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Women with Diabetes: Understanding Urinary Incontinence and Help Seeking Behavior

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Abstract

Purpose—To examine the association of urinary incontinence by diabetes status and race and evaluate beliefs and help-seeking around incontinence in a population-based cohort of women with and without diabetes.

Materials and Methods—We performed a cross-sectional analysis of 2,270 middle-aged and older racially/ethnically diverse women in Diabetes RRISK. Incontinence, help-seeking behavior, and beliefs were assessed by self-report questionnaires and in-person interviews. Incontinence characteristics of diabetics and non-diabetics were compared using univariate analysis and multivariate models.

Results—Women with diabetes reported weekly incontinence significantly more than women without diabetes (Weekly: 35.4% vs. 25.7%, respectively, $p < 0.001$). Race prevalence patterns were similar (white and Latina women with the most prevalent incontinence and African-American and Asian women with the least) among women with and without diabetes. Less than 50% of women with diabetes discussed their incontinence with a doctor (42.2% vs. 55.5% (of women without diabetes) $p < 0.003$). Women with diabetes were more likely than women without diabetes to report believing that incontinence is a rare condition (17% vs. 6%, respectively, $p < 0.001$).

Conclusions—Incontinence is highly prevalent among women with diabetes. Race prevalence patterns are similar among women with and without diabetes. Understanding help-seeking behaviors are important to ensure appropriate care for patients. Physicians should be alert for urinary incontinence because it is often unrecognized and thereby under-treated among women with diabetes.

Keywords

urinary incontinence; diabetes mellitus; attitude to health

Introduction

Diabetes and urinary incontinence are common health problems in older women which have major quality of life and public health implications^{1–3}. Multiple population-based and large epidemiologic studies have linked these two disorders demonstrating higher prevalent and incident urinary incontinence among women with diabetes compared to women without diabetes^{4–7}. In these studies, after adjusting for other common risk factors for incontinence such as age, body mass index, and parity, diabetes remained a significant independent risk factor for incontinence⁸.

Despite studies demonstrating a reproducible increased prevalence and incidence of urinary incontinence among white women with diabetes, there is limited understanding of incontinence prevalence among other racial groups with diabetes. Race/ethnicity may play a more complicated role among women with diabetes, as African-Americans and Latinos, are more than twice as likely to have diabetes than whites of a similar age². However, African-American women have a 3–4 fold decreased risk of incontinence despite a higher risk of diabetes and obesity, both independent risk factors for incontinence⁹.

It has been estimated that incontinence is more prevalent than complications commonly associated with diabetes, such as retinopathy, nephropathy, and neuropathy^{8, 10}, however, there have been limited studies of incontinence care seeking and beliefs specific to women with diabetes^{11, 12}. Among women without diabetes, a number of studies have documented few women seek care¹³. Common reasons include lack of knowledge about the condition and available treatments, embarrassment, and not discussing their incontinence with others^{14–17}. A further understanding of barriers to care among women with diabetes may lead to interventions that improve help seeking behavior for this commonly under diagnosed and under treated disease^{7, 10}.

In this study, we examined help seeking and beliefs about incontinence among middle aged and older women with and without diabetes, using the Diabetes Reproductive Risk factors for Incontinence Study at Kaiser (Diabetes RRISK).

Materials & Methods

From October 1999 through February 2003, 2109 community-dwelling women aged 40–69 were enrolled in the Reproductive Risks for Incontinence Study at Kaiser (RRISK), a population-based, racially diverse cohort of middle-aged and older women. Sampling methods for RRISK were previously described⁹.

Briefly, the RRISK included randomly selected women that were members of Kaiser Permanente Medical Care Program of Northern California (KPMCP). Previous studies have found KPMCP members to under represent the very poor and the very wealthy and to be slightly more educated compared to the general population in the same geographic area, but to be very similar with respect to other demographic characteristics¹⁸.

The Diabetes RRISK is an expansion of the RRISK cohort to evaluate the impact of diabetes on urinary tract function. From Oct 2004 to February 2008, of the 2109 women from the original RRISK cohort, 1413 (67%) participated in Diabetes RRISK. In addition to 106 women in original RRISK cohort that had diabetes, 55 women were identified as having diabetes at the time of the Diabetes RRISK cohort. To maintain a cohort of approximately 2000 participants and to increase the group of women with diabetes, additional women with and without diabetes were identified from the original RRISK membership files. To preserve RRISK sampling, women who met the same enrollment criteria were invited. The Diabetes RRISK cross-sectional study is composed of 1784 women without diabetes and 486 women with diabetes. The Diabetes RRISK was approved by the institutional review (human subjects) boards of the University of California, San Francisco and Kaiser Division of Research.

Demographic characteristics, medical and surgical history, and medication use were assessed by self-administered questionnaires as well as in-person interviews. Race/ethnicity was assessed by asking women to self-identify as non-Latina white, Latina/Hispanic, African-American/Black, Asian, or other. Women were considered postmenopausal if they had not had a natural menstrual period in at least 12 months. Overall health status was self-reported through a standard single-item measure in which participants rated their overall health as “excellent,”

“very good,” “good,” “fair,” or “poor”. Weight was measured at the interview and used to calculate body mass index (BMI) in kg/m².

Urinary Incontinence

Urinary incontinence was assessed by asking a series of detailed questions modified from other epidemiologic studies⁹. Women were asked “During the past 3 months, how often have you typically leaked urine, even a small amount?” Severity was determined using the validated Sandvik Severity score¹⁹. In efforts to maintain validity, interviewers reviewed answers to questions about incontinence, rephrasing and clarifying response inconsistencies.

We chose to investigate care-seeking and beliefs about incontinence among women with weekly or more frequent incontinence because weekly incontinence has been shown to be clinically significant and an important factor as to whether patients seek care^{11, 20}. These women were asked to answer supplemental questions to provide insight into their beliefs about incontinence, if they discussed incontinence with others or physicians, and why they did or did not choose to seek care.

Diabetes Definition

The Northern California Kaiser Permanente Diabetes Registry is a detailed database of all patients with diabetes in the Northern California region of Kaiser Permanente. New cases of diabetes are identified annually by active surveillance of automated databases for pharmacy (diabetes medications), laboratory (HbA1c $\geq$ 6.7%), and medical records listing a diagnosis of diabetes. The registry has been estimated to be 99% sensitive for diagnosed diabetes and have a 2% false positive rate²¹.

We classified women as having diabetes if they self reported a diabetes history and were in the Kaiser Diabetes Registry or had a fasting blood sugar $\geq$ 126 mg/dl. Women were classified as not having diabetes if they self reported no history of diabetes, were not taking a diabetes medication, were not in the Kaiser Diabetes Registry, and had a fasting blood sugar of $\leq$ 125 mg/dl. The cohort includes both type 1 and type 2 diabetics, in the same distribution as the general population.

Women with diabetes completed a supplemental self-reported questionnaire that included questions about their medications, years with diabetes, and self-reported complications of diabetes (retinopathy, nephropathy, peripheral neuropathy symptoms defined as experiencing symptoms of numbness in the feet or hands). The complications of diabetes were self-reported in a questionnaire that was reviewed by the interviewer and rephrased if necessary as to facilitate maximum understanding by the participant.

Statistical Analyses

Characteristics of the diabetes and no diabetes groups were compared using Chi-Square or Fisher’s exact tests as appropriate. Continuous variables were compared using t-tests or Wilcoxon rank-sum tests (Mann-Whitney test). Multilevel variables such as race were further compared for differences between levels if the overall p-value was significant²². Independent associations of incontinence with diabetes and race were examined using separate multivariable logistic regression models to control for incontinence risk factors including age, parity, BMI, hysterectomy status and urinary tract infections. Power analyses indicated that detecting incontinence differences between most race groups were well powered (>0.90 to detect observed effect sizes), with the exception of African Americans vs. Asians and whites vs. Latinas (0.31 and 0.11 respectively). However, power to detect previously reported adjusted diabetes odds ratios for incontinence among diabetics was poor (0.34). We considered p values $< .05$ as statistically significant. All analyses were performed with SAS version 9.2.

Results

Demographic characteristics of Diabetes RRISK are summarized in Table 1. The group with diabetes had 486 women, while the group without diabetes included 1784 women. Women with diabetes compared to women without diabetes were slightly older (mean 56 vs. 55 years, $p<0.01$), more were Latina (22% vs. 17%, $p=0.03$), obese (BMI >30 : 67% vs. 31%, $p<0.001$), and had poorer general health (self reported fair/poor health 22.5% vs. 5.7%, $p<0.001$). Among women with diabetes in the study, the mean ($\pm$ SD) years with diabetes were 10 ($\pm$ 8.8) years. Nearly 95% were being treated with either oral medication (62%) or insulin (33%). The women self-reported complications of diabetes including peripheral neuropathy, retinopathy, and nephropathy (Table 2).

Over half of the women with diabetes had monthly or greater incontinence and over one third reported weekly or greater incontinence, significantly more than women without Diabetes RRISK diabetes (Monthly or greater: 50.9% vs 40.3% $p<0.001$, Weekly or greater: 35.4% vs 24.7% $p<0.001$, respectively) (Table 3). Among women with any incontinence, women with diabetes were more likely to report severe incontinence than women with diabetes (25.7% vs. 16.7% $p<0.001$, respectively). Among women with weekly incontinence, over a quarter of women with diabetes reported significantly greater bother with nocturnal incontinence compared to women without diabetes (Quite a bit or extreme bother: 17.5% vs. 10.5%, $p=0.02$).

After adjusting for common risk factors, the odds ratio of incontinence for diabetics vs. non-diabetics was 1.18 [95% CI 0.92–1.50]. Several race differences in the multivariable analysis were significant, even with adjustment for diabetes status. Whites were more likely than African Americans and Asians to be incontinent (2.15 [1.62–2.86] and 1.58 [1.17–2.14] respectively). Latinas were more likely than African Americans and Asians to be incontinent (2.17 [1.56–3.01] and 1.59 [1.12–2.26], respectively).

Table 4 depicts help-seeking behaviors among women with weekly or greater incontinence by diabetes status. Women with diabetes were more likely to report that incontinence was a rare condition (17% vs. 6%, $p<0.001$) and that treatment does not fix the problem (15% vs. 8%, $p=0.01$). There were some commonly held beliefs among women with and without diabetes. Nearly three quarters of women believed incontinence was a normal part of aging as well as nearly half thought it was normal after childbirth. About 10% of women felt there was no treatment for incontinence, treatment is risky/or harmful, or treatment doesn't fix the problem.

Over 30% of women with diabetes never discussed their incontinence with others, significantly greater than women without diabetes (30.7% vs. 21.7% $p=0.02$, respectively). Women with diabetes were also less likely to discuss their incontinence with their spouse/partner (29% vs. 38% $p=0.03$). Less than 50% of women with diabetes discussed their incontinence with a doctor (37.4% vs. 52.5% $p<0.001$). Women had incontinence about 3–4 years prior to discussing the condition with a doctor (Table 4).

Reasons why women did or did not seek care by diabetes status are summarized in Table 5. Women with diabetes when compared to women without diabetes differed significantly in some reasons they sought care. Women with diabetes sought care because incontinence made them feel older (36% vs 16% $p=0.01$), they were concerned there was a more serious disease (33% vs 13% $p=0.01$), and they were depressed about their incontinence (31% vs. 13% $p=0.01$). Over half of women with and without diabetes similarly sought treatment because their incontinence worsened (52% to 56%) or their incontinence was embarrassing (47 to 55%). Many women also sought treatment because of an odor of urine (35% to 44%). Most reasons for not seeking treatment did not differ by diabetes status and most commonly were that it was considered a normal part of aging, women tended to put up with incontinence, they did not know what types of help were available, and felt they could manage the leakage on their own.

Discussion

The diversity of our cohort provides a unique opportunity to examine differences in incontinence among women with and without diabetes, in four major racial/ethnic groups. We found urinary incontinence to be highly prevalent with over half the women reporting at least monthly incontinence and over a third reporting weekly or more frequent incontinence. Our prevalence estimates are similar to other prior studies^{5, 6}. We also found incontinence was far more prevalent than the commonly recognized diabetes-associated complications such as peripheral neuropathy, retinopathy, and nephropathy, as shown in previous studies^{7, 10}

To the best of our knowledge, our study is the first to investigate incontinence care-seeking and beliefs in women with diabetes compared to women without diabetes. In our study, less than half of women with diabetes discussed their incontinence with a doctor, significantly less than women without diabetes. Encouraging discussions between doctors and patients about incontinence may lead to better identifying and treating of symptoms.

Understanding help-seeking behaviors are important to ensure appropriate patients discuss incontinence with their healthcare provider in order to receive treatment^{15, 23}. Social taboos against discussing incontinence in social situations hinder learning about the condition and may impact help-seeking^{12, 15}. Most of the participants in this study had erroneous notions about the causes and treatments for urinary incontinence. Unfortunately, significantly more women with diabetes than those without diabetes did not discuss their problem with others. It has been previously shown patients do not seek help because they lack knowledge about incontinence and treatment options as well as consider it a normal part of aging^{11, 12, 15}. This appears to be an even greater problem in populations with diabetes. We should therefore focus education and screening efforts on this particular higher risk population.

Prevention of urinary incontinence has been hindered by limited research and incomplete knowledge about social factors²⁴. Because the agenda for most visits is driven by patient complaints, beliefs may contribute to underreporting of incontinence and thus its under-treatment¹⁴. A simple screening tool may aid providers in detecting and treating urinary incontinence in diabetic patients²⁵.

Our study benefits from a large, population-based sample of middle-aged and older women, over sampling of racially/ethnically diverse women with and without diabetes, assessment of multiple dimensions of incontinence, and help seeking behavior for incontinence. Nevertheless, several important limitations of this research should be noted. First, this was a cross-sectional study, and we were unable to examine longitudinal change in incontinence and function over time. Our cohort consists of members of KPMCP, and previous research has suggested that the very wealthy and the very poor may be underrepresented in this population¹⁸. We determined that women who were members since age 18 were similar to all women members of the same age with respect to multiple characteristics⁹. Most of the data was obtained through self-report questionnaires by the participants. By having the interviewers review the answers and rephrase questions if necessary, we improved clarity however, recall bias is possible. Finally, the number of diabetic women in minority categories was relatively small and this resulted in limiting our ability to test difference between those groups. These aspects of the cohort should be considered when generalizing our results to other populations.

Conclusions

As the population ages, diabetes and incontinence will markedly increase in prevalence. Incontinence is highly prevalent among women with diabetes, even more common than diabetes-associated complications such as neuropathy, retinopathy, and nephropathy. Women with diabetes seek care less often than women without diabetes because they have less

knowledge about incontinence and treatment options. Physicians should be alert for urinary incontinence because it is often unrecognized and therefore under-treated among women with diabetes. Future research is needed to identify the mechanisms and effective treatment and prevention strategies to reduce the psychosocial, medical, and economic costs of this chronic disorder affecting many women with diabetes.

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Table 1
 Characteristics of Diabetes Reproductive Risk factors for Incontinence Study at Kaiser (RRISK) Cohort (N =2270)

	Diabetes* (N=486)	No Diabetes** (N=1784)	P-value
Demographics:			
Age: mean ($\pm$ SD)	56.0 ($\pm$ 8.75)	54.7 ($\pm$ 9.31)	<0.01
Race			
White [†]	194 (40.0)	812 (45.5)	0.03
African-American	102 (21.0)	341 (19.1)	
Asian	81 (16.7)	320 (17.9)	
Latina [†]	106 (21.9)	295 (16.5)	
Other	2 (0.4)	16 (0.9)	
Body Mass Index (kg/m ²)			
≤ 25 [†] $\neq$	49 (10.1)	659 (37.3)	<0.001
25–30 [†] $\neq$	114 (23.8)	558 (31.5)	
≥ 30 $\neq$	323 (66.8)	552 (31.2)	
General Health:			
Fair/Poor [†] $\neq$	109 (22.5)	102 (5.7)	<0.001
Good [†] $\neq$	291 (60.0)	702 (39.4)	
Very good/Excellent [†] $\neq$	85 (17.5)	980 (54.9)	
Chronic Medical Conditions:			
Hypertension	337 (69.8)	639 (35.8)	<0.001
Stroke	31 (6.4)	46 (2.6)	<0.001
Menopausal	367 (75.5)	1284 (72.0)	0.12
Reproductive Factors:			
Parity			0.05
0 births	71 (14.7)	335 (18.8)	
1 birth	72 (14.9)	204 (11.5)	
2 births	157 (32.4)	558 (31.3)	

	Diabetes* (N=486)	No Diabetes** (N=1784)	P-value
≥ 3 births	184 (38.0)	684 (38.4)	
Prior hysterectomy	130 (26.8)	403 (22.6)	0.05
Urinary Tract Infections (within the last year)			
0 [‡]	395 (81.8)	1549 (87.0)	0.002
1	53 (11.0)	155 (8.7)	
≥ 2 [‡]	35 (7.3)	76 (4.3)	

Data are mean ± SD or n (%).

* Diabetes: Women that self reported a diabetes history and were in the Kaiser Diabetes Registry or had a fasting blood sugar ≥ 126 mg/dl.

** No Diabetes: Women that self reported no diabetes history, were not taking a diabetes medication, were not in the Kaiser Diabetes Registry, and/or had a fasting blood sugar of ≤ 125 mg/dl.

[‡], [‡], [‡], pairwise comparisons significant at p<0.05

Table 2

Characteristics of Diabetics in Diabetics RRISK

Diabetes Factors:	Diabetics (N=486)
Treatment	
Insulin use	139 (32.9)
Oral agents	261 (61.9)
Diet controlled	22 (5.21)
Years with diabetes: mean ($\pm$ SD)	9.96 ($\pm$ 8.80)
Self-reported complications of diabetes	
Retinopathy	58 (12.9)
Nephropathy	27 (6.0)
Peripheral neuropathy symptoms*	87 (19.3)

Data are mean $\pm$ SD or n (%).

* Self-reported history of experiencing “numbness in the feet or hands”

Table 3

Urinary Incontinence Characteristics of the Diabetes RRISK Cohort (N = 2270)

Urinary Incontinence and Frequency	Diabetes* (N=486)	No diabetes** (N=1784)	p-value
Incontinence in past 3 months			<0.001
None † ‡	237 (49.1)	1061 (59.7)	
Monthly	75 (15.5)	277 (15.6)	
Weekly ‡	87 (18.0)	236 (13.3)	
Daily †	84 (17.4)	203 (11.4)	
Incontinence severity (Among women reporting any incontinence)			<0.001
Slight†	158 (45.1)	640 (54.6)	
Moderate‡	102 (29.1)	337 (28.7)	
Severe† ‡	90 (25.7)	196 (16.7)	
Quite a bit/extreme incontinence bother*** (Among women with ≥ weekly incontinence)			
Diurnal incontinence	54 (32.5)	115 (26.4)	0.15
Nocturnal incontinence	29 (17.5)	46 (10.5)	0.02

Data presented as n (%).

* Diabetes: Women that self reported a diabetes history and were in the Kaiser Diabetes Registry or had a fasting blood sugar ≥ 126 mg/dl.

** No Diabetes: Women that self reported no diabetes history, were not taking a diabetes medication, were not in the Kaiser Diabetes Registry, and/or had a fasting blood sugar of ≤ 125 mg/dl.

*** Bother: self-report on a Likert scale comparing not at all, slightly, and moderately to quite a bit/extreme bother

†, ‡; pairwise comparisons significant at p<0.05

Table 4
Beliefs and Help Seeking Behavior Among Diabetes RRISK Women with Weekly or Greater Incontinence (N= 602)

	Women with Diabetes (N=169)	Women without Diabetes (N=433)	p-value
	N(%) or Mean +/- SD	N(%) or Mean +/- SD	
Incontinence Beliefs			
A rare condition	28 (16.9)	28 (6.4)	<0.001
Treatment doesn't fix problem	24 (14.5)	35 (8.0)	0.01
Normal part of aging	124 (74.7)	325 (74.2)	0.90
Normal after childbirth	75 (45.2)	197 (45.0)	0.96
Treatment risky and/or harmful	20 (12.1)	40 (9.15)	0.28
No treatment for UI	17 (10.3)	29 (6.6)	0.13
Discussion of Urinary Incontinence (UI)			
Never discussed UI with others	51 (30.7)	95 (21.7)	0.02
Discussed w/spouse/partner	48 (28.9)	168 (38.4)	0.03
Discussed w/doctor or nurse	62 (37.4)	230 (52.5)	<0.001
Number of years with UI until discuss with provider	3.8 (±6.4)	2.7 (±4.7)	0.11

Table 5
Among Diabetes RRISK Women with Weekly Incontinence: Reasons Women Did or Did Not Seek Treatment

Sought treatment N= 148	Women with Diabetes N=36 (21.7)	Women without Diabetes N=112 (25.6)	0.32
Urine leakage worsened	20 (55.6)	58 (51.8)	0.69
Leakage was shameful/embarrassing	17 (47.2)	62 (55.4)	0.39
Odor of urine	16 (44.4)	39 (34.8)	0.29
Leakage made feel older	13 (36.1)	18 (16.1)	0.01
Concerned more serious disease	12 (33.3)	15 (13.4)	0.01
Depressed about leakage	11 (30.6)	14 (12.5)	0.01
Did not seek treatment N= 456	N= 130 (78.3)	N= 326 (74.4)	0.32
Thought it was a normal part of aging	76 (58.5)	179 (54.9)	0.49
Tend to put up with leakage	60 (46.2)	194 (59.5)	<0.01
Didn't know what types of help are available	51 (39.2)	116 (35.6)	0.46
Can manage leakage on own	46 (35.4)	129 (39.5)	0.40
Did not know where to seek help	20 (15.4)	31 (9.5)	0.07