



Frequency of patient-reported UTIs is associated with poor quality of life after spinal cord injury: a prospective observational study

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Abstract

Study design Cross-sectional survey of the Neurogenic Bladder Research Group (NBRG) registry; a multicenter prospective observation study.

Objectives To assess how patient-reported urinary tract infections (PRUTIs) in spinal cord injury (SCI) affect quality of life (QOL).

Setting Multiple United States hospitals.

Methods 1479 participants with SCI were asked about neurogenic bladder-related QOL. Eligibility: age ≥ 18 years with acquired SCI. PRUTI frequency over the last year was classified as 0, 1–3, 4–6, or >6 . Four UTI QOL domains were assessed: (1) UTIs limited daily activities, (2) UTIs caused increased muscle spasms, (3) UTIs would not go away, and (4) UTIs made me avoid going out. Multivariable regression identified variables associated with poor QOL.

Results PRUTI frequency was 0 in 388 patients (26%), 1–3 in 677 (46%), 4–6 in 223 (15%), and more than 6 in 190 (13%). Increasing PRUTI rate was independently associated with worse QOL for all four questions. Compared with those with 0 PRUTIs, participants reporting >6 were more likely to limit daily activities (OR 9.0 [95% CI 8.1–21.2] $p < 0.0001$), experience increased muscle spasms (OR 12.4 [95% CI 7.5–20.6] $p < 0.0001$), perceive a UTI would not go away (OR 30.1 [95% CI 15.0–60.4] $p < 0.0001$), and avoid going out because of UTIs (OR 7.2 [95% CI 4.2–12.4] $p < 0.0001$).

Conclusions An increasing rate of PRUTIs is independently associated with worse QOL. Thorough evaluation and treatment may improve QOL in this population.

Introduction

There are ~27–30 million people around the world living with spinal cord injury (SCI) and just under 1 million new cases each year [1]. Neurogenic bladder (NGB) is a common sequela of SCI and ~30–45% of individuals with SCI are hospitalized annually with genitourinary issues, the

most common of which is urinary tract infections (UTIs) [1–3]. Up to 60% of individuals with SCI report experiencing recurrent UTIs [4–6], 40% of whom report that UTIs have a moderate to severe impact on their life [5, 6]. Despite this, there is a paucity of research dedicated to patient-reported quality of life (QOL) as it pertains to UTIs.

Symptoms attributed to a UTI can be nonspecific after SCI due to altered bladder sensation; these may include abdominal pain, skeletal muscle spasticity and lethargy. The ubiquitous presence of bacteriuria makes it difficult to accurately attribute these symptoms to a specific cause. Thus, under/over-diagnosis of UTIs is common. Indeed, data suggests that in 40% of instances when individuals with SCI think they have a UTI, a workup will reveal a negative urine culture and symptoms can be attributed to another problem [7]. UTI symptoms with a negative culture can reflect non-bladder pathology (i.e., constipation), or noninfectious bladder pathology (i.e., detrusor overactivity, reduced bladder compliance, or bladder stones). Even complaints of foul-smelling

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or cloudy urine with a polymicrobial urine culture frequently is treated with antibiotics, despite this not meeting any of the definitions of a UTI in this population [8].

Our group is actively working on means to better differentiate UTI from bacteriuria. In order to understand the magnitude of the problem, we have previously described the frequency of patient-reported UTIs (PRUTIs) in a large registry of community-dwelling people with SCI [9]. These PRUTIs are by patient report, without medical records available for review. Herein, we seek to further understand the burden of disease by studying the association between the frequency of PRUTIs and QOL. We hypothesize that an increase in PRUTI frequency will be associated with decreasing QOL. The implications of this finding would be that even though some of these PRUTIs may not be real UTIs, PRUTIs do represent important health events that need to be better understood. It is important to understand the burden of all events that people with SCI perceive to be UTIs (not just the culture confirmed UTIs) because the perception drives antibiotic use. Only then will we be able to effectively address antibiotic-seeking behavior and work with this population to offer nonantibiotic treatment alternatives for their bothersome symptoms.

Methods

Patient population

Data were obtained using the NBRG (Neurogenic Bladder Research Group) SCI registry (<https://www.NBRG.org>). This is a prospective observational study measuring NGB-related QOL after SCI (ClinicalTrials.gov NTC02616081). Individuals were eligible for registry inclusion if they were ≥ 18 years of age, English speaking, and acquired SCI including traumatic, spinal cord bleed/abscess/stroke, spinal cord tumor without active malignancy, transverse myelitis, iatrogenic (i.e., laminectomy complication), and miscellaneous other disorders. Individuals with a congenital condition or progressive neurologic disorder were excluded.

All participants completed an enrollment interview with a trained study coordinator to collect relevant demographic and clinical data. No formal medical chart review was performed. Frequency of PRUTIs was assessed by participant responses to the question “How many urinary tract infections (bladder or kidney infections) have you had over the past 12 months?”. Answers were categorically reported (0, 1–3, 4–6, or >6). As we have previously reported, these were patient-perceived UTI episodes; no chart review was conducted to link these episodes to positive urine cultures or specific signs and symptoms. We then used the “Bladder Complications Scale” from the Spinal Cord Injury—Quality of Life (SCI-QOL) questionnaire [10] to determine how

PRUTIs affect individual QOL. The SCI-QOL is a validated tool that assesses multiple aspects of the health and psychosocial impact of SCI. The five items in the Bladder Complications Scale relate to UTIs and their effect on different QOL domains. These five items all performed well independently based on Item Response Theory analytics. We did not include one question that assesses the effect of UTI on sexual intimacy because this requires the presence of a partner, thus potentially excluding some participants in our registry. Therefore, we selected four of the five items in this scale: (1) “Lately, a UTI limited my daily activities?”; (2) “Lately, I had an increase in spasms because of a UTI” (referring to skeletal muscle spasms, not bladder spasms); (3) “Lately, I had a UTI that would not go away?”; and (4) “Lately, I avoided going out because of a UTI”. Each question is scored on a 5-point Likert scale from (1) “not at all” to (5) “very much” for the first 2 items, and (1) “never” to (5) “always” for the second two items.

Accounting for baseline bladder dysfunction

The Neurogenic Bladder Symptom Score (NBSS) is a validated questionnaire that assesses bladder symptoms in patients with neurogenic bladder dysfunction as a result of congenital or acquired conditions [11]. Symptoms assessed by the NBSS fall into categories of incontinence, storage/voiding, and complications (like hospital admission, or stones). The NBSS score is predictive of worse quality of life in patients with SCI [12]; by including this in our model we sought to control for the effect of baseline bladder dysfunction in our analysis of PRUTI effects on quality of life.

Assessing for PRUTI effect on overall quality of life

The SCI-QOL Bladder Complications questionnaire is a disease-specific QOL tool and does not characterize overall QOL. However, all participants in our study completed the 12-Item Short Form Health Survey (SF-12) Physical and Mental Health scales [13] at the time of enrollment. This is a widely used instrument to evaluate overall QOL. The physical and mental health scores are calculated based on the responses to twelve questions and range from 0 to 100, where the mean in the general population is 50 and higher scores indicate a higher QOL. We evaluated for variables associated with overall physical and overall mental QOL (by SF12 scores) specifically evaluating the effect of PRUTI rate.

Statistical analysis

Participant demographics, injury characteristics, and bladder management strategy were summarized and compared by the number of PRUTIs using chi-square test. For each of the four QOL items, the frequency distribution of QOL

scores (1 through 5) were compared with the frequency of PRUTIs (0, 1–3, 4–6, and >6) with chi-square tests. We then ran four separate multivariable logistic regression models, one for each QOL question, to identify variables independently associated with poor QOL. Each model calculated the odds of a QOL score being >1 versus 1, with 1 being the best QOL. This cutoff was chosen because across all four QOL questions, approximately half of the population had QOL = 1 and half had QOL > 1. In each case the a priori variable of interest was the number of PRUTIs in the prior year. We controlled for age, gender, body mass index, annual income, in-home support, age-adjusted Charlson comorbidity index [14], NBSS score, level of injury (tetraplegia being cervical level 1 to 8 and paraplegia being thoracic level 1 and below), bladder management strategy, time since injury (years), and whether the participants reported being hospitalized for a UTI in the past year (to serve as a proxy for those who may have experienced severe or febrile UTIs). Bladder management was categorized by the individual's primary bladder management method (i.e., only method used, or method used most frequently if multiple were used). Management options included: (1) clean intermittent catheterization, (2) indwelling catheter (urethral Foley, or suprapubic tube), (3) voiding (condom catheter, volitional, pads), or (4) surgery (bladder augmentation, with or without catheterizable channel, catheterizable channel alone, urinary diversion with conduit, or continent pouch). Participants with prior bladder augmentation who were now using an indwelling catheter were included in the surgery group, not the indwelling catheter group.

We included the number of individuals who stated they were hospitalized in the last year for UTI because these episodes are more likely to represent more severe, or febrile UTIs. These participants who were hospitalized may be more likely to report more UTIs per year and/or worse QOL so we sought to control for this.

Lastly, we performed two separate linear regression models testing for variables associated with overall QOL indicated by SF12 score. The SF12 Physical Health and SF12 Mental Health scores were treated separately. All variables included in our logistic regression model were included in these linear models including the different PRUTI rates. Results for this analysis are reported as (β —beta coefficient, SE—standard error, p value). All analyses were carried out using SAS software (version 9.4; SAS Institute Inc., Cary, NC) and a $p < 0.05$ was considered statistically significant.

Results

We enrolled 1479 people over an 18-month period. PRUTI information was missing for one participant so only 1478 individuals are included in this analysis. Participants were

most frequently male (60%), single (43%), with no in-home support (43%), and an annual income <\$40 K (37%). The median age of the cohort was 45 years (range 18–86), and the majority reported paraplegia (57%) for level of injury. Intermittent catheterization was the most common bladder management strategy (53%).

Baseline demographic data stratified by PRUTI frequency is presented in Table 1. PRUTI frequency over the prior year was 0 for 388 participants (26%), 1–3 for 677 participants (46%), 4–6 for 223 participants (15%), and >6 for 190 participants (13%). For each of the four QOL questions, more PRUTIs was significantly associated with progressively worse QOL (all $p < 0.001$; Fig. 1).

When controlling for age, gender, body mass index, total NBSS score, income, in-home support, Charlson comorbidity index, level of injury, bladder management strategy, time since injury, and being hospitalized for a UTI in the past year in our multivariable model, we found that a higher PRUTI rate was independently associated with worse QOL across all four questions. Specifically, any PRUTIs (e.g., 1–3, 4–6, and >6) significantly increased the odds of worse QOL when compared with 0 PRUTIs per year. In addition, each categorical increase in PRUTI rate up to 4–6 per year increased the risk of worse QOL compared with the categories below. Specifically, individuals with 1–3 PRUTIs had a significantly increased odds of worse QOL compared with those with 0, and those with 4–6 had significantly increased odds of worse QOL compared with those with 0, and those with 1–3 PRUTIs. There was not a significant difference in QOL between the 4–6 and >6 PRUTI groups for questions 1, 2, and 4. There was, however, a significant decrease in QOL between the 4–6 and >6 PRUTI groups for question 3 (Table 2).

Total NBSS score was the only other variable that was independently associated with worse QOL across all four questions: limiting daily activities (OR 1.04 [95% CI 1.03–1.06] $p < 0.001$ per unit increase in NBSS), increased skeletal muscle spasms (OR 1.05 [95% CI 1.03–1.06] $p < 0.001$), perceiving a UTI would not go away (OR 1.06 [95% CI 1.05–1.08] $p < 0.001$), and avoiding going out (OR 1.07 [95% CI 1.05–1.09] $p < 0.001$).

Higher PRUTI rates were significantly associated with a decrease in SF12 Physical Health scores. Specifically, there was a significant decline in SF12 Physical Health reported by individuals experiencing 4–6 PRUTIs ($\beta = -1.93$, SE 0.94, $p = 0.04$), and >6 PRUTIs per year ($\beta = -3.1$, SE 1.0, $p = 0.002$). PRUTI rates were not significantly associated with SF12 Mental Health scores.

Discussion

We show that in an observational registry of people with SCI in the United States, an increasing frequency of

Table 1 Demographic data by number of patient-reported UTIs in the past year ($n = 1478$).

	Rate of patient-reported UTI's in the last year				<i>p</i> value
	0	1–3	4–6	>6	
All patients (%)	388 (26)	677 (46)	223 (15)	190 (13)	
Total NBSS score—median [IQR]	20 [13,28]	23 [16,30]	26 [20,35]	29 [21,37]	<0.0001
By primary bladder management (%)					<0.0001
Spontaneous void into toilet	98 (25)	68 (10)	20 (9)	14 (7)	
Pads/condom catheter	13 (3)	32 (5)	6 (3)	8 (4)	
Clean intermittent catheterization	178 (46)	381 (56)	127 (57)	94 (49)	
Indwelling catheter	49 (13)	126 (19)	44 (20)	52 (27)	
Surgery	50 (13)	70 (11)	26 (11)	22 (11)	
Age—mean (SD)	47 (14)	45 (13)	43 (12)	43 (13)	
Gender (%)					<0.0001
Male	247 (64)	434 (64)	107 (48)	105 (55)	
Female	141 (36)	243 (36)	116 (52)	85 (49)	
Marital status (%)					<0.0001
Single/never married	162 (42)	286 (42)	87 (39)	100 (53)	
Married/living with partner	171 (44)	270 (40)	101 (45)	57 (30)	
Separated/divorced/widowed	53 (14)	120 (18)	33 (15)	32 (17)	
Missing	2	1	2	1	
BMI—mean (SD)	27 (7)	27 (7)	27 (8)	26 (7)	
Income level (%)					<0.0001
<40 K	123 (32)	246 (36)	83 (37)	90 (47)	
40–75 K	78 (20)	127 (19)	48 (22)	28 (15)	
>75 K	88 (23)	126 (19)	38 (17)	29 (15)	
Unknown	99 (26)	170 (25)	53 (24)	41 (22)	
Missing	0	8	1	2	
In-home support (%)					<0.0001
None	189 (49)	304 (45)	87 (39)	62 (33)	
Hire help	107 (28)	193 (29)	69 (31)	78 (41)	
Daily family/friend	18 (5)	56 (8)	27 (12)	16 (8)	
Live in family/friend	73 (19)	120 (18)	39 (18)	33 (17)	
Other	1 (0.3)	3 (0.4)	0 (0.0)	1 (0.5)	
Missing	0	1	1	0	
Tobacco use (%)					<0.0001
Never	247 (64)	437 (65)	138 (62)	107 (56)	
Former	106 (27)	175 (26)	62 (28)	54 (28)	
Current	34 (9)	63 (9)	21 (9)	28 (15)	
Missing	1 (0.3)	2 (0.3)	2 (0.9)	1 (0.5)	
Alcohol use frequency (%)					<0.0001
Never	116 (30)	222 (33)	81 (36)	74 (39)	
Monthly or less	123 (32)	214 (32)	71 (32)	61 (32)	
2–4 times per month	79 (20)	146 (22)	40 (18)	32 (17)	
2 or more times per week	69 (18)	94 (14)	30 (13)	23 (12)	
Missing	1	1	1	0	
Diabetes (%)	28 (7)	41 (6)	20 (9)	18 (10)	<0.0001
Level of injury (%)					<0.0001
Tetraplegic	162 (42)	303 (45)	85 (38)	85 (45)	
Paraplegic	226 (58)	374 (55)	138 (62)	105 (55)	

Table 1 (continued)

	Rate of patient-reported UTI's in the last year				p value
	0	1-3	4-6	>6	
Years since injury—mean (SD)	14.4 (11)	14.3 (12)	12.7 (11)	13.2 (12)	
Hospitalized for UTI in last year (%)	62 (16)	149 (22)	54 (24)	65 (34)	<0.0001
SF12 Physical Health Score—mean (SD)	41 (11)	41 (11)	39 (11)	37 (10)	<0.0001
SF12 Mental Health Score—mean (SD)	49 (11)	49 (11)	47 (11)	45 (12)	<0.0002

Percentages in a group may not add up to 100 due to rounding.

Incontinent includes spontaneously voiding to diapers, spontaneously voiding to pads, and condom catheter.

SD standard deviation, BMI body mass index, UTI urinary tract infection, NBSS neurogenic bladder symptom score, SF12 12 item short form health survey.

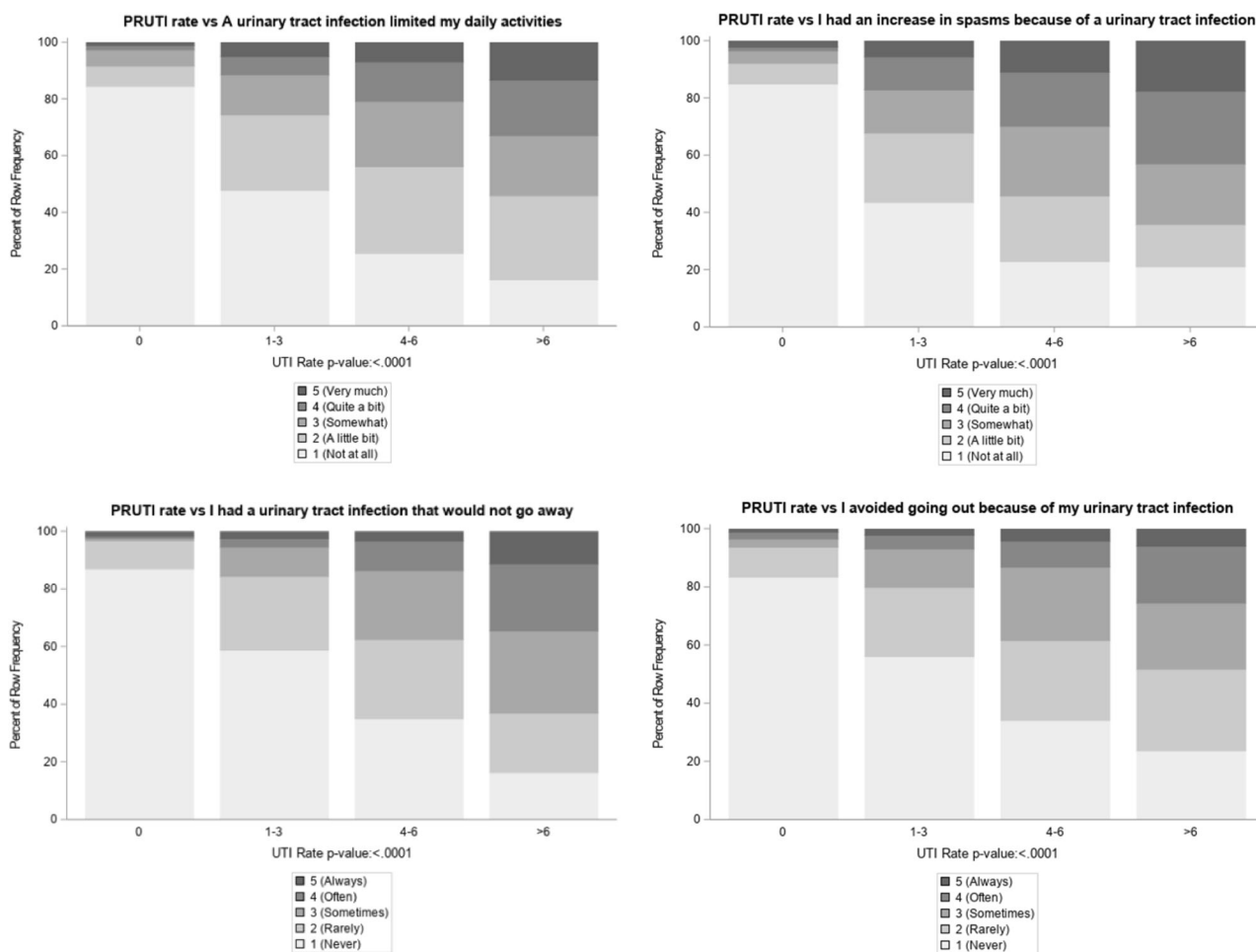


Fig. 1 Increasing PRUTI rate is associated with decreasing QOL in a stepwise fashion. Rate of patient-reported UTIs and the effect on quality of life for four separate quality of life questions.

PRUTIs is inversely related to QOL. When controlling for multiple confounders, we found that increasing frequency of PRUTIs was independently associated with worse QOL across several QOL domains; specifically: limiting daily activities, experiencing increased muscle spasms, perceiving a PRUTI would not go away, and avoiding going out. Importantly, these findings remained significant after

controlling for any baseline bladder dysfunction by including the NBSS score in our multivariable model.

UTIs in people with SCI are a major source of morbidity. One cross-sectional survey of persons with SCI in Switzerland found that 60% of 1549 individuals reported problems with recurrent UTIs, and 40% categorized this as a moderate or major problem [5]. Similarly, a cohort of

Table 2 Rate of patient-reported UTIs in the past year and the effect on quality of life.

UTI rate	UTI limited daily activities		UTI caused increased spasms		UTI would not go away		Avoided going out due to UTI	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
0	Reference	–	Reference	–	Reference	–	Reference	–
1–3	3.4 ^a	2.2–5.2 ($p < 0.0001$)	4.4 ^a	2.9–6.6 ($p < 0.0001$)	4.5 ^a	2.3–8.7 ($p < 0.0001$)	2.8 ^a	1.7–4.6 ($p < 0.0001$)
4–6	6.9 ^b	5.2–13.4 ($p < 0.0001$)	9.6 ^b	5.9–15.6 ($p < 0.0001$)	13.2 ^c	6.6–26.3 ($p < 0.0001$)	6.7 ^b	3.9–11.4 ($p < 0.0001$)
>6	9.0 ^d	8.1–21.2 ($p < 0.0001$)	12.4 ^d	7.5–20.6 ($p < 0.0001$)	30.1 ^e	15.0–60.4 ($p < 0.0001$)	7.2 ^d	4.2–12.4 ($p < 0.0001$)

^aSignificantly different from 0, 4–6, and >6 UTIs per year.

^bSignificantly different from 0 and 1–3 UTIs per year.

^cSignificantly different from 0, 1–3, and >6 UTIs per year.

^dSignificantly different from 0 and 1–3 UTIs per year.

^eSignificantly different from 0, 1–3, and 4–6 UTIs per year.

The odds ratios presented in the table are based on 0 UTIs per year as the reference group. We also ran the model with 1–3 UTIs per year, 4–6 UTIs per year, and >6 UTIs per year as the reference groups and the superscripts indicate which groups were significantly different from each other with a p value < 0.05 indicating statistical significance.

OR odds ratio, CI confidence interval, UTI urinary tract infection.

individuals with SCI in Canada was surveyed and found to have a significant burden from UTIs such that 40% experienced recurrent UTIs, and 60% reported a moderate to severe impact on their life as a result [6]. However, no studies to date have sought to identify the strength and magnitude of the relationship between QOL and UTI-like symptoms. We found that even 1–3 PRUTIs per year was significantly associated with worse QOL and this becomes more pronounced as the rate of PRUTIs increase. The detrimental effect of PRUTIs was not limited to bladder-specific QOL, higher rates of PRUTIs (specifically 4–6 and >6 per year) was significantly associated with a decrease in overall quality of life as indicated by SF12 Physical Health Scores. This finding further argues for the importance of PRUTIs in this population.

We made sure to control for total NBSS in our model. NBSS is a questionnaire that measures overall bladder (dys) function and is validated in the SCI population [11, 12]. In our study, NBSS was predictive of worse urinary QOL which has been previously reported [11]. However, even when controlling for NBSS, the rate of PRUTIs was still strongly and independently associated with worse QOL. Thus, the relationship between PRUTIs and QOL appears to be a distinct from overall bladder (dys)function and worthy of providers’ consideration.

Beyond UTIs, urinary incontinence [15, 16] and bladder management strategy (specifically the use of intermittent catheterization) have been associated with poor QOL [17, 18]. Because the number of UTIs has been correlated with bladder management method [19, 20], we controlled for bladder management strategy in our analysis. Even after taking this into account, the rate of PRUTIs remained strongly associated with worse QOL. So, while bladder management strategy is important for QOL in this population, PRUTIs are an additional and independent factor deserving attention.

Differentiating true UTIs from bacteriuria remains a significant challenge in this population. While there is no universally agreed upon definition of UTI in individuals with neurogenic lower urinary tract dysfunction, the different definitions that currently exist agree that individuals should have a combination of new symptoms and a positive urine culture [8]. People with SCI frequently experience altered bladder sensation and, as a result, true UTIs may present with nonspecific symptoms. Many other medical conditions can present with similar symptoms making it challenging to distinguish between diagnoses. Sadly, the pendulum favors labeling these vague complaints as a UTI because chronic bacteriuria frequently results in cloudy, or foul-smelling urine, which leads patients and providers to over-diagnose UTIs. However, as previously mentioned, up to 40% of patient-reported UTIs in people with SCI can be attributed to other causes [7].

Unfortunately, there is still much patient and provider confusion about this concept and patients are frequently given antibiotics in these situations [21]. Until we better understand the impact and drivers of PRUTIs we will not be able to make an impact on antibiotic overuse. It is not enough to tell someone suffering from symptoms they have attributed to a UTI that they do not have a UTI; this is not patient-centered care. If we do not give them an alternative diagnosis or treatment option, they will often seek antibiotics from another provider, thus preventing a collaborative and patient-centered solution to the problem.

While our study design did not allow us to determine if PRUTIs were true UTIs or not, we did ask a question which serves as a proxy for UTI severity. Specifically, individuals were asked “were you hospitalized in the last year for a UTI?”. We assume that individuals who reported being hospitalized for a UTI were likely to have presented with severe symptoms or febrile infections. As a result, these individuals may report more PRUTIs and worse QOL as a result, thus influencing the findings. When controlling for these individuals in the model, the relationship between PRUTIs and QOL still remains significant. Thus, even these health events that are experienced as a UTI but do not require hospitalization are still critical health events.

Our study has several notable limitations. One limitation is that patient-reported data are based on patient perceptions of care, which was not confirmed using chart review. Our data represents self-reported UTIs as previously mentioned and this was not correlated with culture information or antibiotic use. This is inherent to our novel methods of participant recruitment and data collection. However, an advantage of our internet recruitment and self-reporting registry methods is that we have engaged a population that might not otherwise be included in studies tied to encounters with the healthcare system. Especially in individuals with SCI who tend to be disengaged from the healthcare system after the acute post injury period. Another limitation of this study is potential inclusion bias. Participants with more severe urinary problems may have enrolled in the study at a higher rate in the hope of finding solutions to their problems. Similarly, there is the potential for recall bias in our methodology as individuals who experienced more severe symptoms may report more UTIs than those with less severe symptoms. Lastly, there were several patient factors that were not controlled for, including psychosocial factors, menopausal status, the use of intra-detrusor botulinum toxin, the use of anticholinergics, or data from urodynamic studies.

Conclusions

Many individuals with SCI experience symptoms they perceive to be UTIs. Patient-reported UTI frequency is

strongly associated with worse QOL. This suggests that symptoms being attributed to a UTI should be evaluated and treated. Even if a true UTI is ruled out, diagnosing and treating the underlying cause of the symptoms is still important as it is significantly associated with declining QOL.

Data availability

The datasets generate and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Author contributions KMT helped design the study, played an important role in interpreting the results, drafted, and revised the manuscript. RM helped to revise the manuscript for important intellectual content and approved the final version. JD helped conceive and design the study and approved the final version. JJP helped interpret the results, revise the manuscript, and approved the final version. JTS revised the manuscript for important intellectual content and approved the final version. SML revised the manuscript for important intellectual content and approved the final version. JBM revised the manuscript for important intellectual content and approved the final version. BW revised the manuscript for important intellectual content and approved the final version. SPE conceive and design study, played important role in interpreting the results, revised the manuscript, approved the final version, and agrees to be accountable for all aspects of the work.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

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