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Predictors of Care Seeking in Women with Urinary Incontinence

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Abstract

Aims—To determine predictors of health care utilization in women with urinary incontinence (UI) from the population to specialty care.

Methods—The General Longitudinal Overactive Bladder Evaluation – UI is a population-based study on the natural history of UI in women 40 years of age. Prevalence of UI was estimated by using the bladder health survey (BHS). Survey data were linked with electronic health records (EHR) to examine factors associated with a clinical UI diagnosis using logistic regression. Risk factors analyzed included: UI symptoms, subtypes, bother, severity, duration and effect on quality of life, and demographic and other health characteristics. All statistical tests were two-sided with a p-value < 0.05 being significant.

Results—The overall prevalence of any UI based on responses to the BHS was 1,618/4064 (40%). Of the 1,618 women with UI, there were only 398 (25%) women with EHR (clinical) diagnosis of UI. Women with UI versus those without UI were more likely to have a BMI >25kg/m² (70% versus 58%), more likely to be parous (91% versus 87%) and college educated (54% versus 46%), P<0.001. After adjusting for confounders in the model, variables significantly associated with clinical UI diagnosis included: older age (OR=1.96), higher parity (> 1 birth) (OR=1.76), higher urgency UI (OR=1.08), adaptive behavior (OR=1.2), and UI bother scores (OR=1.01), as well as more frequent outpatient visits (OR=1.03), P<0.05.

Conclusions—UI is a highly prevalent condition with only a minority of women seeking care. Factors associated with health care utilization include older age, parity (1+), number of doctor visits, urgency UI subtype, UI bother and impact on behavior.

Keywords

Urinary Incontinence; prevalence; health care seeking behavior

INTRODUCTION

Urinary incontinence (UI) is very prevalent, affecting women of all ages (1–4). While prevalence of UI increases with age, patterns differ by UI subtype and severity(5). The level of bother and severity is highest for women with mixed UI (1,6,7); however, the impact on an individual's quality of life is significant for all UI subtypes (8, 9,10). Women with UI have lower SF-36 scores, higher CES-D depression scores, and poorer sleep quality (11). Furthermore, UI is associated with increased prevalence of other health conditions (3,12,13).

There is a discrepancy between the high prevalence and high impact of UI and the relatively low proportion of women who seek care. There is limited information on predictors of UI help seeking behavior. Studies have primarily used data from patient or clinic surveys. These indicate that embarrassment from UI symptoms and lack of patient or provider awareness are common reasons for lack of health care delivery for UI (14–17). However, these data reflect, in part, patient perception of health care use and not necessarily actual use of care. Previous studies have not linked patient survey data to actual utilization of care for UI from medical records or electronic health records.

To better understand determinants of seeking care for UI, we linked self-reported survey data to electronic health records (**EHR**) data from a large multi-clinic primary care practice.

METHODS

We used data from a cohort of women age 40 and above participating in the General Longitudinal Overactive Bladder Evaluation – Urinary Incontinence (**GLOBE-UI**) study who were followed with the Bladder Health Survey (**BHS**). The original GLOBE study is described in detail elsewhere (18,19). The cohort consists of women who are Geisinger Clinic primary care patients. In the following section we summarize the source population, study cohort, the BHS, and use of EHR in combination with survey data. The Geisinger Health System (**GHS**) IRB approved the study.

Source Population and Data

The Geisinger Clinic is a large multi-specialty practice in central and northeastern Pennsylvania that offers primary care services through its 38 community practice and hospital-based general internal medicine clinics. It serves a 31-county region with a very stable base population. Census data indicates that with the exception of two counties, the out migration rate is less than 1% per year.

GLOBE-UI Cohort

The GLOBE-UI is a second generation longitudinal study initiated in 2009. It is a follow-up to the original GLOBE study conducted from 2006 to 2008. In the current GLOBE-UI study, a new random sample of eligible primary care patients was selected from the Geisinger Clinic. Patients were eligible for selection if they were female, 40 years of age and older, assigned to a primary care physician, and had at least one visit in the past 4 years with a useable mailing address. The baseline BHS was mailed to all those who did not opt out. An enclosed letter informed patients that they would receive a total of nine questionnaires every 6-months over a period of four and a half years. Study participants who responded to the baseline survey received a follow-up survey every 6-months. Those who did not respond to the baseline survey continued to receive the baseline survey at the subsequent 6-month interval. To date, the first three waves of the nine 6-month mailings have been completed.

After excluding women who refused or opted out of the survey, a total of 7,059 women were sent the baseline BHS during the first wave and those who did not respond were sent the same questionnaire in the subsequent two follow-up six-month surveys. A total of 3,316 women responded to the first wave, 546 to the second wave, and 230 to the third wave of the baseline survey for a total response rate of 58% (n=4,092). Of those, 28 women had no EHR data; therefore, our final sample included a total of 4,064 women who answered to the BHS with adequate EHR data.

Bladder Health Survey

We have previously described the validation of the BHS (18,19). The source of data for this study included only respondents to the baseline survey (i.e. at baseline, all survey respondents; at 6-months, all baseline non-responders who responded at 6-months; at 12-months: all baseline and 6-months non-responders who responded at 12-months).

The BHS was designed to measure lifetime bladder UI symptoms (2 questions) as well as symptoms in the previous six months and four weeks. The BHS also had a host of related measures including duration of time with UI symptoms, stress UI (2 questions) and urgency UI (2 questions) symptoms, and adaptive behaviors in response to UI (2 questions). UI adaptive behavior was defined as change in behavior secondary to UI. These included the following two questions: "... wear clothing that wouldn't show if you lost urine" and "... wear a pad or other material to absorb urine you may have lost". The possible answers (and scores) to the UI and adaptive behavior subtype questions were: never or rarely (0), a few times (1), once to a few times a week (2), and daily (3). An overall adaptive behavior score was also developed using the sum of responses to the two behavior questions with a score range from 0 to 6. Composite scores were also derived for each of the two UI subtypes with a range of 0 to 6 (18). The baseline BHS also included the IIQ-7 and a modified UDI-6 (i.e., 4 out of the 6 questions namely the urgency, frequency, stress UI and urgency UI questions) and their composite scores were used to reflect impact on quality of life and bother (20). Furthermore, severity of UI was defined using the Sandvick severity index (21).

BHS-based definition of UI

Potential cases of UI were identified based on responses to the baseline BHS. An individual was defined as a non-case (N=2,446) if they fulfilled one the following criteria: **1)** she responded as having no lifetime UI symptoms by answering "no" to two screening UI questions (i.e., "Since age 18, have you ever lost urine, even a small amount at least once a month?" and "Since age 18, did you ever lose more than a few drops or small amount of urine at least once a month?"); **2)** reported UI of no significant severity (i.e., mild UI) or duration (i.e., UI for less than 3 months in the past 6 months); **3)** had inconsistent answers to presence or duration of UI symptoms; or **4)** reported a positive history of past UI symptoms explained by urinary tract infections or pregnancy. Conversely, women who answered affirmatively to the UI screening questions, or those who, on subsequent questions, reported UI of significant duration and severity, or reported change in behavior due to UI symptoms were considered to be cases (N=1,618).

Individuals with a reported history of UI were defined as: prevalent active cases if they reported having current UI symptoms of two years duration or more; prevalent inactive cases if they reported history of UI symptoms but no symptoms in the past six months; and incident cases if they reported current and new onset UI symptoms in the previous two-years. Eleven cases had unknown or undetermined UI status.

Electronic Health Record Data

Geisinger completed implementing its EHR in outpatient clinics in 2001. The EHR contains all clinical and other relevant data on patients including demographics, all clinic and hospital notes, diagnoses with their ICD9 codes, clinical measures, medication list, laboratory, and imaging results. In addition, all orders and visits are linked to one or more ICD9 diagnoses. The EHR was queried to identify how many of the GLOBE-UI study participants had a diagnosis associated with UI from January 1, 2004 through October 28, 2010. A clinically confirmed (EHR) UI diagnosis was defined if there were at least 2 encounters with one or more of the following UI ICD9 diagnoses: urge UI (788.31, 788.36, 788.39); detrusor

instability (596.55); stress UI (788.32, 788.35, 625.6, 599.84); mixed UI (788.33); other UI (788.30, 788.34, 788.37, 788.38, 596.54, 596.55, 596.59)..

We identified additional women with clinical UI based on one of the following bladder control medications as an order associated with one of the ICD9 diagnoses listed above: oxybutinin (Ditropan, Ditropan XL, Oxytrol, Gelnique), tolterodine (Detrol, Detrol LA), hyoscyamine (Levsinex, Levsinex SR), solifenacin (Vesicare), darifenacin (Enablex), fesoterodine (Toviaz) and trospium chloride (Sanctura, Sanctura XR). Moreover, using CPT codes, we identified patients who underwent surgeries for bladder control conditions including collagen injections (51715), implantation of neurostimulator (64581), repair of vesico-vaginal fistula (57320), retropubic urethropexy (51990, 51840, 70051990), and vaginal sling (57288). We identified additional patients with clinical UI diagnosis based on self-referral or orders placed by referring physicians to physical therapy, urogynecology and female urology with one of the UI ICD9 diagnoses listed above.

Analysis

Data analysis was performed using a SAS (version 9.2) statistical package (SAS institute, Inc, Cary, NC). We first estimated the prevalence of UI based on the responses to the baseline BHS. To examine factors associated with a clinical UI diagnosis based on the EHR, we used logistic regression with clinical UI as the outcome. Clinical UI diagnosis was defined as women who sought or received care for UI during the study period. We examined the following as potential predictors: UI status (incident, prevalent active, prevalent inactive), UI subtype score (0 – 6), severity of UI symptoms (mild, moderate, or severe) (21), bother score (modified UDI-6; i.e., the first four questions of the UDI-6), UI behavior score (0 – 6), impact on quality of life (IIQ-7), and duration of time with symptoms. Other risk factors analyzed were demographic factors including age, education, marital status, BMI (i.e., self-reported height and weight), parity, previous hysterectomy, smoking, alcohol use history other comorbidities, and number of doctor visits during the study time period.

In univariate analysis we examined relations of the above covariates with the outcome. Variables found to have a significant relationship with clinical UI diagnosis were retained in the multivariate logistic model to identify risk factors for UI care seeking and receipt. A subgroup analysis was performed in women defined as UI incident cases to ensure there was no bias effect on variable selection. Incident UI cases were selected because we hypothesized that recall and ascertainment errors would be smaller in this group and thus resulting in well defined UI case status. Categorical and continuous versions of variables were examined when applicable. All statistical tests were two-sided with a p-value of less than 0.05 considered as a cut-off for statistical significance.

RESULTS

The overall prevalence of any UI based on responses to the BHS was 40% (1,618/4064). The distribution of incident, prevalent active, and inactive cases was 1,042, 143, and 423, respectively. Women with or without UI had a similar age distribution by decile. Women with UI were more likely to have a BMI >25kg/m² (70%) than women without UI (58%). Moreover, women with versus without UI were more likely to be parous (91% versus 87%, P<0.001) and college educated (54% versus 46%, P<0.001). Two thirds of women in either group were married.

Of the 1,618 women with UI based on the BHS, there were only 398 (25%) women with EHR (clinical) diagnosis of UI. Tables 1 and 2 summarize demographic, health, and UI characteristics of the 1,618 women with or without EHR UI diagnosis. Overall, women without clinical UI diagnosis were more likely to be younger, nulliparous, more educated

and drink alcohol; moreover, they had fewer hysterectomies, a lower co-morbidity score and a lower number of doctor visits (Table 1). Conversely, women with a clinical UI diagnosis had UI for a longer duration, higher urgency UI scores, higher UI severity, adaptive behavior, bother, and impact on quality of life; they were also more likely to be active cases (Table 2).

After adjusting for potential confounders in the logistic regression model, the following variables were retained as significantly associated with clinical UI diagnosis: age, urgency UI score, UI adaptive behavior, UI bother scale, parity, and the number of outpatient visits (Table 3). The c-statistics, or area under the receiver-operating characteristic curve (AUC) for the overall logistic model was 0.78 (0.75–0.81) (Figure 1). This corresponds to the probability of seeking care in a woman with UI having the significant risk factors associated with the logistic regression model.

In the subgroup analysis of 423 incident cases, there were 74 (17.5%) patients who had sought care for UI. The demographic and UI characteristics profile of this subgroup was quite consistent with results shown in table 1 and 2. The same six variables were selected and were associated with care seeking and receiving, indicating that recall error did not affect UI self-report case status.

DISCUSSION

Although UI is a highly prevalent condition with a seemingly high disease burden, less than 25% of our cohort with a history of UI had EHR documentation of care seeking or receipt for their UI. These findings are consistent with previous self-reported health care utilization data from epidemiologic studies indicating that the majority of women with UI do not seek care. In one American study, less than 50% of community-dwelling adult women with lower urinary tract symptoms reported having talked with their physicians about UI (22). Moreover, in a European multi-site study, 31% of all women reportedly consulted a doctor about their UI symptoms (23). Furthermore, in another Scandinavian study, only a quarter of women with any UI, and one half of women with significant UI reported that they consulted a doctor (15).

The uniqueness of our study is that it linked population based survey data with patients' electronic health records to determine both survey-based factors as well as clinical determinants of seeking care. Overall, six variables accounted for a substantial share of the variance in identifying women seeking care for UI. The discriminatory power of the predicted model was fairly well, as measured by the c-statistics of 0.78. Seeking care was associated with older age and as expected a higher UI bother score and urgency UI score. Other predictors previously not well established included parity, adaptive behavior secondary to UI, and women with more frequent doctor visits. It is noteworthy that UI bother, urgency UI and UI adaptive behavior were independent contributors in the model. For instance, every 10 point increase on the UDI (range 0–100), one point increase on urgency UI score (range 0–6), or one point increase on UI behavior score (range 0–6), increased the risk for help seeking by 10%, 8%, and 20%, respectively.

Of interest, is that stress UI was not an independent risk factor for UI help seeking behavior. Others have also shown that urgency UI is more bothersome than stress UI (24). Other variables that did not make it in the final model were duration and severity of symptoms. Although symptom severity generally predicts likelihood of seeking care, interestingly, measures such as urgency UI Score and UI adaptive behavior score were stronger independent predictors than the previously validated Sandvick severity score.

One potential complex confounder was time from onset of symptoms to time of presentation (or diagnosis) of UI in the EHR. Women who have had UI symptoms for a longer duration of time are more likely to seek care than those with a shorter duration of UI symptoms (22). However, this is further confounded by other factors such as age of patient at onset of symptoms, age at presentation, duration of time since being a primary care patient, and others. We did include duration of symptoms with UI in our model, and there was a trade-off between duration and age of patient. The C-statistics was similar with both models ([duration in and age out] versus [duration out and age in]). Continued longitudinal follow-up of our patient population will allow us develop more robust models to predict onset of UI symptoms, and care seeking behavior of women with UI.

Our model that included UI symptoms, frequency, duration, severity, and related burden in addition to demographic characteristics such as age and parity does not fully explain health care seeking behavior. There are other reasons why patients do not seek or receive care for UI. These include lack of health care availability, cost, embarrassment from UI symptoms, lack of diagnosis or treatment by caring physicians and others (15,17,22,23,25). One study assessing physician awareness and attitudes revealed that UI and overactive bladder were undiagnosed in over 50% of patients, and half of the remaining 50% did not receive any treatment (17). In an interview study of people with UI about attitudes and health care, lack of knowledge of the condition and the availability of treatments was the main reason for not seeking care. In addition, UI was considered a normal part of aging, or that UI symptoms were inappropriate for medical intervention (25). Surprisingly, in this same study, older people were not only more likely to accept symptoms but were also less likely to want to bother their family doctors (25). Conversely, others have shown that older age and high impact on quality of life (15,22), duration of symptoms (22), willingness to take long-term medications, and having discussed UI with others (23) were factors most strongly associated with seeking health care.

Although we used extensive data from the EHR, it was not possible to review progress notes of all patients. Therefore, in some instances, a patient may have discussed UI symptoms with her provider who could have potentially offered advice (but did not document) on conservative modalities resulting in missed documentation of care delivery to women with UI. Alternatively, others may have sought care from a non-traditional clinical setting such as via acupuncturists, midwives, health club, or even the internet. We do not believe that these are a significant source of error since our prevalence estimates of UI help seeking are similar to other population studies (15,16,22,23). Another potential confounder is that some women may have sought specialty care outside the Geisinger system, and hence are under-reported in our results. Although, this is possible, we believe that the majority of them were internally referred. This is based on orders placed by the referring physicians and the corresponding matching specialist visits in the system (data not shown). Another potential weakness is that our study population included only women with an established primary care physician in a setting where health care is already available. Therefore, one has to use caution when generalizing to other populations where health care may not be readily available. Hence, it is not unreasonable to suggest that rates of UI care seeking or delivery are likely lower in the general population.

In summary, although UI is a highly prevalent condition, our data indicate that only a minority of women seeks or receives care. Factors associated with care-seeking or care-delivery include age, parity, urgency UI subtype, higher UI bother and impact on behavior, and women with a higher number of doctor visits.

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Figure 1. Probability of Care Seeking in Women with UI: Area under the Receiver-Operating Characteristic of the Model.

Table 1

Demographic Characteristics of Women with UI by Survey Including those with and without Clinical UI Diagnosis

	No clinical UI diagnosis (n=1,220)	Clinical UI diagnosis (n=398)	P-value
Age: N (%)			<0.001
40–49	342 (28)	56 (14)	
50–59	366 (30)	96 (24)	
60–69	257 (21)	105 (27)	
70–79	159 (13)	86 (22)	
80+	88 (7)	51 (13)	
BMI (Kg/m ²): N (%)			0.580
<25	371 (30)	113 (28)	
25–29.99	310 (25)	93 (23)	
30–34.99	259 (21)	92 (23)	
35–74	278 (23)	99 (25)	
Parity: N (%)			0.024
0	117 (10)	23 (6)	
1+	1076 (90)	359 (94)	
Smoking: N (%)			0.218
Never	670 (57)	227 (57)	
Yes/Passive	191 (16)	51 (13)	
Quit	317 (27)	118 (30)	
Alcohol: N (%)			<0.001
Never	576 (49)	234 (59)	
Yes	500 (42)	148 (37)	
Not available	103 (9)	14 (4)	
Marital status: N (%)			0.102
Married	780 (65)	235 (60)	
Widowed	186 (15)	80 (20)	
Separated or divorced	188 (16)	65 (17)	
Never married	54 (4)	14 (4)	
Education: N (%)			<0.001
11 th or less	84 (7)	42 (11)	
High school	436 (37)	171 (44)	
Some college	359 (30)	93 (24)	
College graduate	184 (15)	39 (10)	
Post-graduate	125 (11)	44 (11)	

Numbers in columns do not add up to total number in each group due to some missing values

Table 2

Urinary Incontinence Characteristics of Women with UI by Survey Including those with and without Clinical UI Diagnosis

	No Clinical UI diagnosis (n=1354)	Clinical UI diagnosis (n=443)	P-value
Duration of UI: N (%)			0.001
Less than 2 years	349 (29)	74 (20)	
2 to 4 years	328 (28)	100 (27)	
5 to 10 years	283 (24)	97 (26)	
More than 10 years	218 (19)	98 (27)	
Urgency UI: median (IQR)	2 (1, 4)	4 (2, 6)	<0.001
Stress UI: median (IQR)	3 (1, 4)	3 (1, 6)	0.319
UI severity (Sandvick): N (%)			<0.001
Mild	341 (31)	58 (16)	
Moderate	590 (53)	168 (47)	
Severe	180 (16)	129 (36)	
UI adaptive behavior: median (IQR)	2 (0, 3)	3 (2, 6)	<0.001
Modified UDI-6: median (IQR)	50 (25, 67)	67 (47, 83)	<0.001
IIQ7: median (IQR)	5 (0, 24)	24 (5, 57)	<0.001
Co-morbidities: N (%)			<0.001
0	608 (50)	137 (34)	
1+	607 (50)	261 (66)	
Outpatient visits: median (IQR)	22 (12, 36)	42 (25, 63)	<0.001
UI Baseline Case Status: N (%)			<0.001
Active case	760 (62)	282 (71)	
Inactive case	106 (9)	37 (9)	
Incident case	349 (29)	74 (19)	
Unknown/Uncertain	5 (0.4)	5 (1)	

Numbers in columns do not add up to total number in each group due to some missing values

IQR = inter-quartile range

Table 3

Multiple Logistic Regression Model of Predictors of Care Seeking in Women with UI by Survey

	Odds Ratio	95% Wald Confidence Limits		P-value
Age				0.035
40–49 (ref)	---	---	---	---
50–59	1.50	0.98	2.29	0.06
60–69	1.91	1.25	2.93	<0.01
70–79	1.71	1.07	2.73	0.02
80+	1.96	1.15	3.34	0.01
Parity	1.76	1.02	3.04	0.04
Urgency UI	1.08	1.00	1.16	0.04
UI behavior	1.20	1.11	1.29	<0.01
Modified UDI-6	1.01	1.00	1.02	<0.01
Outpatient visits	1.03	1.02	1.03	<0.01