson J, Gervais K. A qualitative assessment of psychosocial aspects that play a role in bladder management after spinal cord injury. *Spinal Cord*. 2020:1–9.
32. Craig A, Nicholson Perry K, Guest R, Tran Y, Middleton J. Adjustment following chronic spinal cord injury: determining factors that contribute to social participation. *Br J Health Psychol*. 2015;20(4):807–23.
33. Braaf S, Lennox A, Nunn A, Gabbe B. Social activity and relationship changes experienced by people with bowel and bladder dysfunction following spinal cord injury. *Spinal Cord*. 2017;55(7):679–86 (**Experiences of people living with spinal cord injury on their social activities and relationships.**).
34. Hearn JH, Selvarajah S, Kennedy P, Taylor J. Stigma and self-management: an Interpretative phenomenological analysis of the impact of chronic recurrent urinary tract infections after spinal cord injury. *Spin Cord Ser Cases*. 2018;4(1):1–8.
35. Kautz DD, Van Horn ER. Sex and intimacy after stroke. *Rehabil Nurs*. 2016;
36. Faleiros F, Cordeiro A, Favoretto N, K appler C, Murray C, Tate D. Patients with spina bifida and their caregivers feelings about intermittent bladder catheterization in Brazil and Germany: a correlational study. *Rehabil Nurs*. 2015;
37. Wu EQ, Birnbaum H, Marynchenko M, Mareva M, Williamson T, Mallett D. Employees with overactive bladder: work loss burden. *J Occup Environ Med*. 2005;47(5):439–46.
38. Rapariz M, Mora A, Roset M. Impact of overactive bladder symptoms on work activity: The ACTIVHA study. *Actas Urol gicas Espa olas (English Edition)*. 2018;42(3):176–84.
39. Camenga DR, Brady SS, Hardacker CT, et al. US adolescent and adult women's experiences accessing and using toilets in schools, workplaces, and public spaces: a multi-site focus group study to inform future research in bladder health. *Int J Environ Res Public Health*. 2019;16(18):3338.
40. Hartigan SM, Bonnet K, Chisholm L, Kowalik C, Dmochowski RR, Schlundt D, Reynolds WS. Why do women not use the bathroom? Women's attitudes and beliefs on using public restrooms. *Int J Environ Res Public Health*. 2020;17(6):2053.

41. Filce HG, LaVergne L. Absenteeism, educational plans, and anxiety among children with incontinence and their parents. *J Sch Health*. 2015;85(4):241–50. <https://doi.org/10.1111/josh.12245>.
42. Reynolds WS, Kowalik C, Kaufman MR, Dmochowski RR, Fowke JH. Women's perceptions of public restrooms and the relationships with toileting behaviors and bladder symptoms: a cross-sectional study. *J Urol*. 2020;204(2):310–5.
43. Reynolds WS, Kowalik C, Delpe SD, Kaufman M, Fowke JH, Dmochowski R. Toileting behaviors and bladder symptoms in women who limit restroom use at work: a cross-sectional study. *J Urol*. 2019;202(5):1008–14.
44. Lawrenz K. Accessibility: why living with a spinal cord injury is so hard in public settings. September 21, 2022. <https://scican.ca/blog/accessibility-why-living-spinal-cord-injury-so-hard-public-settings>
45. Herbert AS, Welk B, Elliott CS. Internal and external barriers to bladder management in persons with neurologic disease performing intermittent catheterization. *Int J Environ Res Public Health*. 2023;20(12) <https://doi.org/10.3390/ijerph20126079>
46. Shenot PJ, Moy ML. Office-based care of the neurogenic bladder patient. *Curr Blad Dysfunct Rep*. 2011;6(2):74–80.
47. Brucker BM, Nitti VW, Kalra S, Herbert J, Sadiq A, Utomo P, Aponte MM. Barriers experienced by patients with multiple sclerosis in seeking care for lower urinary tract symptoms. *Neurourol Urodyn*. 2017;36(4):1208–13.
48. Curtin CM, Suarez PA, Di Ponio LA, Frayne SM. Who are the women and men in Veterans Health Administration's current spinal cord injury population? *J Rehabil Res Dev*. 2012;49(3):351.
49. Hackler RH. A 25-year prospective mortality study in the spinal cord injured patient: comparison with the long-term living paraplegic. *J Urol*. 1977;117(4):486–8. [https://doi.org/10.1016/s0022-5347\(17\)58506-7](https://doi.org/10.1016/s0022-5347(17)58506-7).
50. A Manack SP, Motsko C, Haag-Molkenteller RR, Dmochowski EL, Goehring Jr BA, Nguyen-Khoa JK, Jones 2011. Epidemiology and healthcare utilization of neurogenic bladder patients in a US claims database. *Neurourol Urodyn*. 30:3395–401. <https://doi.org/10.1002/nau.21003>. **Understanding the healthcare utilization of patients with neurogenic lower urinary tract dysfunction to help conceptualize the economic burden.**
51. Coyne KS, Wein A, Nicholson S, Kvasz M, Chen C-I, Milsom I. Economic burden of urgency urinary incontinence in the United States: a systematic review. *J Manag Care Pharm*. 2014;20(2):130–40.
52. Rude T, Moghalu O, Stoffel J, et al. The role of health insurance in patient reported satisfaction with bladder management in neurogenic lower urinary tract dysfunction due to spinal cord injury. *J Urol*. 2021;205(1):213–8.

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