Prevalence of Pelvic Incontinence in Patients With Cystic Fibrosis

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Abstract

Cystic fibrosis (CF) patients are at risk for developing pelvic (urinary and/or fecal) incontinence due to progressive weakness of pelvic floor muscles secondary to recurrent episodes of coughing and respiratory infections. Many patients do not bring these symptoms to the attention of their health care providers because of social embarrassment and lack of knowledge of available effective treatment. Several studies have identified the prevalence of incontinence in CF adults and adolescents. However, few studies identified the problem in children with CF. Our study aims are to identify the prevalence of pelvic incontinence in CF patients aged 6 to 21 years, to identify the correlation between incontinence and severity of lung disease, and to help develop treatment strategy in collaboration with physical therapy to address these issues.

Keywords
pelvic incontinence, urine incontinence, fecal incontinence, cystic fibrosis, prevalence

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Introduction

Pelvic incontinence (PI) (urinary and/or fecal) refers to involuntary or uncontrollable leakage of urine and/or feces. Development of urinary incontinence (UI) in children is usually attributed to 3 etiologies: anatomic lesions, neurologic lesions, or behavioral issues.¹ However, in patients with cystic fibrosis (CF), repeated coughing reduces strength of pelvic floor muscle that causes them to lose control resulting in incontinence.²

Urinary incontinence in CF patients can have a negative impact on their overall health and general well-being. Studies have reported leakage affecting their ability to perform spirometry and airway clearance.³⁻⁵ Patients with symptoms are unaware of treatment options.⁵ Once leakage occurs, there is progressive decline in pelvic muscular function causing worsening symptoms.⁶

The prevalence of UI in women with CF has been reported in several studies and clearly documented (30% to 68%),²⁻⁵,⁷⁻⁸ whereas the prevalence in men (2.4% to 16%) is more controversial.⁹⁻¹⁰ There are few studies that evaluated incontinence in children with CF, mostly reported in small numbers of patients (65 patients,¹¹ 81 patients,¹¹ 54 patients,¹² 128 patients,¹³ and 12 patients¹⁴). The prevalence of incontinence is reportedly higher in girls with CF (31%) when compared with asthmatic and healthy girls (16% and 7%, respectively).¹⁵ However, the prevalence of fecal incontinence (FI) is less well described. One study reported the prevalence of FI in children with CF as 8.6%.¹³

Our study aim is to identify prevalence of PI in patients with CF followed at our center. The correlation between incontinence and severity of lung disease as assessed by lung function (measured by forced expiratory volume at 1 second % predicted [FEV₁% predicted]) and nutritional status as measured by body mass index (BMI) will be discussed.

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Methods

Study Population

CF patients aged 6 to 21 years who attended the Pediatric CF Clinic at Michigan Medicine, Mott Children’s Hospital, Ann Arbor, Michigan, were included in the study. The multidisciplinary clinic manages approximately 270 pediatric CF patients. The study was conducted between June and December 2016. Eligible patients and their parents were approached to complete a questionnaire during routine clinic visit or during hospitalization.

Study Design

This is a quality improvement project. A 13-item questionnaire to assess symptoms of UI (4 questions), urgency and frequency (4 questions), FI (1 question), and bowel dysfunction (4 questions) was administered. The questionnaire took approximately 5 minutes to complete. Demographics of participants were collected including name, age, and sex. Additional information including FEV₁% predicted and BMI percentile were documented on the day of the questionnaire completion. Sweat testing, CF mutations, history of cystic fibrosis related diabetes (CFRD), and frequency of pulmonary exacerbations (PE) requiring oral antibiotics and/or hospitalization in the past 12 months were recorded from the patients’ health records. A scoring system was applied to assess the response to the questionnaire (never = 0, sometimes = 1, often = 2) with a total score range of 0 to 10 for incontinence, 0 to 8 for urgency and frequency, and 0 to 8 for bowel dysfunction. Patients with a score ≥1 were identified as having symptoms of urinary or fecal incontinence or urinary urgency and frequency or bowel dysfunction.

Data Analysis

Data analysis was carried out using GraphPad PRISM 7.0 software. To compare variables, t test, χ² test, and Pearson correlation were used. The results were noted as mean ± standard deviation and as significant when the P value was less than .05.

The study was approved by the University of Michigan Institutional Review Board as a quality improvement project.

Results

Of a total of 186 patients in this age group, 168 patients completed the questionnaire (90.4%). The remainder were not seen during the study period or refused to participate. The baseline demographics is outlined in Table 1.

Sixty-four (38%) respondents reported having symptoms of PI (UI and FI). Patients with incontinence were younger than patients without, and it was more frequent in females (64%) compared with males (36%; Table 1). Eleven (17%) patients reported symptoms occurring as “often” and 53 (83%) reported it occurring only “sometimes.”

FEV₁% predicted and BMI percentile are listed in Table 1 for both groups. There was a negative correlation between nutritional status and PI (Figure 1).

Thirty-nine patients (41.4%) with incontinence required oral antibiotics for PE in the year prior, and 26 required hospitalizations (46.4%). There was a positive correlation between number of exacerbations requiring hospitalization and incontinence symptoms (Table 1).

Nineteen patients were identified with CFRD, of which 8 patients reported symptoms of PI (42%). There was no significant correlation between CFRD and PI (Table 1).
Of the total 64 patients, 36 (56.3%) reported symptoms of UI, 8 (12.5%) reported symptoms of FI, and 20 (31.2%) reported combined symptoms of UI and FI. The average FEV1 in patients with symptoms of FI was lower than those with symptoms of UI; however, the average BMI was similar in the 2 groups (Table 2).

Of the study population, 132 (78.5%) and 123 (73%) patients reported symptoms of urgency and/or frequency and bowel dysfunction, respectively.

**Figure 1.** Forced expiratory volume at 1 second (FEV1) and body mass index (BMI) comparison in patients with and without pelvic incontinence.

**Table 2.** Clinical Characteristics of Patients With Symptoms of Urine and Fecal Incontinence.

| Characteristics                  | Urine Incontinence (n = 36) | Fecal Incontinence (n = 8) | P   |
|----------------------------------|-----------------------------|-----------------------------|-----|
| Age (years)*                     | 12.4 ± 4.5                  | 9.7 ± 3.2                   | .06 |
| Gender (female/male)             | 21/15                       | 7/1                         | .08 |
| FEV1 (% predicted)*              | 88.4 ± 17.2                 | 81.7 ± 21.6                 | .37 |
| BMI (percentile)*                | 56.6 ± 31.5                 | 57.9 ± 23.9                 | .91 |

Abbreviations: FEV1, forced expiratory volume in 1 second; BMI, body mass index.
*Data are shown as mean with standard deviation.

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**Discussion**

The prevalence of PI was 38% among the study population. Of these, 56.3% reported symptoms of UI, 12.5% reported symptoms of FI, and 31.2% reported symptoms of combined UI and FI. This prevalence is much higher than that reported in the general pediatric population. A total of 482 children, aged 4 to 17 years followed at a primary care clinic during routine well-child visit, were screened for symptoms of constipation, UI, and FI. The study showed a prevalence of 10.5% for UI and 4.4% for FI.

The prevalence of UI in our study population (56.3%) was higher than that reported in previous studies in the CF population. The high prevalence highlights the increased risk of having symptoms of incontinence due to frequent coughing episodes that leads to weakening of the pelvic floor muscles. FI was reported at a higher prevalence rate compared with a previous study. That study identified a prevalence of 8.6% among the 128 children (age 6-17 years) surveyed compared with 12.5% in our study population. The difference could be attributed to the larger population surveyed in our study, age of participants, and/or the way the questions were asked in the survey.

Similar to other studies, females reported higher prevalence of incontinence than males. The gender difference could be because of bladder training at a young age without fully relaxing pelvic floor muscles especially in girls, which is usually carried on to adulthood. Reduced collagen in the pelvic floor muscles may also contribute to UI. A study investigating incidence of UI in nulliparous athletes found that a women’s continence threshold depends on the type and frequency of stresses to which the pelvic floor muscles are exposed to, and if this threshold is exceeded, UI can occur. The stresses placed on the pelvic floor muscles from chronic coughing in CF patients could be large enough to exceed this continence threshold.
Interestingly, our study did not find any correlation between severity of lung disease as measured by FEV1% predicted and BMI percentile and symptoms of incontinence. Two studies reported a lower FEV1% and BMI in their patients with incontinence. However, in our study symptomatic patients had normal lung function, which was similar to other previously reported studies. Our study also showed a positive correlation between PE and incontinence symptoms. Therefore, a cough score could be more accurate than FEV1% in predicting prevalence of incontinence. Our study also reported a higher BMI in patients with incontinence, which is different from prior reported studies.

Our study showed that patients with symptoms of FI were younger and had lower FEV1% than patients with symptoms of UI. These findings have not been previously studied.

Our study was limited by the subjective nature of the questionnaire. However, the main focus of the study was to identify the prevalence of these symptoms in our patients and try to correlate them with disease severity. This study is the first step in addressing these symptoms.

Symptomatic patients are currently being referred to a physiotherapist specialized in pelvic floor muscle training exercises. An algorithm is being developed for each stage of incontinence. The algorithm will specify the frequency and length of treatment according to the severity of symptoms. Patients and families have been welcoming to the intervention. Close follow-up of the intervention and patient responses will be monitored.

In conclusion, PI is more prevalent in children with CF, both males and females, compared with the general population. Since patients with incontinence in our study had normal lung function and BMI, screening for these symptoms is crucial in all CF patients regardless of disease severity. It can prevent long-term consequences on their overall health and improve quality of life.

**Author Contributions**

FN: Contributed to conception and design; contributed to acquisition, analysis, and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

FA: Contributed to acquisition and analysis.

SZN: Contributed to conception and design; contributed to acquisition, analysis, and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

**Declaration of Conflicting Interests**

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**References**

1. Schaeffer AJ, Diamond DA. Pediatric urinary incontinence: classification, evaluation, and management. *Afr J Urol*. 2014;20:1-13.

2. Cornacchia M, Zenorini A, Perobilli S, Zanolla L, Mastella G, Braggion C. Prevalence of urinary incontinence in women with cystic fibrosis. *BJU Int*. 2001;88:44-48.

3. Reichman G, De Boe V, Braeckman J, Michielsen D. Urinary incontinence in patients with cystic fibrosis. *Scand J Urol*. 2016;50:128-131.

4. Judi MC, Connett GJ. Stress incontinence problems in the pediatric population. *Pediatr Pulmonol*. 2002;110(suppl 24):a399.

5. Nixon GM, Glanzner JA, Martin JM, Sawyer SM. Urinary incontinence in female adolescents with cystic fibrosis. *Pediatrics*. 2002;110(2 pt 1):e22.

6. Gunnarson M, Mattiasson A. Female stress, urge and mixed urinary incontinence are associated with a chronic and progressive pelvic floor/vaginal neuromuscular disorder: an investigation of 317 healthy and incontinent women using vaginal surface electromyography. *Neurourol Urodyn*. 1999;18:613-621.

7. Orr A, McVean RJ, Webb AK, Dodd ME. Questionnaire survey of urinary incontinence in women with cystic fibrosis. *BMJ*. 2001;322:1521.

8. Moran F, Bradley JM, Boyle L, Elborn JS. Incontinence in adult females with cystic fibrosis: a Northern Ireland survey. *Int J Clin Pract*. 2003;57:182-183.

9. White D, Stiller K, Roney F. The prevalence and severity of symptoms of incontinence in adult cystic fibrosis patients. *Physiother Theory Pract*. 2000;16:35-42.

10. Gurney L, Lee J, Whitehouse J, Honeybourne D. The prevalence of urinary incontinence in adult cystic fibrosis males. *J Cyst Fibros*. 2005;4(suppl 1):S97.

11. Browne WJ, Wood CJ, Desai M, Weller PH. Urinary incontinence in 9-16 year olds with cystic fibrosis compared to other respiratory conditions and a normal group. *J Cyst Fibros*. 2009;8:50-57.

12. Van Schaijik M, Arets HGM, Sinnema G, De Jong TPVM, De Kort LMO. Urinary incontinence in girls and female adolescents with cystic fibrosis. *J Pediatr Urol*. 2007;3(suppl 1):S96.

13. Moraes T, Carpenter S, Taylor L. Cystic fibrosis and incontinence in children. *Pediatr Pulmonol*. 2002;110(suppl 24):a398.

14. Blackwell K, Malone PS, Denny A, Connett G, Maddison J. The prevalence of urinary incontinence in patients with cystic fibrosis: an under recognized problem. *J Pediatr Urol*. 2005;1:5-9.

15. Prasad SA, Balfour-Lynn IM, Carr SB, Madge SL. A comparison of the prevalence of urinary incontinence in girls with cystic fibrosis, asthma, and healthy controls. *Pediatr Pulmonol*. 2006;41:1065-068.
16. Loening-Baucke V. Prevalence rates for constipation and faecal and urinary incontinence. *Arch Dis Child*. 2007;92:486-489.

17. Bauer RM, Huebner W. Gender differences in bladder control: from babies to elderly. *World J Urol*. 2013;31:1081-1085.

18. Keane DP, Sims TJ, Abrams P, Bailey AJ. Analysis of collagen status in premenopausal nulliparous women with genuine stress incontinence. *Br J Obstet Gynaecol*. 1997;104:994-998.

19. Nygaard IE, Thomson FL, Svengalis SL, Albright JP. Urinary incontinence in elite nulliparous athletes. *Obstet Gynecol*. 1994;84:183-187.

20. Korzeniewska-Eksterowicz A, Stelmach I, Stelmach W. Urinary incontinence in adolescent females with cystic fibrosis in Poland. *Open Med*. 2014;9:778-783.