Urinary Incontinence in Adults With Cerebral Palsy: Prevalence, Type, and Effects on Participation

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Objective: To assess the prevalence, type, and impact of urinary problems in adults with cerebral palsy and their relation with the Gross Motor Function Classification System for cerebral palsy.

Design: A cross-sectional prospective survey study.

Setting: An outpatient, urban, academic rehabilitation clinic.

Participants: Ninety-one adults with cerebral palsy (45 women, 46 men).

Interventions: Subjects were approached at clinic presentation and were interviewed regarding current function, type and incidence of bladder issues, and concerns with bladder problems.

Main Outcome Measures: The International Consultation on Incontinence Questionnaire—Female, or the International Consultation on Incontinence Questionnaire—Male Lower Urinary Tract Symptoms Module, Gross Motor Function Classification System, employment, and type of residence.

Results: The mean age for both women and men was 36 years (range, 18-79 years). The subjects were currently assessed with the Gross Motor Function Classification System scales I-V: I, 4.4%; II, 19.8%; III, 13.2%; IV, 40.7%; and V, 22.0%. 95.6% of females and 84.7% of males were living at home. Twenty-three percent were currently employed. Twenty percent of the women indicated that they had bladder urgency most to all of the time and 46.7% of the women had leakage that occurred 2-3 times per week to several times per day. In men, urgency that occurred more often than "occasionally" was reported by 45.7%, and 19.6% reported this occurred "most to all of the time." Multivariable analyses found that obesity compared with normal weight was significantly related to leaking before reaching a toilet (odds ratio [OR] 4.3, 95% confidence interval [CI] 1.3-14.7), to leaking with cough, exercise, or sneeze (OR 5.6, 95% CI 1.3-23.1), and to nocturia (OR 5.4, 95% CI 1.2-25.1). Women were more likely to leak with cough, exercise, or sneeze (OR 5.5, 95% CI 1.5-20.0). On scales that indicate symptom interference with life, high levels of interference were reported for women with symptoms of leaking and for men with urgency and leaking. No significant differences in living situation or employment were related to incontinence scores for women or men.

Conclusion: There are high levels of incontinence in adults with cerebral palsy, and these individuals report interference with quality of life. Despite these issues, most participants were living in the community, and incontinence scores were not related to employment.

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INTRODUCTION

Cerebral palsy (CP) is a group of nonprogressive disorders that result in motor dysfunction [1]. The prevalence of this disorder has increased throughout the latter part of the 20th century [2,3]. Although CP is often considered a pediatric disorder with many studies that investigated childhood manifestations and coexistent disorders, the lifespans of individuals living with CP are increasing over time, and CP is a disorder that has become increasingly prevalent in the adult population [4,5]. Results of studies have recognized that other

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medical conditions associated with CP and loss of function are increasingly important issues for adults as they age with impairments related to CP [4,6].

Neurogenic bladder is a common disorder among children with CP. Symptoms include stress incontinence, dribbling, diurnal and nocturnal enuresis, and urgency to void [7]. It has been reported that children with CP, on average, gained urinary continence after 8 years of age [8]. This same study determined that children with CP-related spastic quadriplegia and individuals with CP-related cognitive disturbances achieve later urinary continence [8]. In individuals undergoing urodynamic studies, neurogenic detrusor overactivity is most commonly observed [9].

Although information is known about the prevalence of bladder dysfunction and toileting difficulties within the pediatric population, few studies have investigated the prevalence of bladder dysfunction in adults and any effects on quality of life (QOL). Hilberink et al [10] interviewed 54 young adults with CP, aged 18-36 years, and 9% reported bladder incontinence. A recent retrospective evaluation by Murphy et al [9] of the records of adults and children with CP reported a prevalence of 16.4% for symptomatic neurogenic bladder. In contrast, a survey study by Turk et al [11], which focused on the health status and comorbidities of only women living with CP, found that 49% of women reported urinary difficulties, although the types of urinary issues were not further characterized. Problems related to the genitourinary system are among the more common reasons that young adults with CP require hospital admission, and thus these urologic issues may also affect morbidity [12].

In addition to the neurogenic changes described above, mobility and upper limb impairments may also affect continence [4]. Thus, urinary symptoms in adults with CP may be related to a variety of factors, which could also then be affected by toilet accessibility and limit community participation. This study explores the prevalence of bladder dysfunction that both male and female adults living with CP regularly experience, and how these difficulties affect their QOL. Specifically, this study examines the difficulties that adults living with CP face in terms of bladder control, public or community toilet accessibility, and functional mobility for this activity, and how these factors affect their QOL and employment.

METHODS

Design and Study Participants

In this cross-sectional survey study, a convenience sample of adults (18 years of age or older) with the primary diagnosis of CP presenting to outpatient clinics at our urban academic facility and who were able to provide informed consent were approached for participation at the time of their visit. This research study was approved by our local institutional review board. After consent, the subjects were interviewed by the research assistants (M.J., S.A.O., E.B.) who were unaware of what reports the subjects had provided to their physicians regarding bladder symptoms. The research interviews were completed at the time of their clinic visit, or the subjects completed the questionnaires over the telephone.

Demographics and Medical Status Assessments

Education level (highest grade completed), gender, types of residence, and employment status were obtained by interview. Medication lists also were obtained from participants and from charts, including any medications that assisted in bladder function. The subjects were asked to rate the effectiveness of any bladder medications currently being taken to control their symptoms on a scale of 1-3, in which 1 was "very effective"; 2, "somewhat effective"; and 3, "not at all effective." Medical diagnoses and surgical histories were also obtained, and medical records were reviewed, when applicable, for weight, height, and diagnoses.

Functional Mobility Status

To gauge the range of participant functional mobility during toilet transfers, toileting hygiene, and the type of toileting assistive equipment required, the participants were assessed with the Functional Independence Measures (FIM) scale (Uniform Data System for Medical Rehabilitation, Amherst, NY) [13]. Each item is ranked on a scale from 1 to 7, with 1 being completely dependent and 7 being independent of assistive devices/equipment and supervision. Specifically, the FIM scale designates activity "Total Assist," 1; "Maximum Assist," 2; "Moderate Assist," 3; Minimal Assist," 4; "Patient needs verbal cues and supervision," 5; Patient requires additional time or equipment, 6; or "Independent," 7. Self-reported FIM has been shown to be comparable with ratings done in person, if a standardized question format is used [14].

The Functional Mobility Scale is a 6-level ordinal scale that rates individual walking ability, equipment and devices used while ambulating, and how far participants can walk when using the required equipment [15]. The participants designated their mode of ambulation, specifically wheelchair (1), walker (2), crutches (3), walking stick (4), independent on level surfaces (5), and independent on all surfaces (6). The participants were also asked if they crawled at home and if they could complete a particular distance (5 m, house; 50 m, school and/or work; 500 m, outside) [15].

The Gross Motor Function Classification System (GMFCS) for cerebral palsy was used to describe the participant's performance in daily activities [16,17]. The GMFCS includes a scale commonly used in pediatric CP management that describes an individual's usual activity performance and also has been validated for adults with CP [18,19]. This ordinal, 5-level classification system emphasizes the World Health Organization's International

Table 1. *Subject characteristics*

	Women (n = 45)	Men (n = 46)	Total (N = 91)
Age, mean (range), y	36.39 (18-71)	35.82 (18-79)	36.10 (18-79)
Race/ethnicity, n (%)			
White	30 (66.67)	25 (54.36)	55 (60.44)
African American	12 (26.67)	18 (39.13)	30 (32.97)
Other	3 (6.67)	3 (6.52)	6 (6.59)
Weight, mean (SD), kg	63.96 ± 17.68	67.39 ± 20.25	65.69 ± 18.99
Height, mean (SD), cm	152.10 ± 13.28	163.54 ± 14.45	157.89 ± 14.95
BMI, mean (SD), kg/m^2	28.69 ± 11.34	25.76 ± 7.02	27.21 ± 9.46
Primary residence, n (%)			
Home	39 (84.78)	43 (95.56)	82 (90.11)
Assisted living	0	3 (6.52)	3 (3.30)
Nursing home	1 (2.22)	0	1 (1.10)
Group home	0	3 (6.52)	3 (3.30)
Other	1 (2.22)	1 (2.17)	2 (2.20)
Employed, n (%)	12 (26.67)	9 (19.57)	21 (23.08)
Education, n (%)			
High school or less	24 (53.33)	32 (69.57)	56 (61.54)
Any college or BA or more	20 (44.44)	12 (26.09)	32 (35.16)
Not available or other	1 (2.22)	2 (4.34)	3 (3.30)

SD = standard deviation; BA = bachelor's degree.

Classification of Functioning, Disability and Health. This scale is a good indicator of professionally determined levels of gross motor function because the correlation coefficients between professionally and self-determined motor function levels range from 0.93 to 0.95 [20]. The participants who walked without limitations were designated as level I; walked with limitations, II; walked with hand-held mobility device, III; experienced self-mobility limitations and/or used power mobility, IV; or transported in manual wheelchair, V [17].

Equipment and Accessibility

To assess the functional mobility with regard to toileting, the participants were asked if special equipment or devices were necessary to assist in the toileting process. Examples of such equipment are bars and raised seats. The participants also were asked if they ever encountered limitations while finding or using public restroom facilities in the community and if continence supplies, such as pads or diapers, were used while in their community or at home.

Urinary Incontinence Scoring

International Consultation of Incontinence Questionnaire—Female Lower Urinary Tract Symptoms Module. Each female participant completed the gender-specific International Consultation of Incontinence Questionnaire (ICIQ) survey, which is a psychometrically robust survey that analyzes the way that lower urinary tract symptoms affect everyday activities and overall QOL [20,21]. The ICIQ: Female Lower Urinary Tract Symptoms Module (ICIQ-FLUTS) assessed urinary continence and multiple factors that affect or are related to urinary continence with respect to toileting activities within 4 weeks before the time of the survey. The symptoms assessed included quantity of daily voids, quantity of nighttime voids, occurrence of "rushing" after onset of urge to void, occurrence of bladder pain, completeness of voids, occurrence of stress incontinence symptoms, occurrence of void straining, interruption of void, daily urine leakages with and without the urge to void, unpredictability of voids, and urine leakage during sleep. Scores are divided into 3 subcategories: filling (range, 0-15), voiding symptoms (range, 0-12), and incontinence (range, 0-20) After each symptom was assessed, participants were asked to rate the degree to which each of these factors affected their lives or bothered them on a scale of 0-10 (0, not at all; 10, a great deal).

ICIQ—Male Lower Urinary Tract Symptoms Module. Male participants were administered the ICIQ Male Lower Urinary Tract Symptoms Module (MLUTS), which assessed similar symptoms as the ICIQ-FLUTS [21,22]. Symptoms assessed included void frequency and occurrence of delay, strain, strength of urinary stream, completeness, "rushing," and nonconstant stream during void. The participants were also questioned about leakage before reaching the toilet, after void, and during sleep, and the incidence of stress incontinence. Male scores are divided into 2 subscores: voiding symptoms and incontinence symptoms. Similar to that described for the female version of the ICIQ, the male participants were asked to rate the degree to which each symptom affected them.

Statistical Analysis

Subject characteristics, urinary symptoms, and use of toileting aids were summarized in mean (standard deviation [SD]), percentages, and/or rates. Percentages were rounded

Table 2. *Subject function*

	Women n (%) (n = 45)	Men n (%) (n = 46)	Total n (%) (N = 91)
GMFCS level			
I	3 (6.7)	1 (2.2)	4 (4.4)
II	12 (26.7)	6 (13.4)	18 (19.8)
III	5 (11.1)	7 (15.2)	12 (13.2)
IV	18 (40.0)	19 (41.3)	37 (40.7)
V	7 (15.6)	13 (28.3)	20 (22.0)
FMS level (distance, 5 m)			
6 (Ind all surfaces)	3 (6.7)	2 (4.4)	5 (5.49)
5 (Ind level surfaces)	9 (20.0)	6 (13.0)	15 (16.5)
4 (Canes without help)	3 (6.7)	3 (6.5)	6 (6.6)
3 (Crutches without help)	4 (8.9)	2 (4.4)	6 (6.6)
2 (Walker without help)	6 (13.3)	7 (15.2)	13 (14.3)
1 (Uses a wheelchair)	15 (33.3)	20 (43.38)	35 (38.46)
Crawls for mobility at home	1 (2.2)	0	1 (1.1)
Not given	4 (8.9)	6 (13.0)	10 (11)
FIM: toilet transfers			
7 (Ind)	25 (55.6)	19 (41.3)	44 (48.4)
6 (Modified Ind)	5 (11.1)	4 (8.7)	9 (9.9)
5 (Supervision/cueing)	1 (2.2)	0 (0)	1 (1.1)
4 (Minimal assistance)	0 (0)	3 (6.5)	3 (3.3)
3 (Moderate assistance)	5 (11.1)	2 (2.2)	7 (7.7)
2 (Maximal assistance)	2 (4.4)	1 (2.17)	3 (3.3)
1 (Dependent/total)	6 (13.3)	13 (28.26)	19 (20.9)
0 (Does not occur)/NA	1 (2.2)	4 (8.7)	5 (5.5)

GMFCS = Gross Motor Function Classification System; FMS = Functional Mobility Scale; Ind = independent; FIM = Functional Independence Measures; NA = not available.

to tenths. Potential risk factors for urinary dysfunction (age, GMFCS level, FIM transfer, body mass index [BMI]) for specific incontinence outcomes were evaluated by using the Fisher exact test, with ratings grouped into 4 categories (none/occasional, sometimes, most of the time, all the time). Differences in incontinence scores were compared between living situation and employment status by using the Wilcoxon rank sum test and among GMFCS groups by using the Kruskal-Wallis test. Differences were considered significant at $P \leq .05$. Factors associated with urgency or leakage (sometimes, most, or all of the time versus none or occasional) were evaluated by logistic regression; an associated 95% confidence interval of odds ratio that was greater than 1 indicated a significant association.

RESULTS

Demographics, Medical Conditions, and Functional Status

Ninety-one adult participants were enrolled, 45 women and 46 men. Information regarding subject demographics is presented in Table 1. The mean ages of the subjects was 36 years, and ranged from 18 to 71 years and from 18 to 79 years for women and men, respectively. The subjects were most often living in a residence in the community. For those who resided with another person, 40% were living with parents and 15% were with spouses. Approximately 35% of all the subjects had attended some college or had completed a degree beyond high school. Twenty-three percent of the subjects were currently employed.

Subject mean (SD) BMI (n = 85) was 27.21 ± 9.46 kg/m^2, which is overweight. Four women and men reported having been treated for urinary tract infections. Four women had given birth vaginally (range, 1-6 births). Two subjects, both women, had had ileostomies (one due to bladder cancer and the other due to repeated infections). The subjects' current GMFCS levels ranged from I to V, with greater numbers of subjects at levels IV and V (40.7% and 22.0%, respectively). This information is detailed with other functional measures in Table 2. More than 50% of all the subjects reported that they were independent or modified independent with toilet transfers.

Urinary Symptoms

The questions and scores for each item of the ICIQ-FLUTS and ICIQ-MLUTS are listed in Table 3 and Table 4, respectively. Twenty percent of the women reported bladder urgency most to all of the time. Twenty-six percent reported, "leaking before reaching the toilet" sometimes, and an additional 17.7% reported that this occurred most to all of the time. Sixty-two percent of women reported any urinary leakage before they were able to reach the toilet, with 46.7% of women who reported leakage that occurred 2-3 times per week to several times per day. Leakage and urgency were

Table 3. *Female urinary symptoms*

Question	Symptom	Frequency, % Reporting					Symptoms Reported as Bothersome (0-10 scale), % Reporting			
							0-2	3-5	6-7	8-10
Filling symptoms										
		None	1	2	3	≥4				
2A	Nocturia (no. voids)	40	31.1	13.3	8.9	6.7	77.8	11.1	2.2	8.9
		Never	Occasionally	Sometimes	Most of the time	All of the time				
3A	Urgency	33.3	28.9	17.8	15.6	4.4	60	6.7	6.7	12.2
4A	Pain in bladder	66.7	17.8	13.3	2.22	0	68.9	20	2.2	8.9
		1-6	7-8	9-10	11-12	≥13				
5A	Urination during day (no. voids)	77.8	11.1	8.9	0.	2.2	64.4	13.3	6.7	15.6
Total filling score: range, 0-15										
Voiding symptoms										
		Never	Occasionally	Sometimes	Most of the time	All of the time				
6A	Hesitancy	44.4	24.4	26.7	4.4	0	68.9	8.9	8.9	13.3
7A	Straining	82.2	8.9	4.44	4.4	0	86.7	6.7	2.2	4.4
8A	Stream starts and stops	62.2	15.6	17.8	4.4	0	77.8	6.6	8.9	8.9
Total voiding score: range, 0-10										
Incontinence symptoms										
		Never	Occasionally	Sometimes	Most of the time	All of the time				
9A	Leaking before reaching toilet	37.8	17.8	26.7	13.3	4.4	40	26.7	8.9	24.4
		Never	≤1/wk	2-3/wk	Once/d	Several/d				
10A	How often do you leak urine	31.1	22.2	26.7	2.2	17.8	46.7	15.6	11.1	26.7
		Never	Occasionally	Sometimes	Most of the time	All of the time				
11A	Leaking with exercise, cough, or sneeze	51.1	13.3	20	8.9	6.7	66.7	2.2	15.6	15.6
12A	Leaking for no obvious reason	73.3	13.3	4.4	6.67	2.2	80	0	6.7	13.3
13A	Nighttime incontinence	73.3	6.7	13.3	2.2	4.4	80	4.4	6.7	8.9

Total incontinence score: range, 0-19.

the most common symptoms reported by men as well: 57.7% reported leaking before reaching the toilet at least "occasionally." Urgency more often than "occasionally" was experienced by 45.7%, and 19.6% reported that this occurred "most to all of the time." The degree to which these symptoms affected their lives or were bothersome is also summarized in Tables 3 and 4, with higher levels of interference (8-10 on a 10-point scale) most often reported for the symptoms of "leaking before reaching the toilet" and "frequency of leaking" in women, and urgency and leaking in men. Comparison graphs for male and female symptoms are provided in Figure 1 (bladder urgency) and Figure 2 (frequency of urinary leakage). Seven percent of the subjects were taking medications to treat bladder symptoms. All of these individuals were using anticholinergic medications. Five persons rated their anticholinergic medications as very effective, and 2 reported that the medications were somewhat effective.

Table 4. *Male urinary symptoms*

Question	Symptom	Frequency, % Reporting					Symptoms Reported as Bothersome (0-10 scale), % Reporting			
							0-2	3-5	6-7	8-10
Voiding symptoms										
		Never	Occasionally	Sometimes	Most of the time	All of the time				
2A	Hesitancy	52.2	17.4	24	4.4	2.2	82.6	13	0	4.3
3A	Straining	76.1	2.2	17.4	2.2	2.2	89.1	8.6	0	2.2
4A	Strength of stream	80.4	4.4	13.4	0	2.2	91	4.4	0	4.3
5A	Starting and stopping	56.5	28.3	8.7	4.4	2.2	80.43	15.2	0	4.3
6A	Bladder does not feel empty	58.7	26.1	4.4	6.5	4.4	82.6	13	0	4.3
Total voiding score: range, 0-12										
Incontinence symptom										
		Never	Occasionally	Sometimes	Most of the time	All of the time				
7A	Urgency	26.1	28.3	26.1	15.2	4.4	60.9	15.2	2.2	21.7
8A	Leaking before reaching toilet	42.2	22.2	31.1	4.4	0	66.7	11.1	0	22.2
9A	Leaking with cough or sneeze	89.1	0	10.9	0	0	90.5	2.2	0	4.3
10A	Leak, reason unknown	84.8	0	15.2	0	0	93.5	2.2	2.2	2.2
11A	Leaking at night	76.1	6.5	10.9	0	6.6	84.8	2.2	2.2	10.9
12A	Wetting after urination	78.3	6.5	13	0	2.2	84.8	2.2	4.4	8.7
		1-6	7-8	9-10	11- 12	≥13				
13A	Urination during day (times)	65.2	21.7	2.2	6.5	4.4	76.1	2.2	4.4	13
		None	1	2	3	≥4				
14A	Nocturia (times)	34.78	37	19.6	2.2	6.6	84.8	2.2	2.2	11.1

Total incontinence score: mean, 3.9 ± 3.9 (0-16).

Urinary Symptoms and Surgery

The impact of hip and proximal lower limb surgeries on continence subscores for the ICIQ-FLUTS and ICIQ-MLUTS were separately examined for women and men, respectively. No significant differences were noted when comparing subscores by gender between those who had undergone adductor release surgery, hamstring release surgery, or other any other hip surgical procedures (data not shown).

Urination Aids or Devices

Grab bars were the most common devices used with toilet transfers (by 36%), followed by raised toilet seats (12%). Briefs, diapers, or pads were required for 27.2% of men and 44.1% of women, with 4 reporting that they used these only when out in the community due to inaccessible toilets. Other aids (adaptive clothing or devices) were less commonly used (data not shown).

Forty subjects reported difficulty with the accessibility of the restrooms when out in the community, most often those GMFCS IV and V. However, 7 additional subjects reported "no difficulty," because they never used toilet facilities in the community. The most common reported problems with toileting accommodations were described as stalls or bathrooms that were too narrow, small, or short, and did not accommodate an assistant, a wheelchair, or a walker adequately. One subject mentioned that there was "no privacy" due to the size of the stalls. Two subjects mentioned steps to the bathroom were a problem. The lack of grab bars or raised toilet seats were mentioned as a frequent limitation as well, although 1 subject said that the toilets are too high. Two subjects reported that doors were problematic, with 1 stating they were "difficult to negotiate" and suggested that more automatic doors with push pads would be helpful. One subject suggested that more unisex bathrooms be provided in the community to accommodate caregivers.

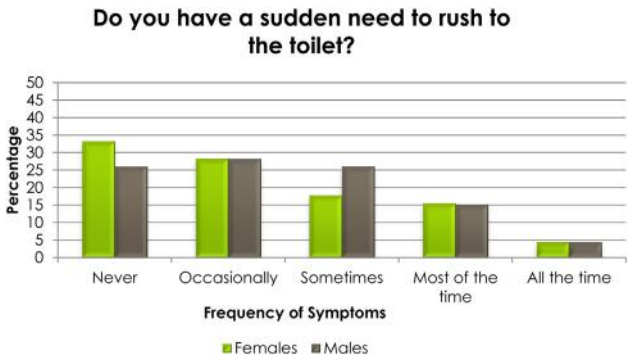

Figure 1. Frequency of urinary urgency symptoms for females versus males.

Risk Factors for Urinary Symptoms

The association of age, GMFCS, and BMI with regard to urgency and leakage is provided in Table 5. Symptoms of incontinence that were evaluated for women, men, and all the subjects for these associations were the following: (1) leakage before reaching the toilet, (2) leakage with cough or exercise, (3) leakage for no obvious reason, and (4) nocturia. These 4 items were chosen because they are common across the 2 ICIQ instruments, in addition to being areas of reported symptoms. All symptom scores were similar in women across the 3 age groups (<35, 36-50, and >50 years) evaluated. For men, only nocturia was significantly associated with age. GMFCS across all the subjects was significant only for leakage, with cough, exercise, or sneezing with more individuals GMFC III and IV reporting this symptom. There were no differences found across the 3 GMFCS groups (I or II versus III versus IV or V) for the incontinence subscores for leaking before reaching the toilet versus GMFCS comparison for all the subjects ($P = .16$), women ($P = .72$), or men ($P = .06$). Similarly, there were no differences across these same GMFCS groups of ratings of urgency for women (χ^2 (degree of freedom [df]=2) = 2.32; $P = .31$) or for urinary leakage between voids for men (χ^2 (df=2) = 1.13; $P = .57$). BMI was associated with 2 symptoms in that those with higher BMI reported higher scores on the incontinence measure of leakage with cough or exercise (women) or leakage before reaching the toilet (men). Multivariable analyses (Table 6) with gender, age, BMI, GMFCS, and FIM transfer showed similar results: Obesity compared with normal weight was significantly related to leaking before reaching the toilet (OR 4.3, 95% CI 1.3-14.7); to leaking with cough, exercise, or sneeze (OR 5.6, 95% CI 1.3-23.1); and to nocturia (OR 5.4, 95% CI 1.2-25.1). Women were more likely to leak with cough, exercise, or sneeze (OR 5.5, 95% CI 1.5-20.0). Those aged less than 35 years were more likely to have nocturia (OR 9.6, 95% CI 1.7-53.9). No significant differences in living situation (home versus other residence) were related to incontinence scores in either women or men (Wilcoxon rank-sum test: women, $z = 1.11$, $P = .27$; men, $z = 0.94$, $P = .35$). Employment was not related to incontinence scores (Wilcoxon rank-sum test: women, $z = -0.32$, $P = .75$; men $z = 0.57$, $P = .57$).

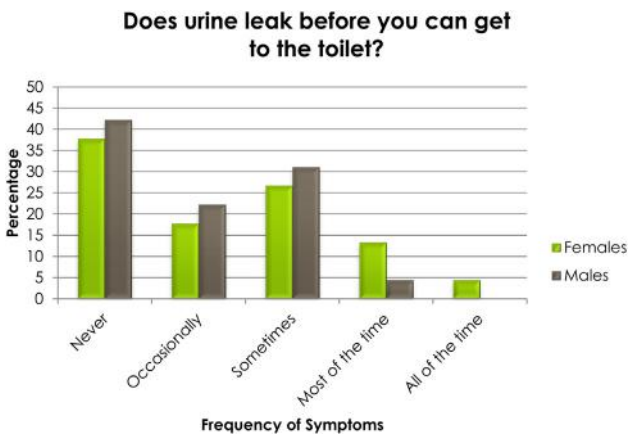

Figure 2. Frequency of urinary leakage symptoms for females versus males.

DISCUSSION

This study is among the first to prospectively evaluate and quantify urinary symptoms in adults with CP. The findings of this study indicate that specific bladder-related problems are more common in this population than in nondisabled adults and are present in young as well as older individuals with CP, and many of these adults report that symptoms are bothersome with life activities.

The pathophysiology of CP-related bladder dysfunction has been extensively explored within the pediatric population; detrusor hyperactivity as well as reduced bladder capacity has been documented. In a study by Decter et al [23], urodynamic studies demonstrated decreased volitional control and uninhibited bladder contractions, consistent with upper motor neuron lesions. Lower motor neuron lesions, which are less commonly associated with CP, also were identified and result in sphincter dysfunction [23]. These researchers suggested that injury to the brain results in the upper motor neuron symptoms, whereas the lower motor neuron symptoms are caused by hypoxic injury to the spinal cord because the lumbosacral cord tends to be more prone to injury during anoxic events [23]. In a study that evaluated continence by age 6 years, only 54% of children with spastic quadriplegia had gained continence, whereas 80% of those with spastic diplegia or hemiplegia were continent by this age. In children with CP (mean age, 8.2 years), 66.6% were found to have voiding difficulties, including incontinence and difficulty urinating [8]. Urodynamic findings of neurogenic detrusor overactivity and low bladder capacity were

Table 5. *Risk factors for incontinence*

	None or Occasional: 0 or 1, n (%)			Sometimes, Most or All of the Time: 2, 3, or 4, n (%)			*P* (Fisher exact test)
	Women	Men	All	Women	Men	All	
Leaking before reaching toilet (ICIQ-F 9A and ICIQ-M 8A)							
Total n (% with symptom severity)	25 (56)	29 (64)	54 (60)	20 (44)	16 (36)	36 (40)	
Age							
<35 y	16 (64)	19 (70)	35 (67)	9 (36)	8 (30)	17 (33)	.40 (women)
35-49 y	5 (42)	7 (54)	12 (48)	7 (58)	6 (46)	13 (52)	.60 (men)
≥50 y	4 (50)	3 (60)	7 (54)	4 (50)	2 (40)	6 (46)	.25 (all)
GMFCS level							
I or II	10 (67)	7 (100)	17 (77)	5 (33)	0 (0)	5 (23)	.72 (women)
III	3 (60)	3 (43)	6 (50)	2 (40)	4 (57)	6 (50)	.06 (men)
IV	9 (47)	10 (53)	19 (50)	10 (53)	9 (47)	19 (50)	.16 (all)
V	3 (50)	9 (75)	12 (67)	3 (50)	3 (25)	6 (33)	
FIM transfer level**							
0, 1, 2	5 (63)	12 (71)	17 (68)	3 (38)	5 (29)	8 (32)	.80 (women)
3 or 4	2 (40)	1 (20)	3 (60)	3 (60)	4 (80)	7 (70)	.09 (men)
5, 6, or 7	17 (55)	16 (70)	33 (61)	14 (45)	7 (30)	21 (39)	.13 (all)
BMI (kg/m^2)***							
Normal/underweight	14 (64)	20 (80)	34 (72)	8 (36)	5 (20)	13 (28)	.28 (women)
Overweight	3 (33)	4 (57)	7 (44)	6 (68)	3 (43)	9 (56)	**.02 (men)***
Obese	5 (46)	3 (30)	8 (38)	6 (55)	7 (70)	13 (62)	**.01 (all)***
Leaking with cough, exercise, or sneeze (ICIQ-F 11A and ICIQ-M 9A)							
Total n (% with symptom, by severity)	29 (64)	41 (89)	70 (77)	16 (36)	5 (11)	21 (23)	
Age							
<35, y	17 (68)	25 (93)	42 (81)	8 (32)	2 (7)	10 (19)	.64 (women)
35-49 y	8 (67)	11 (85)	19 (76)	4 (33)	2 (15)	6 (24)	.50 (men)
≥50 y	4 (50)	5 (83)	9 (64)	4 (50)	1 (17)	5 (36)	.42 (all)
GMFCS level							
I or II	12 (80)	7 (100)	19 (86)	3 (20)	0 (0)	3 (13)	.20 (women)
III	2 (40)	6 (86)	8 (67)	3 (60)	1 (14)	4 (33)	.22 (men)
IV	10 (53)	15 (79)	25 (66)	9 (47)	4 (21)	13 (34)	**.04 (all)***
V	5 (83)	13 (100)	18 (95)	1 (17)	0 (0)	1 (5)	
FIM transfer level**							
0, 1, 2	5 (63)	16 (89)	21 (81)	3 (38)	2 (11)	5 (19)	.48 (women)
3 or 4	2 (40)	4 (80)	6 (60)	3 (60)	1 (20)	4 (40)	.65 (men)
5, 6, or 7	21 (67)	21 (91)	42 (78)	10 (32)	2 (9)	12 (22)	.40 (all)
BMI (kg/m^2)***							
Normal/underweight	18 (82)	24 (92)	42 (88)	4 (18)	2 (8)	6 (13)	**.04 (women)***
Overweight	4 (44)	7 (100)	11 (69)	5 (56)	0 (0)	5 (31)	.12 (men)
Obese	5 (46)	7 (70)	12 (57)	6 (55)	3 (30)	9 (43)	**.01 (all)***
Leaking with no obvious reason (ICIQ-F 12A and ICIQ-M 10A)							
Total n (%, for degree of leakage)	39 (87)	39 (85)	78 (86)	6 (13)	7 (15)	13 (14)	
Age							
<35 y	23 (92)	22 (81)	45 (87)	2 (8)	5 (19)	7 (13)	.42 (women)
35-49 y	10 (83)	12 (92)	22 (88)	2 (17)	1 (8)	3 (12)	.85 (men)
≥50 y	6 (75)	5 (83)	11 (79)	2 (25)	1 (17)	3 (21)	.71 (all)
GMFCS level							
I or II	12 (80)	6 (86)	18 (82)	3 (20)	1 (14)	4 (18)	.80 (women)
III	5 (100)	5 (71)	10 (83)	0 (0)	2 (29)	2 (17)	.21 (men)
IV	17 (89)	15 (79)	32 (84)	2 (11)	4 (21)	6 (16)	.67 (all)
V	5 (83)	13 (100)	18 (95)	1 (17)	0 (0)	1 (5)	
FIM transfer level**							
0, 1, 2	7 (88)	16 (89)	23 (88)	1 (13)	2 (11)	3 (12)	.81 (women)
3 or 4	4 (80)	4 (80)	8 (80)	1 (20)	1 (20)	2 (20)	.73 (men)
5, 6, or 7	27 (87)	19 (83)	46 (85)	4 (13)	4 (17)	8 (15)	.82 (all)
BMI (kg/m^2)***							

Table 5. *Continued*

	None or Occasional: 0 or 1, n (%)			Sometimes, Most or All of the Time: 2, 3, or 4, n (%)			*P* (Fisher exact test)
	Women	Men	All	Women	Men	All	
Normal/underweight	21 (95)	24 (92)	45 (94)	1 (5)	2 (8)	3 (6)	.24 (women)
Overweight	7 (78)	5 (71)	12 (75)	2 (22)	2 (29)	4 (25)	.21 (men)
Obese	9 (82)	8 (80)	17 (81)	2 (18)	2 (20)	4 (19)	.08 (all)
Nocturia (ICIQ-F 13A and ICIQ-M 11A)							
Total n (% for degree of leakage)	36 (80)	38 (83)	74 (81)	9 (20)	8 (17)	17 (19)	
Age							
<35 y	21 (84)	25 (93)	46 (88)	4 (16)	2 (7)	6 (12)	.68 (women)
35-49 y	9 (75)	10 (77)	19 (76)	3 (25)	3 (23)	6 (24)	**.03 (men)***
≥50 y	6 (75)	3 (50)	9 (64)	2 (25)	3 (50)	5 (36)	.07 (all)
GMFCS level							
I or II	12 (80%)	7 (100)	19 (86)	3 (20)	0 (0)	3 (14)	.06 (women)
III	4 (80%)	6 (86)	10 (83)	1 (20)	1 (14)	2 (17)	.81 (men)
IV	15 (79%)	15 (79)	30 (79)	4 (21)	4 (21)	8 (21)	.92 (all)
V	5 (83%)	10 (77)	15 (79)	1 (17)	3 (23)	4 (21)	
FIM transfer level**							
0, 1, 2	7 (88)	15 (83)	22 (85)	1 (13)	3 (17)	4 (15)	.09 (women)
3 or 4	2 (40)	4 (80)	6 (60)	3 (60)	1 (20)	4 (40)	>.99 (men)
5, 6, or 7	26 (84)	19 (83)	45 (83)	5 (16)	4 (17)	9 (17)	.24 (all)
BMI (kg/m^2)***							
Normal/underweight	20 (91)	22 (85)	42 (88)	2 (9)	4 (15)	6 (13)	.19 (women)
Overweight	7 (78)	6 (86)	13 (81)	2 (22)	1 (14)	3 (19)	.55 (men)
Obese	7 (64)	7 (70)	14 (67)	4 (36)	3 (30)	7 (33)	.14 (all)

ICIQ-F = International Consultation of Incontinence Questionnaire—Female; ICIQ-M = ICIQ—Male; GMFCS = Gross Motor Function Classification System; FIM = Functional Independence Measures; BMI = body mass index.

*Statistically significant at .05 level.

**For FIM transfer level, women n = 44 due to missing score.

***For BMI, women n = 42 and men n = 43 due to height missing for 6 subjects.

present in 47% of children, with bladder capacity on average 52% of that expected [24,25].

Urinary symptoms have been assessed in adults without CP who live in the community. The Boston Area Community Health Survey reported findings on more than 5000 adults 30-79 years old, and, for this group, the prevalence of weekly urinary leakage was 8% overall, with 10.4% of women and 5.3% of men reporting this symptom [26]. The findings of our study indicate much greater levels of urinary incontinence; although a similar age range, women in the present study reported at least weekly urinary incontinence rates approximately 4 times greater. In addition to neurologic bladder changes, an additional hypothesis is that genitourinary dysfunction may be related to toileting difficulties and toilet accessibility [4]. A prospective study of U.S. adults with self-reported mobility limitations found that adults with mobility issues reported greater numbers of secondary health conditions, with disorders of the genitourinary tract found in 21.7% compared with 13.3% of individuals without limitations [27].

Bladder-related symptoms in the present study are more frequent than those reported recently in adults and children with CP by Murphy et al [9]. This difference may be related to our more-detailed questioning regarding symptoms or may be because our subjects were on average older, as suggested by a greater number of individuals older than 30 years in the present study. However, 93% of our subjects were 49 years or younger, and most incontinence scores did not differ across GMFCS levels, which indicates that factors beyond mobility limitations play a role in the incontinence.

Urinary symptoms associated with greater levels of interference in the present study were leakage and urgency. These symptoms could potentially be amenable to medication or exercise interventions. Despite the high levels of urinary symptoms, the subjects in the present study were rarely using medications for symptomatic control. Whether this is due to subjects not reporting incontinence, physicians not exploring this issue, or subjects not using medications due to ineffectiveness is unknown. Thus, it is imperative that physicians who treat and manage adults with CP actively assess for these symptoms. Although not queried in this study, it is possible that some adults with CP become accommodated to the stress and embarrassment related to bladder problems and do not actively complain to the physicians who could alleviate some of the problems. Addressing such symptoms has the potential to improve their QOL.

Central obesity has previously been identified as a risk factor for stress incontinence in nondisabled individuals [26]. Our findings of higher BMI being associated with

Table 6. *Odds ratios for leakage (sometimes, most or all of the time vs none or occasional)*

Adjustment Factors	Leaking before reaching toilet, OR (95% CI)	Leaking With Cough, Exercise, or Sneeze, OR (95% CI)	Leaking With No Obvious Reason, OR (95% CI)	Nocturia, OR (95% CI)
Gender				
Male	Reference	Reference	Reference	Reference
Female	1.81 (0.66-4.96)	5.45 (1.49-19.95)*	0.53 (0.12-2.34)	0.85 (0.23-3.13)
Age				
<35 y	Reference	Reference	Reference	Reference
35-49 y	2.60 (0.81-8.34)	1.60 (0.38-6.73)	0.98 (0.18-5.44)	4.80 (1.00-23.06)
50+ y	1.95 (0.46-8.32)	3.20 (0.64-15.93)	2.77 (0.45-16.97)	9.61 (1.72-53.89)*
BMI				
Normal	Reference	Reference	Reference	Reference
Overweight	3.08 (0.80-11.85)	3.17 (0.58-17.30)	4.23 (0.70-25.49)	0.89 (0.14-5.46)
Obese	4.30 (1.26-14.67)*	5.56 (1.34-23.08)*	4.67 (0.84-26.09)	5.42 (1.17-25.09)*
GMFCS				
1,2	Reference	Reference	Reference	Reference
3	2.27 (0.37-13.71)	3.60 (0.42-30.90)	0.25 (0.02-3.32)	0.52 (0.05-5.06)
4,5	3.30 (0.76-14.32)	2.01 (0.33-12.16)	0.45 (0.08-2.69)	0.93 (0.16-5.53)
FIM transfer				
1, 2	Reference	Reference	Reference	Reference
3, 4	2.99 (0.49-18.20)	1.90 (0.26-13.86)	1.29 (0.08-20.20)	5.96 (0.74-48.28)
5, 6, 7	1.17 (0.31-4.40)	0.65 (0.12-3.56)	1.43 (0.18-11.50)	1.55 (0.23-10.27)

OR = odds ratio; CI = confidence interval; BMI = body mass index; GMFCS = Gross Motor Function Classification System; FIM = Functional Independence Measures.

*Statistically significant at .05 level.

urinary leakage before reaching the toilet and of stress incontinence are concordant with this information. In addition, this finding suggests that interventions to reduce obesity in adults with CP could result in reductions in urinary symptoms.

Urinary incontinence in men was approximately half of that reported by women in a general population study. For men, urinary incontinence has been found to increase with age [28]. Age was a factor in this study for nocturia and, certainly in men, could have been affected by issues beyond CP, for example, prostatic hypertrophy, which, although we asked if present by history, was not screened for more objectively. For individuals with mobility limitations, nocturia may be more problematic and may result in the need to use products such as diapers due to caregiver unavailability. Of note, prior studies found that, in the general population, incontinence results in greater social or emotional impact on QOL in men compared with women, and that men are less likely to seek care for urinary incontinence [29]. Men with urinary incontinence also have a higher risk of institutionalization compared with those without, a finding that was not present in this study [30].

More than 50% of individuals in this study reported that they had difficulty with accessing toilets in the community. However, this included the need for assistance, which was not always available; the individuals interviewed for this study also described difficulty with access in the "accessible" toileting facilities, primarily with use of power wheelchairs. Thus, measures to improve continence in this population will not only need to be taken medically but also through addressing barriers in the community.

Limitations to this study include that only persons who were able to provide informed consent (and for this reason could rate the impact of urinary issues), and those at a single center were included. Thus, this study does not report the incidence in individuals with CP with severe cognitive deficits, the inclusion of whom would likely reflect greater levels of incontinence. Also, we had few subjects who were GMFCS level I and greater numbers of individuals who were GMFCS levels IV and V, which may have affected our ability to detect differences in symptoms across all GMFCS levels.

CONCLUSION

Bladder incontinence is common in adults with CP across a range of ages and GMFCS levels. Urgency and leakage symptoms are the most common issues identified. BMI affects incontinence in this population. Despite these symptoms, employment was not associated with urinary symptoms, and most adults were living in the community. However, the symptoms are perceived as interfering with QOL and should be addressed in the clinic. There are opportunities to improve bladder symptoms with medications and other interventions, and to reduce the burden of care and improve the QOL for adults with CP.

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CME Question

Females with higher body mass index (BMI) reported higher scores on which incontinence measure of leakage?

a. before reaching the toilet
b. with cough or exercise
c. for no obvious reason
d. while sleeping at night

Answer online at me.aapmr.org