

Urinary Incontinence in Female Adolescents With Cystic Fibrosis

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ABSTRACT. *Objectives.* Urinary incontinence is common in healthy women and occurs with increased frequency in adult women with chronic lung disease, including cystic fibrosis (CF). This study aimed to determine the prevalence, severity, and impact on daily life of urinary incontinence in female adolescents with CF.

Methods. An interviewer-administered questionnaire was conducted with females who were aged 12 years and older and attend the CF Clinic at the Royal Children's Hospital in Melbourne, Australia.

Results. Fifty-five (96%) of 57 eligible adolescents (age: 12–19 years) participated. Twenty-six (47%) reported ever having been incontinent of urine; 12 (22%) reported daytime incontinence twice a month or more. Median age of onset of incontinence was 13 years (range: 7–16 years). No relationship was seen with age, lung function, body mass index, or menarchal status. Coughing and laughing were the most commonly reported precipitants (affecting 84% and 68%, respectively). Of those with incontinence once a year or more, 42% reported that it sometimes prevented them from doing effective physiotherapy. Social life was affected by incontinence in approximately one third of respondents. Nearly half (42%) of affected adolescents had told no one, and only 2 had discussed the problem with their physician.

Conclusions. Urinary incontinence is common in female adolescents with CF and is not related to illness severity. Urinary incontinence has a negative impact on the performance of chest physiotherapy. Given the lack of adolescent report and knowledge of treatment availability, inquiry about symptoms of urinary incontinence should be part of the routine assessment of female adolescents with CF. *Pediatrics* 2002;110(2). URL: <http://www.pediatrics.org/cgi/content/full/110/2/e22>; *cystic fibrosis, adolescents, urinary incontinence.*

ABBREVIATION. CF, cystic fibrosis.

Daytime urinary incontinence is common among women, increasing in frequency with age and parity.^{1–6} There are few reports in adolescents, but 2 studies have reported a prevalence of incontinence occurring twice or more per month

of 4% to 5% in healthy 15- to 24-year-old girls and women^{2,7} and 1 study reported daytime incontinence in 3.6% of 17-year-old girls.⁸ Higher rates are reported in this age group for “ever” having experienced urinary incontinence.^{4,9}

Adult women with chronic respiratory disease have increased rates of urinary incontinence.^{3,10,11} Repeated coughing may promote the earlier development of the anatomic and pressure transmission abnormalities that are associated with development of stress incontinence.³ Women with cystic fibrosis (CF) may be at particular risk, as frequent coughing is a feature of the disease, in terms of both difficulty with clearing tenacious secretions and as part of airway clearance techniques that are recommended from a young age.^{12–14} Adult men with CF or other forms of chronic respiratory disease seem to be at far less risk of urinary incontinence.¹¹

Urinary incontinence has considerable social and psychological impact, including leading some women to change their exercise habits.^{15–19} Importantly, adult women with CF have reported that incontinence affected their ability to cough effectively.^{12,14} As many women delay seeking help from medical professionals for this problem,^{7,16} unrecognized and untreated urinary incontinence may have a significant impact on respiratory disease in women with CF. This study aimed to determine the prevalence and severity of urinary incontinence in a population of female adolescents with CF and its association with severity of lung disease and its impact on daily life and personal health care, including physiotherapy.

METHODS

Population

The study sample consisted of female patients with CF who were aged 12 years or older and attend the Cystic Fibrosis Clinic, Department of Respiratory Medicine, Royal Children's Hospital (Melbourne, Australia). This specialist multidisciplinary CF service manages approximately 320 infants, children, and adolescents with CF. Between December 2000 and March 2001, eligible patients and their parents were approached at a routine outpatient visit to participate in the study. Ethical approval was obtained from the Ethics in Human Research Committee of the Royal Children's Hospital.

Demographic data recorded for each participant included age, weight, height, lung function (best forced vital capacity and forced expiratory volume in 1 second in the previous 6 months), number of hospitalizations for respiratory exacerbations in the previous 12 months, and type and frequency of chest physiotherapy and exercise. A list of medications was also sought.

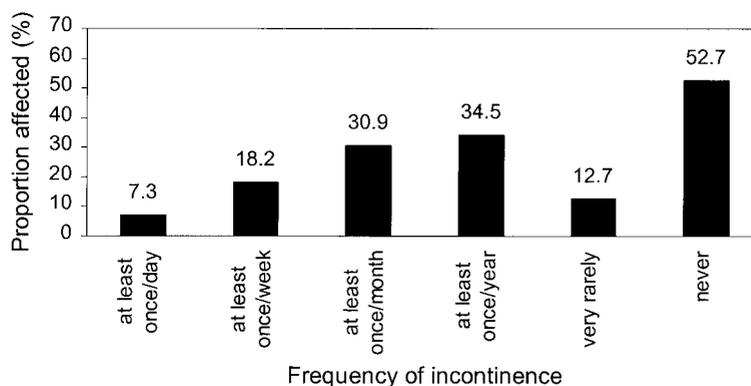
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Fig 1. Proportion of female adolescents with CF reporting urinary incontinence, by frequency of incontinence.



Questionnaire

An interviewer-administered questionnaire was developed to assess prevalence, severity, and impact of urinary incontinence. Questions relating to severity and precipitants of incontinence were modeled on a previously validated questionnaire²⁰ and thus were similar to those used by White et al¹² in their study of urinary incontinence in adults with CF. Minor modifications were made to make the questionnaire more appropriate for adolescents. Three young women were asked to complete the draft questionnaire and encouraged to make comments or seek clarification from the interviewer. As a result, several changes were made to the content and wording of the questionnaire. The final questionnaire is included in Appendix 1 and took approximately 20 minutes to complete. A brief questionnaire was also developed for parents, asking whether they knew whether their daughter experienced incontinence and, if so, how often (questions 12 [with an additional option “don’t know”], 20, 22, and 27 of the questionnaire in Appendix 1).

Data Analysis

Analyses were predominantly descriptive. Continuous variables were compared between groups using the *t* test for parametric data (lung function, age at menarche, body mass index) and the Wilcoxon rank-sum test for nonparametric data (age, hospitalizations, frequency of physiotherapy and exercise). Fisher exact test was used for comparisons of proportions involving fewer than 5 subjects per group. Data analysis was performed using the Stata statistical software package (Stata Corp, College Station, TX).

RESULTS

Participants

Fifty-five (96%) of 57 eligible female adolescents completed the questionnaire. One adolescent attended the clinic very infrequently and could not be

contacted to take part in the study. One adolescent was excluded because of a moderate intellectual disability. No patient declined to take part. All participants were nulliparous. None was prescribed diuretic medications. Positive expiratory pressure techniques were the most commonly reported form of regular physiotherapy (70%).

Daytime urinary frequency was stated as being up to 6 times per day in 50 respondents (91%), with only 1 having a urinary frequency of >10 times per day. Nocturnal urinary frequency was given as once or less per night in 96% of respondents (including all 3 with overnight gastrostomy feeding). These patterns of urinary frequency are comparable to those described in healthy adolescents.²¹

Incontinence

Twenty-six (47%) respondents reported ever having been incontinent of urine. One respondent had primary daytime incontinence, whereas the others had previously achieved daytime continence. Median age of onset of secondary daytime incontinence was 13 years (range: 7–16). Ten respondents (18%) reported urinary urgency, being unable to delay daytime urination for longer than 5 minutes. Of these, 5 adolescents had actually experienced incontinence.

Incontinence was reported once a year or more in 19 (73%) of those who reported ever being incontinent. Incontinence occurred at least weekly in 10 (18%) and at least monthly in 1 in 3 adolescents (Fig

TABLE 1. Clinical Characteristics of Incontinent (Once a Year or More) and Continent Adolescents

	Incontinent (n = 19)	Continent (n = 36)	P Value
Age (y)*	15 (13–19)	15 (12–19)	.35
Postmenarchal (%)‡	15 (79%)	24 (67%)	.53
Age at menarche†	13.2 (1.3)	13.3 (1.1)	.81
BMI (kg/m ²)†	19.1 (2.7)	19.1 (2.9)	.99
Best FVC (% predicted) in previous 6 mo†	89.8 (19.4)	85.3 (16.8)	.38
Best FEV ₁ (% predicted) in previous 6 mo†	82.4 (21.5)	78.3 (20.5)	.50
No. of hospitalizations in past 12 mo*	0 (0–7)	0 (0–6)	.57
CF-related diabetes (n)‡	1	1	1.0
Gastrostomy in situ (n)‡	0	3	.54
Constipation more than occasionally (%)‡	4 (21%)	5 (14%)	.70
Reported frequency of PEP physiotherapy/wk†	5.1 (3.8)	6.4 (5.7)	.43
Reported frequency of exercise/wk†	4.3 (3.5)	3.3 (2.5)	.25

BMI, body mass index; FVC, forced vital capacity; FEV₁, forced expiratory volume in 1 second; PEP, positive expiratory pressure.

* Values are reported as median (range) with difference assessed by Wilcoxon rank-sum test.

† Values are reported as mean (standard deviation) with differences assessed using *t* tests.

‡ Proportions were compared using the Fisher exact test.

1). Eight of the 19 adolescents with at least annual incontinence reported having urge incontinence, but all of these participants also reported stress incontinence. The clinical characteristics of those who experience incontinence at least once a year and those who do not are shown in Table 1. None of the factors examined identified a group at higher risk of incontinence.

Of those who reported incontinence once a year or more, 79% described small-volume incontinence ("damp/a few drops"), with the remainder describing moderate incontinence ("wet/a small amount"). None reported flooding of urine. Coughing "fits" and laughing were the most commonly identified precipitants of incontinence (reported by 84% and 68% of respondents, respectively), with sneezing (42%), chest physiotherapy (37%), and exercise (37%) being less common precipitants.

Eight of the adolescents with urinary incontinence (42%) reported that it "sometimes" prevented them from performing effective physiotherapy, with the remainder saying that their physiotherapy routine was not affected. More frequent urination was the most common behavior modification made in response to incontinence (37%), with 21% reporting that they specifically made a point of passing urine before physiotherapy sessions. Only 1 participant admitted suppression of cough or reduced exercise as a response to incontinence. Limitation of fluid intake was reported by a minority (16%), and none specifically reduced intake of caffeine-containing beverages. Only 1 adolescent used sanitary napkins to manage incontinence.

Most respondents reported that their incontinence did not affect their daily life. Seven (37%) adolescents reported that their social life was affected "a little bit" (see question 17 of questionnaire for scale). Family life, holidays, school life, hobbies, and intimate relationships were affected "a little bit" in a small number of respondents (10%–20% for each). Greater impact was reported by only 1 adolescent, who had daily incontinence and said that her school life was affected "a fair bit."

Forty-two percent of adolescents with incontinence had not told anyone about the problem, including their parents. Only 2 adolescents (11%) had discussed the problem with a physician; another 2 had told their CF physiotherapist but not their doctor. Half of those affected (53%) did not know that treatment is available for urinary incontinence, and 16 (84%) of 19 had not received any treatment. Two of the 3 adolescents who reported that they had received treatment had undertaken pelvic floor exercises without specific training or discussion with a physiotherapist or a physician. Only the adolescent with primary incontinence had been referred for specialist investigation and treatment.

The mothers of 51 participants (93%) were interviewed separately. Twenty (39%) said that they did not know whether their daughter experienced urinary incontinence. Of this group, 9 (45%) of 20 daughters were incontinent 1 to 2 times per year or more, and 5 (25%) of 20 experienced incontinence 2 to 4 times per month or more. Eight mothers re-

ported that their daughter experienced incontinence at least once or twice a year, and these mothers accurately estimated the frequency of incontinence when compared with their daughter's report (the same or adjacent points on the frequency scale; see questionnaire). Twenty-three mothers (45%) said that their daughter never or very rarely experienced incontinence. Again, this was correct in most cases, although 2 adolescents in this group reported incontinence once a week or more.

DISCUSSION

Urinary incontinence is a common symptom in female adolescents with CF. In this population, 22% reported 2 or more episodes of daytime incontinence per month. It was reported to have mild but significant effects on daily life in up to one third of those affected, with reports of a negative impact on physiotherapy being a particular concern. Mothers were frequently not aware that their daughter experienced incontinence. Urinary incontinence was not usually reported to the adolescent's physician, and most adolescents were not aware that treatment is available for the condition.

This prevalence of incontinence is very much higher than reports of urinary incontinence in healthy young people. Questionnaire surveys in England² and New Zealand⁷ have reported urinary incontinence twice or more per month in 4% to 5% of women younger than 25 years. A large study of a Swedish cohort reported that 3.6% of 17-year-old girls experienced daytime incontinence.

Three recently published studies have examined urinary incontinence in largely adult populations of women with CF.^{13,14} An Australian study reported a prevalence of incontinence of 38% in 29 women aged 18 to 44 years.¹² The number of respondents who reported incontinence twice a month or more in our study (22%) is comparable with the rate of 24% described in that study. A study of 176 Italian women aged 15 to 41.5 years found an overall prevalence of 59%, with 24% experiencing incontinence twice or more a month for at least 2 consecutive months,¹³ also consistent with the findings of the current study. The other study, of 75 British women with CF aged 16 to 52 years, described a prevalence of 68%, including 64% of those aged 16 to 20 years.¹⁴ These studies all include adult women with CF, some of whom have other risk factors, such as parity. The present study highlights that despite being nulliparous, the rate of incontinence is also very high in adolescents with CF.

We used an interviewer-administered questionnaire (in contrast to the anonymous questionnaires in the adult studies) as we wanted to ensure that participants fully understood the questions and to promote a high participation rate. Despite our best efforts to put the participants at ease, embarrassment may have led to underreporting of the symptoms and the effect of incontinence on daily life. The prevalence that we report here and the reported impact may therefore underestimate the true problem.

Our results are consistent with the finding of published studies in adults with CF that incontinence is

usually of small volume.^{12–14} These adult CF studies similarly report that only a minority of respondents believed that their daily lives were significantly influenced by incontinence. It is not clear why girls and women with CF report such a modest impact on their daily life when studies of large populations of adult women with incontinence demonstrate considerable impact on activities and high levels of distress.^{15–17,22} That incontinence was usually of small volume may be important, although the relationship between the severity or frequency of incontinence and the impact on daily life is not straightforward.^{16,22} Stress incontinence, as experienced by adolescents in this population, may also have less social impact than urge incontinence, which may be more unpredictable,^{18,19} although coughing “fits” were the major precipitant and are by no means predictable. The threshold for complaint may be different in this group, with the effect of mild incontinence being overshadowed by the impact of CF on daily life.¹⁴

Failure of the pelvic floor muscles to contract adequately enough to counter increases in abdominal pressure (and thus intravesical pressure) caused by certain activities is thought to be responsible for stress incontinence. Contraction of abdominal muscles during coughing leads to a rapid rise in intra-abdominal pressure, and it has been previously described that people with chronic lung disease are at higher risk of developing urinary incontinence.³ In this study, we examined several additional factors that might contribute to the development of urinary incontinence in this population: age, body mass index (both obesity and a severely reduced muscle mass are risk factors), severity of lung disease,¹³ diabetes, constipation, and menarchal status. None of these factors was identified as being associated with incontinence. A potential explanation for this lack of association is that cough itself is responsible. Coughing is frequently a feature of CF from a young age, even before a decline in forced expiratory volume in 1 second, and also occurs as part of daily airway clearance techniques. We believe that repeated coughing is the most likely explanation for the high rate of incontinence described and the lack of a demonstrable relationship with the severity of lung disease.

Regular performance of airway clearance techniques is a central component of the treatment regimen in CF and important to the maintenance of lung health.²³ It is of considerable concern that nearly half of those who experience incontinence in this population reported a significant negative impact on their performance of chest physiotherapy. As some of the questionnaires were administered by a physiotherapist, these participants may have underreported the effect of incontinence on physiotherapy. The true impact may be even higher. The prognostic implications of this are not known, and this cross-sectional study is unable to determine any effect of incontinence on the progression of disease. However, the differential survival of men and women with CF is known to date from early adolescence.²⁴ Given our lack of explanation for this differential, measures to

promote fully effective participation in airway clearance techniques should be a priority for girls. This may include the suggestion to use absorptive panty liners designed for urinary leakage for short-term (exacerbation-related) or small-volume incontinence or training in the simultaneous contraction of pelvic floor muscles during coughing.¹³ Additional studies are needed to evaluate treatment of incontinence in this population. Education and prevention strategies may also play an important role.

Our population is not unique in the low rate of reporting of urinary symptoms to doctors.^{2,16} Embarrassment and lack of knowledge of treatment options may have played a role in underreporting, as in other populations and other aspects of CF.^{13,14,16,25,26} However, we are particularly concerned about the lack of reporting in this population because of the high proportion of respondents who said that incontinence affected their performance of chest physiotherapy. Adolescents should be questioned about the problem directly, particularly as this study highlights that the mothers of adolescents are often not aware of their daughter’s incontinence.

CONCLUSION

Urinary incontinence is a common and underreported problem in female adolescents with CF that is unrelated to the severity of respiratory disease. It has the capacity to have a significant impact on the performance of chest physiotherapy and exercise with potential ramifications for long-term lung health and ultimately prognosis. Specific assessment of urinary incontinence should be part of the routine assessment of women with CF, including adolescents.

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Appendix 1. Interviewer-Administered Questionnaire

THE STRESS INCONTINENCE STUDY QUESTIONNAIRE

Date completed:

1. Name:
2. Date of birth: Age:
3. Weight: Height:
4. Number of admissions (longer than 4 days) for respiratory exacerbations in the past 12 months: _____
5. Best FEV₁ % predicted in past 6 months: _____
Best FVC % predicted in past 6 months: _____
6. Form of physiotherapy (tick as many as apply that are used >1 times/week):

		How often/week?
Exercise (what sort?)	<input type="checkbox"/>	_____
PEP/Flutter	<input type="checkbox"/>	_____
Percussion	<input type="checkbox"/>	_____
Musical instruments	<input type="checkbox"/>	_____
Other _____		_____

7. Please list all the medication you take for CF and other reasons.
8. How many times do you pass urine during the day?
 - less than 4 times
 - 4-6 times
 - 7-10 times
 - more than 10 times
9. How many times do you pass urine during the night?
 - 0-1 times
 - 2-4 times
 - more than 4 times
10. If you need to go to the toilet to pass urine, how long can you hold on?
 - 0-1 Minutes
 - 1-5 minutes
 - 5-10 minutes
 - more than 10 minutes
11. Have you ever accidentally passed urine during the day? Yes No

If the answer to question 11 was NO, please go to question 23.

If the answer to question 11 was YES, please answer the remaining questions.

12. How often do you wet or leak urine?

- | | | |
|--------------------------|--------------------------|-----------------------|
| More than once a day | <input type="checkbox"/> | How many times? _____ |
| Once a day | <input type="checkbox"/> | |
| 2-4 times a week | <input type="checkbox"/> | |
| Once a week | <input type="checkbox"/> | |
| 2-4 times a month | <input type="checkbox"/> | |
| Once a month | <input type="checkbox"/> | |
| 1-2 times a year or less | <input type="checkbox"/> | |
| Very rarely | <input type="checkbox"/> | |
| Never | <input type="checkbox"/> | |

If "never" or "very rarely", please go to question 23.

13. How old were you when you first had this problem? _____ years

14. How much urine do you leak?

- | | |
|---------------------|--------------------------|
| Damp / a few drops | <input type="checkbox"/> |
| Wet/ a small amount | <input type="checkbox"/> |
| Quite wet (cupful) | <input type="checkbox"/> |
| Very wet (floods) | <input type="checkbox"/> |

15. Do you ever need to go to the toilet and leak urine on the way to the toilet?

- Yes No

16. What activities have caused it? (tick as many as apply to you)

- | | | | |
|----------------------|--------------------------|-----------------------------------|--------------------------|
| Bad coughing fits | <input type="checkbox"/> | Lifting things | <input type="checkbox"/> |
| Any coughing | <input type="checkbox"/> | Running/jumping/physical activity | <input type="checkbox"/> |
| Laughing | <input type="checkbox"/> | Change in position e.g. stand up | <input type="checkbox"/> |
| Sneezing | <input type="checkbox"/> | Seems to happen for no reason | <input type="checkbox"/> |
| During physiotherapy | <input type="checkbox"/> | Uncertain which activities | <input type="checkbox"/> |

17. Does your bladder problem affect your...? (please write n/a if not applicable)

	Not at all	A little bit	A fair bit	A lot	Most of the time
Holidays	<input type="checkbox"/>				
Family life	<input type="checkbox"/>				
Social life	<input type="checkbox"/>				
School or work	<input type="checkbox"/>				
Interests/hobbies	<input type="checkbox"/>				
Intimate relationships	<input type="checkbox"/>				

18. Does your bladder problem prevent you from coughing effectively e.g. doing full physiotherapy?

- Never
- Sometimes
- About half the time
- Most of the time
- Always

19. In what way have you changed your activities because of this problem? (tick as many as apply to you)

- Going to the toilet more often
- Always going to the toilet before physio
- Doing less physio/ trying to cough less
- Doing less exercise
- Only visiting places where you know there is a toilet
- Reducing caffeine-containing drinks (coffee/tea, Coke, etc)
- Reducing fluid intake
- Use sanitary pads
- Other ways _____
- None of the above

20. Have you spoken to anyone about this problem? Who? (tick as many as apply to you)

- | | |
|---|--|
| No-one (except you) <input type="checkbox"/> | Friends with CF <input type="checkbox"/> |
| Your mother <input type="checkbox"/> | Your CF doctor <input type="checkbox"/> |
| Your father <input type="checkbox"/> | Your family doctor (GP) <input type="checkbox"/> |
| Other family members <input type="checkbox"/> | Your physio <input type="checkbox"/> |
| Friends <input type="checkbox"/> | Another member of the CF team <input type="checkbox"/> |

21. Do you know that treatment is available for this problem?

Yes No

22. Have you received any treatment for this problem?

Pelvic floor exercises training

Referral to a specialist (gynaecologist/urologist etc)

Medication

Other _____

None

The last few questions will help us understand who might be at risk of developing stress incontinence.

23. How old were you when you started having periods?

_____ years Haven't started yet

24. Do you have CF-related diabetes? Yes

No

25. Do you have a gastrostomy? Yes

No

About how many nights a week do you use it? _____

26. Do you suffer from constipation and/or push or strain to empty your bowels?

Never

Occasionally

Sometimes

A fair bit

Most of the time

Always

27. Lastly, do you have any other comments about any of the issues raised in this questionnaire?

Thank you very much for your time

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