



## Racial Differences in Self-Reported Healthcare Seeking and Treatment for Urinary Incontinence in Community-Dwelling Women From the EPI Study

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**Aims:** Objectives of this study are: (1) to examine the prevalence of healthcare seeking among black and white women with self-reported urinary incontinence (UI), (2) to investigate barriers to treatment for incontinence, and (3) To investigate commonly used therapeutic modalities for UI. **Methods:** This is a planned secondary analysis of responses from 2,812 black and white community-dwelling women living in southeastern Michigan, aged 35–64 years, who completed a telephone interview concerning UI, healthcare-seeking behaviors and management strategies. The study population was 571 subjects (278 black, 293 white) who self-identified as having urinary incontinence. **Results:** Of these women with UI, 51% sought healthcare with no statistically significant difference between the two races (53% black, 50.6% white,  $P = 0.64$ ). In multivariate logistic regression analysis, a higher likelihood of seeking healthcare was associated with increased age, body mass index lower than  $30 \text{ kg/m}^2$ , prior surgery for UI, having regular pelvic exams, having a doctor, and worsening severity of UI. There was no significant association between hypothesized barriers to care seeking and race. Almost 95% of the subjects identified lack of knowledge of available treatments as one barrier. Black and white women were similar in percentage use of medications and some self-care strategies, for example, pad wearing and bathroom mapping, but black women were significantly more likely to restrict fluid intake than white women and marginally less likely to perform Kegels. **Conclusions:** Black and white women seek healthcare for UI at similar, low rates. Improved patient-doctor relationships and public education may foster healthcare seeking behavior. *Neurourol. Urodynam.* 30:1442–1447, 2011. © 2011 Wiley Periodicals, Inc.

**Key words:** bladder control; coping strategies; fluid intake; health knowledge; healthcare treatment; Kegel exercises; obesity; population study; treatment barriers; treatment seeking

### INTRODUCTION

Urinary incontinence (UI) is the most prevalent pelvic floor disorder, affecting up to half of all women.<sup>1–5</sup> UI leads to more than \$12 billion in annual costs,<sup>6</sup> and results in social ostracism and suffering.<sup>7</sup>

Epidemiologic data on UI has historically been gathered primarily from white women.<sup>4,8</sup> Recently, however, studies have shown racial differences in incontinence characteristics and treatment patterns.<sup>9–16</sup> These studies indicate that there are indeed differences in the physiologic continence mechanisms, bladder care habits, and the prevalence and types of UI experienced by different racial groups. However, there is still little understanding about how race influences healthcare seeking or how women cope with urinary leakage.<sup>12</sup>

The aims of this study are to investigate the prevalence of, and to identify racial differences in healthcare seeking behaviors in women with self-reported UI from a population-based sample of black and white community-dwelling women. We also examined factors associated with healthcare seeking and potential barriers to seeking care within these populations. Finally, we explored rates of utilization of common self-care management strategies or healthcare treatment modalities for UI.

### MATERIALS AND METHODS

#### Study Sample

The Establishing the Prevalence of Incontinence (EPI) Study was conducted at the University of Michigan with the

primary focus of examining racial differences between white and black women in UI prevalence, type, and risk factors with adequate representation of black women.<sup>14</sup> Briefly, this study collected data from community-dwelling black and white women aged 35–64 years via telephone interviews by trained female professional telephone interviewers from the Survey Research Center of the University of Michigan Institute for Social Research. Households were identified through purchased telephone records from areas of known racial composition in southeastern Michigan in order to adequately sample both racial groups. Women were considered eligible participants if they self-identified as either white or black, were 35–64 years of age and had not been pregnant in the previous 12 months. The protocol for the sampling of the population and the questionnaire survey has been described previously.<sup>14</sup> The research protocol was approved by the institutional review board of the University of Michigan Medical School (IRB 2000-0824).

Linda Brubaker led the review process.

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### Data Collection

The telephone interview consisted of questions regarding demographics and health and lifestyle factors. Overall, 892 white and 1922 black women completed the survey, yielding a 69% response rate. This is a secondary analysis of the 571 women (278 black and 293 white) who self-identified as having UI, defined as 12 or more episodes of involuntary urine loss in the prior 12 months, and also affirmed that they had ever had urinary loss or leakage that they had considered to be a problem since the age of 18 years old. These women were further queried about their urine loss, including items specific to stress UI or urge UI. Their type of incontinence was determined based on a 10-item questionnaire modified from the Medical, Epidemiologic, and Social Aspects of Aging (MESA) questionnaire.<sup>17</sup> The severity of their incontinence was assessed with a modified Sandvik scale, as described previously.<sup>18</sup> All were asked, "Have you ever talked with a healthcare provider about having urine loss or leakage?" If the subject had sought healthcare for UI, she was then asked, "Did the healthcare provider recommend or prescribe anything for the urine loss?" If the subject had not sought healthcare, she was asked, "What are the main reasons that you never talked with a healthcare provider about having urine loss or leakage?" and was provided with six possible reasons, from which each subject could select any or all that applied, including "Doctor never asked; Too embarrassed; Didn't think anything could be done, Can't afford doctor/no health insurance; Afraid of doctors, surgery, medications, etc.; and Other (specify)." All of the subjects, regardless of whether they had spoken to a healthcare provider, were asked to, "Please tell me all of the things you are now doing to control or manage urine loss," followed by a set of incontinence self-care and/or treatment management strategies including, "Take medication; Do Kegels; Locate bathroom immediately; Toilet regularly; Restrict fluids; Avoid certain foods or beverages; Avoid certain exercises or physical activities; Wear pads or other protection; Other (specify); and Do nothing." Again, each subject could select multiple strategies if they were applicable.

### Data Analysis

Distributions of categorical variables were compared using Chi-square tests. Variables found to be statistically significant were included in a multivariable logistic regression model predicting healthcare seeking for UI. Reasons for not seeking healthcare for UI, and management strategies for self-care of UI, were compared by race using Chi-square test. All statistical analyses were performed with SAS software (version 9.1; SAS Institute, Cary, NC). All data have been weighted to represent the population from which the sample was taken, as previously described.<sup>14</sup>

## RESULTS

Characteristics of the study population have been published previously.<sup>14,18</sup> For the women in this secondary analysis with self-reported UI, 51% of the subjects reported ever seeking healthcare for UI, and this did not differ significantly by race (53.0% black vs. 50.6% white subjects,  $P = 0.64$ ). Demographic, health and lifestyle factors showing associations with healthcare seeking behavior are presented in Table I (including factors with marginal  $P$  values). Other demographic and health/life factors not associated with healthcare seeking include currently working for pay, needing to wait for scheduled breaks to use the bathroom while at work, income level, marital

status, diabetes, mobility impairment, chronic lung disease, depression, self-reported health, type of UI, nocturia or nocturnal enuresis, pain with a full bladder, fecal incontinence, constipation, history of a vaginal delivery, menopausal status, or performing breast self-examinations (data not shown).

Associations between healthcare seeking and these demographic, lifestyle and health history factors were next examined within each racial group. For white women, the characteristics that were significantly associated with healthcare seeking were the same as those for the entire study population, with the addition of less healthcare seeking by women with pure stress urinary incontinence (44.6%,  $P = 0.04$ ). Within the black cohort, however, the only characteristics significantly associated with healthcare seeking were having regular pelvic exams (58.0%,  $P = 0.03$ ) and performing breast self-examinations (58.7%,  $P = 0.08$ ).

Multivariate logistic regression analysis was then performed to evaluate healthcare seeking for UI, with the model generated from all demographic characteristics initially found to be significantly associated with healthcare seeking in bivariate analysis within the overall study population. The final model contains seven variables, including age, obesity, prior surgery for pelvic organ prolapse or UI, having regular pelvic exams, having an established relationship with a healthcare provider, and severity of UI (stratified as mild vs. severe and moderate vs. severe). The odds ratios for healthcare seeking adjusted for these variables are shown in Table II.

TABLE I. Demographic, Health History and Healthcare Seeking Behavior Characteristics Associated With Healthcare Seeking for Urinary Incontinence

Characteristic	% Respondents seeking healthcare for urinary incontinence (N = 571)	P-Value
Demographics		
Age (years)		0.0002
35-44	38.3	
45-54	54.3	
55-64	59.6	
Education (years completed)		0.07
<12	33.1	
12	46.7	
13-15	51.8	
≥16	56.0	
Health history		
Urinary tract infection	60.1	0.06
Obesity (BMI ≥30 kg/m <sup>2</sup> )	44.3	0.0006
Sandvik score		<0.0001
Mild	38.1	
Moderate	39.4	
Severe	59.2	
Obstetric/gynecologic history		
Current estrogen use	63.2	0.02
Prior surgery for prolapse or UI	83.3	0.0008
Prior hysterectomy	57.6	0.08
Health treatment/seeking behaviors		
Regular pelvic exams	57.3	<0.001
Have a regular doctor	53.5	<0.0001

Data are reported as percentage of subjects. For multinomial distributions, the  $P$  values test the null hypothesis that the percentage of subjects who seek healthcare is the same for all listed levels of the independent variables. For dichotomous independent variables, the  $P$  values test the null hypothesis that the subjects with the behavior or condition do not differ from respondents who do not have the characteristic. BMI, body mass index; UI, urinary incontinence.

TABLE II. Results of Multivariable Logistic Regression Model Predicting Healthcare Seeking Behavior

Independent characteristic	Odds ratio point estimate	95% CI
Age	1.054	1.028–1.081
Obesity (BMI $\geq 30$ kg/m <sup>2</sup> )	0.421	0.284–0.624
Prior surgery for POP or UI	3.675	1.188–11.370
Have regular pelvic exams	4.260	2.529–7.176
Have a doctor	3.690	1.489–9.149
Sandvik score–severe (referent)	1.0	—
Sandvik score–mild vs. severe	0.398	0.221–0.715
Sandvik score–moderate vs. severe	0.367	0.236–0.570

CI, confidence interval; BMI, body mass index; POP, pelvic organ prolapse; UI, urinary incontinence.

The women who complained of having bothersome UI but who had not sought healthcare were asked about specific reasons for not talking to a healthcare provider (Table III). No statistically significant differences were observed between black and white women.

All of the women, whether or not they had seen a healthcare provider, were asked about specific strategies that they were using for self-care or treatment of their UI (Table IVa). The only strategies suggesting differences between the black and white women was fluid restriction, which was used nearly twice as often by black women than white women ( $P = 0.01$ ), and black women used Kegel exercises two-thirds as often as white women ( $P = 0.07$ ). By contrast, when we examined the management strategies used only by women who had seen a healthcare provider regarding UI, avoidance of certain exercises or physical activities was used significantly more by black women as compared to white subjects (Table IVb). Racial differences by use of fluid restriction and Kegel exercises continued to be significant showing proportionately approximately the same split between black and white women as that shown for the total sample (Table IVb).

### DISCUSSION

There are important differences in the prevalence and types of UI experienced by different racial/ethnic groups.<sup>1,3,5,9,11,14,19,20</sup> The higher rates of UI seen in white women as compared to black women can be partially explained by differences previously reported in urethral function and in intake/output patterns.<sup>15,16,19,21</sup> These biological and habit variances represent only a limited understanding of the observed differences of UI by different racial groups. Psychocultural responses to incontinence play important roles in mediating how different groups adapt their lifestyles and behaviors to the loss of urine.<sup>22</sup>

We find that only approximately half of our subjects had ever sought healthcare for UI. These results are similar to those seen in other large surveys of ethnically diverse populations,<sup>8,10,12,23</sup> as well as in more homogeneous populations.<sup>24–27</sup> These data suggest that a large portion of women may be needlessly suffering with UI.

Racial differences in rates of healthcare seeking were not identified amongst our study population. This is similar to what has been seen in two other large surveys of ethnically diverse populations.<sup>10,12</sup> The lack of an effect of race on health-seeking persists despite variations in data collection methodologies (telephone interviews in our study as compared to in-person interviews in the subjects' homes in the other studies) and geographic locations between the studies, suggesting that this finding may be applicable to a wide swath of the US population.

We identify several demographic characteristics associated with healthcare seeking behaviors that have also been confirmed in other large studies, including increasing age, worsening severity of UI, and regular access to healthcare.<sup>8,12</sup> Analyses within racial groups do highlight differences in factors associated with healthcare seeking. Notably, we were only able to identify two such characteristics for black women—having regular pelvic exams and performing breast self-examinations. These two factors certainly suggest that regular access to healthcare providers and active participation in health maintenance are associated with a higher likelihood of healthcare seeking for UI. Interestingly, breast self-examination was only associated with healthcare seeking amongst black women, but not for the overall study population or white women in our study cohort.

Our study was underpowered to detect significant associations between healthcare seeking and several of these factors in black women, including current estrogen usage, prior surgery for pelvic organ prolapse or UI, and history of a hysterectomy. However, it is not clear why other characteristics, such as age, education, urinary tract infection in the past year or UI severity, associate differently with healthcare seeking between white and black women. To our knowledge, this is the first study to present within-racial group analyses of factors associated with healthcare seeking for UI between black and white women. As such, these differences represent an important area for further research.

The type of UI (stress, urge or mixed UI) was not significantly associated with healthcare seeking within the entire study cohort, despite the fact that mixed UI is more bothersome than pure urge or stress UI alone,<sup>18,28,29</sup> and that both urge and mixed incontinence more adversely affect quality of life than pure stress incontinence.<sup>30</sup> Others have similarly shown that type of incontinence is not associated with healthcare seeking,<sup>8,31</sup> despite these differences in effects on quality

TABLE III. Percentage of Subjects Endorsing Specific Reasons for not Seeking Healthcare for UI

Reason for not seeking care	Total % (N = 258)	Black % (N = 127)	White % (N = 131)	P-Value
Doctor never asked	9.1	6.5	9.7	0.47
Too embarrassed	8.8	9.2	8.6	0.89
Did not think anything could be done	94.2	93.7	94.4	0.85
Cannot afford doctor/no health insurance	7.6	4.3	8.4	0.32
Afraid of doctors, surgery, medications, etc.	2.8	2.5	2.9	0.88
Other	81.7	87.1	80.9	0.23

Data are weighted to reflect the complex sampling design to project the sample to the population. *P* values test the null hypothesis that there is no difference between black and white women.

TABLE IVa. All Subjects Were Queried About Self-Care Management and Treatment Strategies Used for UI

Management strategy	Total % (N = 571)	Black % (N = 278)	White % (N = 293)	P-Value
Take medications	8.5	9.0	8.4	0.84
Do Kegels	21.2	14.9	22.8	<b>0.07</b>
Locate bathroom immediately	12.3	14.3	11.8	0.47
Toilet regularly	39.1	38.1	39.3	0.82
Restrict fluids	12.0	18.7	10.3	<b>0.01</b>
Avoid certain foods or beverages	5.8	8.6	5.1	0.15
Avoid certain exercises or physical activities	2.7	4.9	2.1	0.10
Wear pads or other protection	59.2	60.8	58.8	0.70
Other	21.0	23.7	20.4	0.44
Do nothing	8.7	8.3	8.8	0.86

Data are reported as percentage of subjects using each strategy, weighted to reflect the complex sampling design used to project the subject sample to the population. *P* values test the null hypothesis that there is no difference between black and white subjects.

Significant *P* values are highlighted in bold font.

TABLE IVb. Racial Differences in Self-Care Management and Treatment Strategies Used Only by Women Who Had Sought Healthcare for UI

Management strategy	Total % (N = 290)	Black % (N = 147)	White % (N = 143)	P-Value
Take medications	16.5	15.7	16.7	0.85
Do Kegels	29.4	20.5	31.8	<b>0.09</b>
Locate bathroom immediately	12.6	15.8	11.7	0.39
Toilet regularly	35.7	39.0	34.8	0.54
Restrict fluids	15.3	25.3	12.7	<b>0.02</b>
Avoid certain foods or beverages	7.4	10.9	6.4	0.23
Avoid certain exercises or physical activities	1.9	6.6	0.6	<b>0.002</b>
Wear pads or other protection	60.8	61.7	60.5	0.87
Other	25.0	26.6	24.5	0.75
Do nothing	5.3	5.7	5.2	0.86

Data are reported as percentage of subjects, weighted to reflect the complex sampling design projecting the recruited subjects to the population. *P* values test the null hypothesis that there is no difference between black and white subjects.

of life. This seemingly anomalous finding represents an interesting and important area for future research.

In within-racial-group analysis, there is no significant association between SUI and healthcare seeking in black women, whereas white women with SUI are less likely to seek care than those without SUI. This finding is somewhat surprising given that black and white women were found to be similarly bothered by SUI.<sup>18</sup> This finding likely stems from the fact that pure SUI is much less common in black than white women, and as such, our study was underpowered to identify a relationship between healthcare seeking and pure SUI in black women. We speculate that white women with SUI are less likely to seek healthcare due to their UI as they are able to compensate through usage of modalities such as Kegel exercises (Tables IVa and IVb).

We find that obese women are less likely to seek healthcare for UI than non-obese women. We would a priori expect the opposite given that obesity has consistently been shown to be an independent risk factor for UI,<sup>32,33</sup> and obesity is generally associated with increased overall healthcare utilization and cost.<sup>34,35</sup> However, decreased utilization of other healthcare provisions by obese women have been similarly reported, such as for cervical cancer screening.<sup>36,37</sup> It is also interesting that an inverse relationship between healthcare seeking and

obesity held for our overall study population and white women, but there was no statistically significant relationship between obesity and healthcare seeking for black women. Similar findings have been reported for other healthcare seeking behaviors, such as colorectal cancer screening<sup>38</sup> and mammography.<sup>39</sup>

We did not identify any racial differences in reasons for not seeking healthcare. The subjects in our study generally reported multiple reasons for not seeking healthcare. Given that our subject sample was population-based, it is possible that socioeconomic status and/or lack of medical insurance might represent barriers to access to care. However, less than 10% of our subjects reported that economic constraints inhibited their healthcare-seeking behaviors, consistent with the findings of a similar large, population-based survey of healthcare seeking for UI.<sup>12</sup>

Approximately 10% of our subjects also indicated that they had not sought healthcare, at least in part, because a doctor had never asked about incontinence. It is often suggested that physicians need to inquire about UI as many patients may not volunteer information about this topic. The impact of healthcare providers simply inquiring about a subject has certainly been shown to be effective, for example, with smoking cessation.<sup>40</sup> Similarly, it has been documented that negative

physician–patient interactions can adversely affect treatment seeking for UI.<sup>41,42</sup> Our data therefore suggest that rates of treatment for UI may improve if providers were to simply ask women about urinary leakage.

The most commonly reported reason for not seeking healthcare was a belief that nothing could be done to help with UI. Other studies have similarly shown that subjects with UI feel, at least to some degree, that it is not worth seeking help from a healthcare provider for UI because there are no effective treatments.<sup>25,43–45</sup> However, a larger proportion of the subjects in our study expressed this sentiment as compared to the rates published in earlier reports. It is unknown if this is due to differences, for example, in subject sampling variation, population bases, declining public knowledge about incontinence, or other factors. It is nonetheless suggested that campaigns designed to educate women about UI and available therapies may be beneficial in improving healthcare seeking and treatment.

Of the women who sought healthcare, 64% expressed that something was recommended or prescribed, with no statistically significant difference in this response between the two racial groups (55% black subjects, 66% white subjects,  $P = 0.12$ ). We similarly find few significant racial differences in coping strategies used by the subjects to manage their incontinence. It is interesting that amongst women who have sought care from a provider, avoidance of exercise or physical activity is significantly more common in black subjects as compared to white subjects, especially as stress UI is more prevalent in white subjects.<sup>14</sup> It is unknown at this time if the differences in self-care management and treatment strategies used by those who have sought healthcare and those who have not are due to information/recommendations provided by their providers or for other reasons.

Strengths of the EPI study include its population-based sample, large sample size, broad age range, and high response rate. Several limitations of the study should also be considered. This analysis was based on self-reported UI data rather than on clinical/urodynamic evaluations or voiding diaries, thus introducing potential recall bias. All of the subjects volunteered to take part in the study through telephone requests, so volunteer bias may be present. This survey, like many other similar studies, only included women who had UI in the previous 12 months, whereas healthcare seeking behaviors were determined based on any experience in the subjects' past. As such, women who may have been successfully treated in the past and no longer leak urine would be excluded from our study pool, resulting in a potentially decreased estimate of the prevalence of healthcare seeking. Our study design defined urinary incontinence as having at least 12 episodes of involuntary urinary leakage during the previous 12 months, whereas other studies use different inclusion criteria, thus potentially limiting the ability to compare our results to others in the literature. The subjects in our study were geographically limited to southeastern Michigan, and only included black and white women, so the results may not be generalizable to other populations.

### CONCLUSIONS

Despite high prevalence and bother, only about one-half of women in our study sought healthcare for UI. Black and white women seek healthcare for UI at similar frequencies, but within each group there are unique demographic and health-history characteristics that predict this behavior. The two racial groups also use self-care management and treatment strategies somewhat differently. The vast majority of women

who do not seek healthcare for UI believe, at least in part, that there are no available treatments. Improving relationships between providers and patients, and educating the public about incontinence and treatment options are two factors which are likely to reduce the burden of this prevalent disorder.

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