#### ORIGINAL RESEARCH

# Bladder Emptying Strategies, Active Follow-up Adherence and Barriers in Post-Discharge Spinal Cord Injury individuals: A Multiple Center Cross-Sectional Study

Hongxia Pan<sup>1,2,\*</sup>, Liang Zhu<sup>1,2,\*</sup>, Jingfei Xu<sup>1,2</sup>, Mingfu Ding<sup>1,2</sup>, Haidan Lin<sup>3</sup>, Yang Chen<sup>4</sup>, Xin Sun<sup>1,2</sup>, Chengqi He<sup>1,2</sup>, Quan Wei<sup>1,2</sup>

<sup>1</sup>Rehabilitation Medicine Center and Institute of Rehabilitation Medicine, West China Hospital, Sichuan University, Chengdu, Sichuan, People's Republic of China; <sup>2</sup>Key Laboratory of Rehabilitation Medicine in Sichuan Province, Chengdu, Sichuan, People's Republic of China; <sup>3</sup>Rehabilitation Medicine Center of The First Affiliated Hospital of Chongqing Medical University, Chongqing, People's Republic of China; <sup>4</sup>Sichuan China 81 Rehabilitation Center (Sichuan Provincial Rehabilitation Hospital), Chengdu, People's Republic of China

\*These authors contributed equally to this work

Correspondence: Quan Wei, Rehabilitation Medicine Center and Institute of Rehabilitation Medicine, West China Hospital, Sichuan University, Chengdu, Sichuan, People's Republic of China, Email weibuyi98@163.com

**Background:** Adherence plays a crucial role in the long-term management of chronic conditions, including neurogenic lower urinary tract dysfunction (NLUTD) in individuals with spinal cord injury (SCI). Poor adherence can lead to complications, reduced quality of life, and increased healthcare costs.

**Purpose:** This study aimed to evaluate the post-discharge bladder-emptying practices and adherence to follow-up in SCI individuals with NLUTD, identifying key factors influencing adherence to improve long-term care strategies.

**Methods:** A cross-sectional survey was conducted in Southwest China from May 1 to September 30, 2023. Online questionnaires were employed to collect data on sociodemographic characteristics, bladder emptying methods, active follow-up adherence and related barriers. **Results:** Out of 412 fully completed questionnaires, as for bladder-emptying method, 70.15% of respondents opted for clean intermittent catheterization (CIC) as their primary or preferred mode. CIC usage was more prevalent among participants with thoracic and lumbar SCI, while those with cervical SCI demonstrated a higher reliance on indwelling catheterization (IDC) and cystostomy. A significant 63.55% did not engage in regular hospital follow-ups participants with thoracic SCI had the lowest adherence rate (49.79%), followed by lumbar (72.62%) and cervical (77.59%) groups. Preferences for medical consultation were highest for rehabilitation physicians at 65.68%, with neurourologists following at 33.83%. Key barriers to follow-up adherence were identified as the more severity of SCI, lack of disease knowledge, increasing age, and reliance on adult children for care. In contrast, positive predictors of follow-up adherence were ample financial support and previous medical consultation experiences.

**Conclusion:** This study revealed insufficient follow-up adherence among SCI individuals with NLUTD, with CIC emerging as the preferred method for bladder emptying strategy. Age and injury level significantly influenced adherence. To improve long-term management of NLUTD, future initiatives should focus on enhancing health education accessibility, optimizing healthcare services, and providing comprehensive financial support to high-risk groups.

Keywords: neurogenic lower urinary tract dysfunction, bladder-emptying methods, surveillance, follow-up

#### Introduction

Spinal cord injury (SCI) represents a category of profoundly incapacitating conditions, which are known to exert a significant detrimental impact on sensory and motor functions, as well as autonomic nervous system regulation.<sup>1</sup> Globally, an estimated 20.6 million individuals were affected by SCI in 2019.<sup>2</sup> In China, approximately 234,190 new SCI cases were reported during

Patient Preference and Adherence 2025:19 623-633

© 2025 Pan et al. This work is published and licensed by Dove Medical Press Limited. The full terms of this license are available at https://www.dovepress.com/terms.php you hereby accept the firms. Non-commercial uses of the work are permitted without any further permission from Dove Medical Press Limited, provided the work is properly attributed. For permission for commercial use of this work, please see paragraphs 4.2 and 5 of our Terms (http://www.dovepress.com/terms.php).

623

the same year.<sup>3</sup> Among these patients, over 80% experience neurogenic lower urinary tract dysfunction (NLUTD),<sup>4,5</sup> making it one of the top health concern among SCI.<sup>6</sup> Unlike motor and sensory recovery, NLUTD often persists for a prolonged period, even after other neurological functions improve,<sup>7–9</sup> imposing a lasting burden on patients.

The economic impact of NLUTD is substantial. Previous study has estimated the annual supportive costs of NLUTD to range from \$2,039.69 to \$12,219.07, with lifetime costs reaching \$112,774 when complications are included.<sup>10</sup> With the increasing survival of SCI patients, both in China and other countries worldwide,<sup>11–13</sup> the long-term management of NLUTD has become an even greater challenge. Lifelong urological follow-up is imperative for improving survival rates,<sup>14–16</sup> reducing the complications associated with NLUTD<sup>14,17,18</sup> and enhancing the quality of life.<sup>19,20</sup> However, despite its importance, only a minority of NLUTD participants actively engage in regular follow-ups to seek professional guidance.<sup>21</sup> This highlights the critical need for optimizing NLUTD management strategies following SCI.<sup>22–24</sup>

Low adherence to follow-up is an important patient-related barrier to effective chronic diseases management,<sup>25,26</sup> including SCI-related NLUTD. Clean intermittent catheterization (CIC) is one of the most highly recommended and widely used methods of bladder management for NLUTD individuals,<sup>27</sup> with adoption rates ranging from 51% to 75% among SCI individuals in the United States.<sup>14,19,28</sup> In Canada, it is noted that 60% of SCI individuals adhere to CIC as a long-term management strategy.<sup>29</sup> In contrast, a report by Dr. Xu indicates that only 21.3% of SCI participants in China utilize CIC for extended periods.<sup>30</sup>

Previous studies in China have mainly focused on in-hospital management of NLUTD among SCI patients and are limited to a few developed provinces and cities.<sup>30,31</sup> However, there is little available evidence concerning the post-discharge bladder-emptying status and long-time surveillance of SCI participants with NLUTD in China.

Therefore, the primary objective of this study aimed at providing a comprehensive description of post-discharge NLUTD practices in SCI individuals. Specifically, this study aims to: (1) describe bladder-emptying methods according to SCI characteristics, (2) identify factors influencing follow-up adherence, and (3) explore patient-reported obstacles in neuro-urological management. We anticipate that these findings will offer valuable insights for improving long-term healthcare support for the SCI population.

### **Methods**

### Study Design and Patient Population

This was a multi-center, cross-sectional survey. All participants were SCI participants with NLUTD discharged from the following SCI rehabilitation centers: West China Hospital of Sichuan University, the First Affiliated Hospital of Chongqing Medical University, and the Sichuan Provincial Rehabilitation Hospital.

The inclusion criteria were as follows: 1) Individuals diagnosed as SCI in accordance with the American Spinal cord Injury Association(ASIA)<sup>32</sup> with no restrictions on age or gender; 2) Individuals diagnosed with NLUTD based on the criteria set by International Continence Society;<sup>33</sup> 3) Participants with clear consciousness or those whose caregiver was well-acquainted with their health condition; 4) Participants who voluntarily consent to take part in the survey and 5) Participants who have the ability to complete the survey online using a smartphone or computer.

There were no specific exclusion criteria. However, questionnaires with logically inconsistent responses or duplicate submissions were excluded from the final analysis.

# Data Collection and Analysis

#### Questionnaire Distribution

The questionnaire was distributed primarily through online surveys. It was shared in social media groups comprising SCI patients from the three participating SCI rehabilitation centers. The data collection period lasted from May 2024 to August 2024.

# Validity, Reliability, and Objectivity

The development and validation of the questionnaire were carried out as follows:

Drafting: The initial version of the questionnaire was jointly created by the China Association of Persons with Physical Disabilities and the Spinal Cord Injury Team at the Rehabilitation Medicine Center of West China Hospital, Sichuan University.

Expert Review: Sixteen experts in the field of SCI rehabilitation and staff involved in disabled persons' services provided feedback, which helped refine the initial draft.

Pilot Testing: Thirty SCI participants were invited to complete the trial version of the questionnaire and provide feedback. Their responses were used to revise and finalize the questionnaire content, ensuring its validity and reliability for the subsequent study.

# Questionnaire Contents

The questionnaire was organized into three main sections for clarity and ease of completion:

# Section I: Demographic Information

This section gathered some demographic details including:

- 1. Age and gender
- 2. Marital status, categorized as married/remarried or single/divorced
- 3. Place of residence
- 4. Educational attainment, with options for middle school and below, high school, bachelor's degree, and above
- 5. The presence of a family member with a medical education background

# Section 2: Medical Profile, Bladder Management, and Follow-up Related Factors

- 1. The duration since the SCI occurred
- 2. The level of SCI classified as cervical, thoracic, lumbar, or below
- 3. The current method of bladder emptying, with options including indwelling catheters (IDC), CIC, cystostomy, external urine collector, or pad use
- 4. History of prior medical consultations for NLUTD
- 5. Accessibility to hospitals with specialized departments such as rehabilitation, neurosurgery, neurology, urology, and orthopedics
- 6. Assessment of the convenience of hospital visit procedures: yes or no
- 7. Self-evaluated knowledge on NLUTD, rated from not at all familiar to awfully familiar
- 8. Frequency of follow-up visits, with options for never, sometimes, and regularly

# Section 3: Family and Social Support

The final section addressed concerns related to family or social support:

- 1. Self-reported economic burden, ranging from free to mild, moderate, or heavy
- 2. Identification of the primary caregiver, such as spouse, parent, adult children, or hired home care worker
- 3. Payment methods for healthcare, including self-paying, new rural cooperative medical scheme (NRCMS), urban resident basic medical insurance (URBMI), or urban employee basic medical insurance (UEBMI)
- 4. Availability of a person to accompany the patient for outings: yes or no
- 5. Transportation methods for going out, including personal, public, assisted transportation, or shared mobility vehicles
- 6. Modes of transportation used, such as road, rail, air, or waterway

Participants were invited to identify all potential factors, based on their personal experiences, that could influence their attendance at follow-up visits. They were then asked to rank these barriers according to the degree of impact they believe each factor has, ensuring a thorough and individualized reflection of the real-life factors affecting follow-up adherence.

# Statistical Analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences<sup>®</sup> (SPSS<sup>®</sup>) for Windows, version 25.0 (IBM Corporation, Armonk, New York, United States) software. The Shapiro–Wilk test was used to evaluate the normality of continuous variables. The data showed that they were not normally distributed and were thus expressed as median values (inter-quartile range [IQR]) and were compared between the two groups (adhere and non-adhere to follow-up) using the non-parametric test (Mann–Whitney *U*-test). For categorical variables, frequency and percentages were used to describe participants demographics. Logistic regression was utilized to analyze the relative factors affecting follow-up compliance, with p value < 0.05 considered statistically significant.

# Ethics of Approval and Participation Consent Statement

This study was conducted in accordance with the tenets of the Declaration of Helsinki and its later amendments. This survey was approved by the Clinical Research and Biomedical Ethics Committee of West China Hospital, Sichuan University (Approval No. 2023NO1105), and informed consent was obtained from the participants or their legal guardians.

# Results

# General Information

After excluding incomplete or duplicate responses, a total of 412 participants were enrolled in the present study. Detailed characteristics are presented in Table 1. The participants' ages ranged from 16 to 76 years, with a median age of 45 years and an IQR of 34 to 51 years. The duration of the disease ranged from 0.17 to 25 years, with a median duration of 3 years (IQR, 2–5 years). Males constituted 70.15% of the participants, yielding a male-to-female ratio of 2.35:1. Although all the participants were sourced from three SCI rehabilitation centers located in the southwestern region, their places of residence spanned various provinces and territories across China. The distribution of participants by region was as follows: 60.82% resided in the southwestern region, 31.19% in the northwestern region, 10.19% in the central region, and 3.35% in the eastern region. In the survey, the distribution of SCI levels was as follows: cervical SCI accounted for 24.03%, thoracic SCI for 43.69%, and lumbar and below SCI for 32.28% of the participants. These percentages reflect the prevalence of different SCI levels within the study's population.

Overall	CSCI	TSCI	LSCI				
Continuous variables (Median (Q1-Q3))							
45 (34, 51)	43 (32, 48)	46 (30, 49)	49 (38, 51)				
3.6 (2, 5)	2.3 (1.6, 4.5)	6.1 (1.8, 7.3)	7 (2.3,8.7)				
n(%))							
N = 412	99 (24.03%)	180 (43.69%)	133 (32.28%)				
hods							
261 (63.35%)	50 (19.16%)	128 (49.04%)	83 (31.80%)				
87 (21.12%)	24 (27.59%)	29 (33.33%)	34 (39.08%)				
47 (11.41%)	17 (36.17%)	18 (38.30%)	12 (25.53%)				
17 (4.12%)	8(47.06%)	5(29.41%)	4(23.53%)				
ιÞ							
171 (41.50%)	45 (26.32%)	59 (34.50%)	67 (39.18%)				
241 (58.50%)	54 (22.41%)	121 (50.21%)	66 (27.38%)				
	45 (34, 51) 3.6 (2, 5) (n(%)) N = 412 hods 261 (63.35%) 87 (21.12%) 47 (11.41%) 17 (4.12%) 10 171 (41.50%)	Median $(QI-Q3)$ )         45 $(34, 51)$ 3.6 $(2, 5)$ 2.3 $(1.6, 4.5)$ in(%))         N = 412         99 $(24.03\%)$ hods         261 $(63.35\%)$ 50 $(19.16\%)$ 87 $(21.12\%)$ 44 $(27.59\%)$ 47 $(11.41\%)$ 17 $(4.12\%)$ 8(47.06\%) $tp$ 171 $(41.50\%)$ 45 $(26.32\%)$	Median $(QI-Q3)$ )         45 $(34, 51)$ 3.6 $(2, 5)$ 2.3 $(1.6, 4.5)$ 6.1 $(1.8, 7.3)$ in(%))         N = 412         99 $(24.03\%)$ 180 $(43.69\%)$ hods         261 $(63.35\%)$ 50 $(19.16\%)$ 24 $(27.59\%)$ 29 $(33.33\%)$ 47 $(11.41\%)$ 17 $(4.12\%)$ 847.06\%)         50 $(29.41\%)$ 17         171 $(41.50\%)$ 45 $(26.32\%)$ 59 $(34.50\%)$				

 Table I Demographic Characteristics and Bladder Emptying Status

Abbreviations: CSCI, cervical SCI; TSCI, thoracic SCI; LSCI, lumbar SCI; CIC, clean intermittent catheterization; IDC, indwelling catheter; CC, condom catheter.

# **Bladder Emptying Methods**

The bladder emptying methods among respondents varied significantly, as detailed in Table 1. Participants were stratified into three groups based on their limb mobility and the location of their injury: cervical SCI (quadriplegia), thoracic SCI, and lumbar and below SCI groups. Overall, CIC emerged as the predominant method for bladder emptying, utilized by 63.35% of the participants.

However, there were significant differences across the injury levels. Participants with cervical SCI had the lowest proportion of CIC use (19.16%), compared to 49.04% in the thoracic group and 31.80% in the lumbar group. In contrast, IDC was more frequently used among cervical SCI participants (27.59%), while the lumbar group showed the highest proportion of IDC use (39.08%).

External urine collection (CC) was utilized by 11.41% of the overall population, with cervical SCI patients showing the highest proportion (36.17%), followed by thoracic (38.30%) and lumbar (25.53%). Finally, cystostomy was the least used method (4.12%), with the highest proportion among cervical SCI patients (47.06%). These differences reflect the influence of injury severity and physical limitations on bladder management choices.

# Active Follow-up Adherence in Post-SCI NLUTD

In the study, it was found that over half of participants, specifically 58.50%, defaulted on their scheduled follow-up appointments, indicating a generally low level of compliance across all injury levels (Table 1). Although there were no statistically significant differences in follow-up adherence among participants with cervical, thoracic, and lumbar SCI, lumbar SCI participants showed relatively higher follow-up adherence (39.18%) compared to thoracic (34.50%) and cervical SCI (26.32%). However, when considering the rates of those who were absent for follow-ups, a clear trend emerged: the prevalence was most pronounced in individuals with thoracic SCI, with 50.21% failing to attend, a figure that exceeded the rates for those with lumbar (27.38%) and cervical (22.41%) SCI. These findings suggest that while the differences are modest, certain injury-level-specific factors may influence adherence behavior, highlighting the importance of customized follow-up strategies to improve long-term management outcomes.

# Factors Associated with Follow-Up Adherence in Post-SCI NLUTD

The results of this study indicated that six factors exert distinct influences on the likelihood of follow-up visits (as Table 2): Participates with a better understanding of disease-related knowledge are more likely to return for follow-ups ( $\beta = 1.178$ , p = 0.031). Those with prior similar medical experiences tend to be more compliant with follow-up appointments ( $\beta = 3.186$ , p < 0.001). Additionally, participates with available companions for transportation ( $\beta = 1.863$ , p = 0.005) and those in better financial situations ( $\beta = 0.857$ , p < 0.001) are more inclined to complete their follow-up care.

Variables	Categories	Exp (B)	95% CI		P-value
Lack of disease knowledge	Yes	1.178	0.658	2.109	0.031
	No	Ref.			
Gender	Male	0.986	0.599	1.622	0.955
	Female	Ref.			
Age (years)	≥60y	-1.024	1.005	1.043	0.011
	18–59y	Ref.			
Caregiver	Spouse	0.692	0.151	3.165	0.635
	Parents	0.990	0.203	4.836	0.990
	Healthcare assistant	0.943	0.196	4.528	0.941
	Children	Ref.			
Economic burden of disease management	No	0.857	0.694	1.057	<0.001
	Yes	Ref.			
Previous consultant experience	Yes	3.186	1.745	5.817	<0.001

 Table 2 Logistic Regression Analysis of Factors Affecting Follow-up Adherence

(Continued)

Variables	Categories	Exp (B)	95% CI		P-value
	No	Ref.			
Education level	Elementary	0.965	0.763	1.221	0.766
	Middle school	0.675	0.214	2.873	0.613
	High and above	Ref.			
SCI duration (year)	-	1.038	0.997	1.080	0.069
Public transportation accessibility	Yes	2.936	0.542	15.886	0.608
	No	Ref.			
Availability of personal transportation	Yes	0.644	0.120	3.464	0.211
	No	Ref.			
Family medical education background	Yes	0.701	0.361	1.362	0.081
	No	Ref.			
Convenience of medical institution process	Yes	1.452	0.920	2.292	0.109
	No	Ref.			
Accessibility of accompanying support	Yes	1.863	1.206	2.878	0.005
	No	Ref.			
SCI level	Quadriplegia	-4.661	-	-	0.031
	Paraplegia	Ref.			

#### Table 2 (Continued).

On the other hand, Factors negatively associated with follow-up adherence included age and the SCI level. Elderly participants (aged  $\geq 60$  years) demonstrated a significantly lower rate of follow-up adherence compared to their younger counterparts ( $\beta = 1.024$ , p = 0.011). Additionally, individuals with quadriplegia had a reduced follow-up rate compared to those with paraplegia ( $\beta = -4.661$ , p = 0.031).

Moreover, a majority of the participants (67.23%) reported seeking medical advice for NLUTD. Among these individuals, there was a pronounced preference for neurorehabilitation specialists (58.84%) over urologists (29.96%) and neurologists (10.83%).

In this study, factors including gender, primary caregiver, education level, SCI duration, transportation accessibility, family medical background, and the convenience of medical institution processes did not demonstrate statistically significant correlations with follow-up adherence (p > 0.05).

### Patient-Reported Barriers to Follow-up Care

The study identified several key barriers to follow-up care reported by respondents post-discharge with SCI. As depicted in Figure 1, the most frequently reported barriers were financial constraints, followed by the scarcity of local specialists and the complexity of referral procedures. Additionally, a significant proportion of individuals cited a knowledge deficit regarding their condition and the importance of follow-up care. Figure 2 presented the cumulative frequency of the reported barriers, illustrating the proportion of participant affected by each barrier. The chart showed that 71.12% of participants were affected by financial constraints, the scarcity of local specialists impacted 54.13%, and 32.04% found referral procedures too complex. Notably, 19.17% of them reported a lack of disease-related knowledge as a barrier.

### Discussion

This study revealed three key insights. Firstly, the preferred method for bladder emptying after SCI differed by injury level, with CIC being the most prevalent, especially among those with thoracic and lumbar SCI. Secondly, adherence to follow-up adherence among Chinese SCI participants with NLUTD was notably insufficient. Thirdly, financial constraints were the primary factors impacting follow-up adherence, compounded by healthcare access barriers such as a shortage of local specialists and cumbersome referral processes, and knowledge barriers stemming from an inadequate understanding of the significance and procedures of follow-up care. Furthermore, these barriers were influenced by age,



Figure I Ranking of barriers Barriers to Follow-up Care.



Figure 2 Cumulative frequency of Follow-up Care Barriers.

the level of SCI, and the availability of travel companions, underscoring the intricate relationship between demographic and social factors in healthcare adherence.

Demographically, our study's cohort of SCI participants with NLUTD was predominantly composed of middle-aged and young males, notably over-representing those with thoracic SCI. This demographic pattern aligns with prior research,<sup>34,35</sup> highlighting the consistent prominence of this group in the NLUTD post-SCI population. However, our findings diverge from previous studies<sup>2,36</sup> which more commonly identified cervical SCI. A higher prevalence of

participants with thoracic SCI was noted, and several factors may account for this observation. Firstly, thoracic SCI often results in more severe or even complete injuries, leading to more persistent and significant functional impairments,<sup>37</sup> which likely increases these participants' motivation to participate in the study. Secondly, individuals with lumbar-sacral SCI, benefiting from the protective lumbar enlargement, tend to have less severe injuries and improved functional recovery. This may diminish their inclination to engage in studies concentrated on severe dysfunction. Finally, cervical SCI participant who experience more profound functional impairments, particularly in upper limb and hand functions, are also more susceptible to related complications, which make it more challenging for them to engage in such surveys. Consequently, thoracic SCI respondents were over-represented, while cervical and lumbar-sacral SCI groups were underrepresented.

The preferences for bladder emptying methods among the post-SCI community reveal two key characteristics. Overall, CIC is the preferred choice for bladder emptying, with a significant proportion of 63.35%, followed by IDC and CC. The selection of cystostomy accounts for 4.12%. These findings are likely related to the recent promotion of CIC for individuals post-SCI. However, it is essential to interpret these results cautiously, as the survey participants were individuals willing to engage in research on NLUTD management. There is a possibility that those who are less accepting or involved in NLUTD management were not represented in this survey. Secondly, there are differences in the choice of bladder emptying methods among participants with SCI at various levels. CSCI tend to opt for cystostomy and CC more frequently, while nearly half of the TSCI choose CIC. This discrepancy may correlate with the severity of limb function in these participants. Individuals with CSCI often require more caregiver assistance to perform bladder emptying, whereas those with TSCI typically have sufficient hand function to independently perform CIC. These differs from previous studies.<sup>38,39</sup>

The follow-up rate of our surveyed (41.50%) population is significantly lower than the 71–80% reported in previous studies,<sup>38–40</sup> falling short of the guidelines' recommendations for risk-based follow-up schedules for upper urinary tract damage.<sup>14,15,41,42</sup> Moreover, in our survey, preferences for follow-up specialists among individuals with SCI accompanying with NLUTD show distinct patterns: 58.84% tend to consult rehabilitation specialists, while 29.96% opt for urologists. This preference diverges from traditional perceptions where urological professionals are typically engaged in the long-term management of such conditions.<sup>42</sup> A contributing factor may be that our study was initiated by professionals in the rehabilitation field, and participants in this study often required rehabilitation for mobility restrictions beyond urinary tract management. It is more conducive to the comprehensive and holistic rehabilitation of SCI individuals, including limb mobility, activities of daily living, and lower urinary tract function. Moreover, establishing a long-term accessible multi-disciplinary teams that includes urology, rehabilitation, and neurology specialists is a systemic safeguard for better managing this population. However, achieving this ideal system remains a work in progress.<sup>43</sup>

Our results highlight that the multifaceted factors influencing NLUTD individuals' follow-up adherence, which can be distilled into three principal dimensions:

Cognitive and experiential factors: The level of knowledge about NLUTD coupled with the previous medical experience significantly enhances their likelihood of returning for follow-up appointments. Previous studies have shown that early education on disease management can improve patient follow-up compliance;<sup>41</sup> however, feedback from respondents indicates that our education efforts were inadequate. Several factors may contribute to this issue. Comparing to other chronic conditions such as hypertension and diabetes, spinal cord injury is much less common and thus less familiar. Participants often first consult orthopedic or neurosurgery specialists, and the limited inpatient treatment time coupled with the complexity of early-stage conditions makes it challenging for participants to acquire comprehensive knowledge about managing this long-term condition in a short period. Public awareness and educational efforts regarding NLUTD following SCI are insufficient. Many primary and secondary healthcare institutions or rehabilitation centers have not yet established dedicated teams, which hampers ongoing disease education, follow-up, and appointments. Especially as age increases, it becomes more challenging to comprehend diseases that one has never experienced.

Socioeconomic and resource access: Social support, exemplified by companions providing transportation, and the financial status of participants positively influence follow-up rates by making these resources more accessible. Despite the fact that over 60% of respondents in this study had medical insurance, they still rated financial pressure as the most significant barrier to follow-up visits. Several possibilities could account for this discrepancy: Firstly, there was insurance

coverage gaps, many rehabilitation treatments have not yet been included in insurance coverage, which is a critical component of long-term NLUTD management. Subsequently, few regions incorporate NLUTD following SCI into their long-term chronic disease management insurance program. Unlike diabetes or hypertension, which, despite also requiring lifelong management, are more frequently covered. Last and most important, SCI individuals often face challenges in reemployment and maintaining economic stability after the onset of their condition, which can exacerbate the financial burden of ongoing medical care. In conclusion, enhancing insurance coverage for rehabilitation services and integrating NLUTD management into chronic disease insurance plans, along with improving reemployment prospects for SCI, could significantly alleviate the financial barriers to follow-up care.

Demographic and SCI condition: Older age and quadriplegia are associated with reduced follow-up rates, representing negative predictors of adherence in this patient cohort. Our findings highlight that family members, particularly spouses and parents, are the primary caregivers for SCI individuals. Older participants often grapple with more complications, increasing the caregiving burden. Thus, an accessible and affordable social care system could enhance follow-up adherence among elderly SCI participants. CSCI group face more severe functional impairments and poorer abilities in daily living activities and self-care, making follow-up visits more challenging without effective companionship. Therefore, enhancing their self-care capabilities and providing more accessible companionship or more convenient medical follow-up processes could improve the completion rate of follow-up visits for elderly SCI participants.

Upon considering the limitations of this study, it is crucial to acknowledge that a significant constraint is its execution primarily by neurorehabilitation practitioners, which might have introduced a bias in the surveyed sample. To address this, future research endeavors will aim to engage a more extensive and varied cohort, incorporating interdisciplinary approaches. Moreover, although allowing participants to select multiple answers reflects clinical practices in the real world, it complicates statistical comparisons. Future studies will prioritize enhancing the research methodology to overcome this limitation.

## Conclusions

In conclusion, this study has focused on evaluating bladder management practices and compliance with follow-up among SCI with NLUTD. The findings reveal that, despite advancements in NLUTD management, adherence to follow-up is still inadequate, impacted by various factors. The study suggests that future improvements in health education, healthcare systems, and financial support are likely to be instrumental in bolstering adherence to follow-up protocols and optimizing the long-term management of NLUTD.

# **Author Contributions**

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

# Funding

This work was funded by the National Key Research and Development Program of china, (Grant No.2023YFC3603800 and 2023YFC3603801) and the National Natural Science Foundation of China, (Grant No.82172534 and 82372574) and 1.3.5 Project for Disciplines of Excellence, West China Hospital, Sichuan University(Grant No. ZYJC21038).

# Disclosure

The authors declare no conflicts of interest.

# References

<sup>1.</sup> McDonald JW, Sadowsky C. Spinal-cord injury. Lancet. 2002;359:417-425. doi:10.1016/S0140-6736(02)07603-1

Collaborators GBDSCI. Global, regional, and national burden of spinal cord injury, 1990-2019: a systematic analysis for the global burden of disease study 2019. *Lancet Neurol.* 2023;22:1026–1047. doi:10.1016/S1474-4422(23)00287-9

- 3. Hu S, Wang P, Dong Y, Li F. Incidence, prevalence and disability of spinal cord injury in China from 1990 to 2019: a systematic analysis of the global burden of disease study 2019. *Eur Spine J.* 2023;32:590–600. doi:10.1007/s00586-022-07441-2
- 4. Przydacz M, Denys P, Corcos J. What do we know about neurogenic bladder prevalence and management in developing countries and emerging regions of the world? *Ann Phys Rehabil Med.* 2017;60:341–346. doi:10.1016/j.rehab.2017.02.008
- 5. Panicker JN. Neurogenic bladder: epidemiology, diagnosis, and management. Semin Neurol. 2020;40:569-579. doi:10.1055/s-0040-1713876
- 6. Loftus CJ, Ratanawong JP, Myers JB, et al. Bladder management is the top health concern among adults with a spinal cord injury. *Neurourol Urodyn*. 2024;43:449–458. doi:10.1002/nau.25369
- 7. Sekido N, Igawa Y, Kakizaki H, et al. Clinical guidelines for the diagnosis and treatment of lower urinary tract dysfunction in patients with spinal cord injury. *Int J Urol.* 2020;27:276–288. doi:10.1111/iju.14186
- Knight SL, Riley C, Wagh Y, Lee F, Shah J, Hamid R. A retrospective review of the long term clinical outcomes of patients with neurogenic lower urinary tract dysfunction following transverse myelitis. *Neurourol Urodyn*. 2021;40:219–227. doi:10.1002/nau.24537
- Divanoglou A, Augutis M, Sveinsson T, Hultling C, Levi R. Self-reported health problems and prioritized goals in community-dwelling individuals with spinal cord injury in Sweden. J Rehabil Med. 2018;50:872–878. doi:10.2340/16501977-2383
- 10. Abedi A, Sayegh AS, Ha NT, et al. Health care economic burden of treatment and rehabilitation for neurogenic lower urinary tract dysfunction: a systematic review. J Urol. 2022;208:773-783. doi:10.1097/JU.0000000002862
- 11. Wang S, Kang H, Wang Q, et al. Incidence and influencing factors of urinary incontinence in stroke patients: a meta-analysis. *Neurourol Urodyn*. 2024;43:680–693. doi:10.1002/nau.25398
- 12. Erden E, Ersöz M, Tiftik T, Erden E. The neurogenic bladder characteristics and treatment approaches in the patients with multiple sclerosis. *Mult Scler Relat Disord*. 2022;58:103439. doi:10.1016/j.msard.2021.103439
- 13. Hamid R, Averbeck MA, Chiang H, et al. Epidemiology and pathophysiology of neurogenic bladder after spinal cord injury. *World J Urol.* 2018;36:1517–1527. doi:10.1007/s00345-018-2301-z
- 14. Ginsberg DA, Boone TB, Cameron AP, et al. The AUA/SUFU guideline on adult neurogenic lower urinary tract dysfunction: treatment and follow-up. J Urol. 2021;206:1106–1113. doi:10.1097/JU.00000000002239
- 15. Vince RA Jr, Klausner AP. Surveillance strategies for neurogenic lower urinary tract dysfunction. Urol Clin North Am. 2017;44:367–375. doi:10.1016/j.ucl.2017.04.004
- 16. Sinha S. Follow-up for the upper urinary tract in patients with high-risk neurogenic lower urinary tract dysfunction. *World J Urol.* 2023;41:3309–3316. doi:10.1007/s00345-023-04602-w
- 17. Skelton F, Salemi JL, Akpati L, et al. Genitourinary complications are a leading and expensive cause of emergency department and inpatient encounters for persons with spinal cord injury. *Arch Phys Med Rehabil.* 2019;100:1614–1621. doi:10.1016/j.apmr.2019.02.013
- Akkoc Y, Ersoz M, Cinar E, Gok H. Evaluation and management of neurogenic bladder after spinal cord injury: current practice among physical medicine and rehabilitation specialists in Turkey. *Turk J Phys Med Rehabil*. 2021;67:225–232. doi:10.5606/tftrd.2021.5817
- 19. Velaer KN, Welk B, Ginsberg D, Myers J, Shem K, Elliott C. Time burden of bladder management in individuals with spinal cord injury. *Top Spinal Cord Inj Rehabil.* 2021;27:83–91. doi:10.46292/sci20-00007
- Tapia CI, Khalaf K, Berenson K, Globe D, Chancellor M, Carr LK. Health-related quality of life and economic impact of urinary incontinence due to detrusor overactivity associated with a neurologic condition: a systematic review. *Health Qual Life Outcomes*. 2013;11(13). doi:10.1186/1477-7525-11-13
- 21. Przydacz M, Chlosta M, Golabek T, Chlosta P. Population-based study of prevalence, bother and behavior related to treatment for lower urinary tract symptoms and overactive bladder among polish neurogenic patients. *Brain Sci.* 2021;11:712. doi:10.3390/brainsci11060712
- 22. Joshi AD, Shukla A, Chawathe V, Gaur AK. Clean intermittent catheterization in long-term management of neurogenic bladder in spinal cord injury: patient perspective and experiences. Int J Urol. 2022;29:317–323. doi:10.1111/iju.14776
- 23. Blé O, Levy J, Lefèvre C, et al. Neurogenic bladder in patients with paraplegia: a two-center study of the real-life experience of the patients' journey. *World J Urol.* 2022;40:1743–1749. doi:10.1007/s00345-022-04044-w
- 24. Milligan J, Goetz LLK, Ennelly MJ. A PRIMARY CARE PROVIDER'S GUIDE TO MANAGEMENT OF NEUROGENIC LOWER URINARY TRACT DYSFUNCTION AND URINARY TRACT INFECTION AFTER SPINAL CORD INJURy. *Top Spinal Cord Inj Rehabil.* 2020;26:108–115. doi:10.46292/sci2602-108
- 25. Hamine S, Gerth-Guyette E, Faulx D, Green BB, Ginsburg AS. Impact of mHealth chronic disease management on treatment adherence and patient outcomes: a systematic review. J Med Internet Res. 2015;17:e52. doi:10.2196/jmir.3951
- 26. Kini V, Ho PM. Interventions to improve medication adherence: a review. JAMA. 2018;320:2461-2473. doi:10.1001/jama.2018.19271
- 27. Theron F, Wilson V, Scriba E, et al. Best practice recommendations for bladder management in spinal cord-afflicted patients in South Africa. S Afr Med J. 2019;109:12569.
- 28. Myers JB, Lenherr SM, Stoffel JT, Neurogenic Bladder Research Group. Patient reported bladder related symptoms and quality of life after spinal cord injury with different bladder management strategies. J Urol. 2019;202:574–584. doi:10.1097/JU.0000000000270
- 29. Shamout S, Nazha S, Dragomir A, Baverstock R, Corcos J, Campeau L. A cost-effectiveness analysis of bladder management strategies in neurogenic lower urinary tract dysfunction after spinal cord injury: a publicly funded health care perspective. *Spinal Cord.* 2023;61:269–275. doi:10.1038/s41393-023-00883-5
- Liu J, Luo C, Xiao W, Xu T. Urinary tract infections and intermittent catheterization among patients with spinal cord injury in Chinese community. Sci Rep. 2023;13(17683). doi:10.1038/s41598-023-44697-0
- 31. Chang F, Xie H, Zhang Q, et al. Quality of life of adults with chronic spinal cord injury in mainland China: a cross-sectional study. *J Rehabil Med.* 2020:52:jrm00058. doi:10.2340/16501977-2689
- 32. Rupp R, Biering-Sørensen F, Burns SP, et al. International standards for neurological classification of spinal cord injury: revised 2019. *Top Spinal Cord Inj Rehabil.* 2021;27:1–22. doi:10.46292/sci2702-1
- Gajewski JB, Schurch B, Hamid R, et al. An International Continence Society (ICS) report on the terminology for adult neurogenic lower urinary tract dysfunction (ANLUTD). *Neurourol Urodyn*. 2018;37:1152–1161. doi:10.1002/nau.23397
- 34. Hao D, Du J, Yan L, et al. Trends of epidemiological characteristics of traumatic spinal cord injury in China, 2009-2018. *Eur Spine J*. 2021;30:3115–3127. doi:10.1007/s00586-021-06957-3

- 35. Zhou H, Lou Y, Chen L, et al. Epidemiological and clinical features, treatment status, and economic burden of traumatic spinal cord injury in China: a hospital-based retrospective study. *Neural Regen Res.* 2024;19:1126–1133. doi:10.4103/1673-5374.382257
- 36. Hu Y, Li L, Hong B, et al. Epidemiological features of traumatic spinal cord injury in China: a systematic review and meta-analysis. Front Neurol. 2023;14:1131791. doi:10.3389/fneur.2023.1131791
- Kirshblum S, Snider B, Eren F, Guest J. Characterizing natural recovery after traumatic spinal cord injury. J Neurotrauma. 2021;38:1267–1284. doi:10.1089/neu.2020.7473
- 38. Yıldız N, Akkoç Y, Erhan B; Neurogenic Bladder Turkish Research, et al. Neurogenic bladder in patients with traumatic spinal cord injury: treatment and follow-up. *Spinal Cord*. 2014;52:462–467. doi:10.1038/sc.2014.41
- 39. Lofvenmark I, Wikmar LN, Hasselberg M, Norrbrink C, Hultling C. Outcomes 2 years after traumatic spinal cord injury in Botswana: a follow-up study. *Spinal Cord*. 2017;55:285–289. doi:10.1038/sc.2016.114
- Andretta E, Pagliacci MC, Zuliani C, Filocamo MT, Losavio E, Krassioukov A. A survey of clinical practice concerning long-term follow-up of neurogenic lower urinary tract dysfunction due to spinal cord injury in Italy. J Spinal Cord Med. 2022;45:907–915. doi:10.1080/ 10790268.2020.1863899
- 41. Przydacz M, Chlosta P, Corcos J. Recommendations for urological follow-up of patients with neurogenic bladder secondary to spinal cord injury. *Int Urol Nephrol.* 2018;50:1005–1016. doi:10.1007/s11255-018-1852-7
- 42. Kavanagh A, Baverstock R, Campeau L, et al. Canadian urological association guideline: diagnosis, management, and surveillance of neurogenic lower urinary tract dysfunction. *Can Urol Assoc J*. 2019;13:E157–E176. doi:10.5489/cuaj.5912
- 43. Conti A, Dimonte V, Rizzi A, et al. Barriers and facilitators of education provided during rehabilitation of people with spinal cord injuries: a qualitative description. *PLoS One*. 2020:15:e0240600. doi:10.1371/journal.pone.0240600

Patient Preference and Adherence

**Dovepress** Taylor & Francis Group

Publish your work in this journal

Patient Preference and Adherence is an international, peer-reviewed, open access journal that focusing on the growing importance of patient preference and adherence throughout the therapeutic continuum. Patient satisfaction, acceptability, quality of life, compliance, persistence and their role in developing new therapeutic modalities and compounds to optimize clinical outcomes for existing disease states are major areas of interest for the journal. This journal has been accepted for indexing on PubMed Central. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit http://www.dovepress.com/testimonials.php to read real quotes from published authors.

Submit your manuscript here: https://www.dovepress.com/patient-preference-and-adherence-journal

🖪 🗙 in 🔼