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Care-seeking for stress incontinence and overactive bladder among parous women in the first two decades after delivery

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Abstract

OBJECTIVE—To establish the extent to which care-seeking for urinary incontinence is a function of symptom bother; and to identify bother-score thresholds that predict care-seeking in the first two decades after delivery.

METHODS—In this longitudinal cohort, women were assessed annually for symptom bother related to stress urinary incontinence (SUI) and overactive bladder (OAB), as well as for recent episodes of care-seeking for urinary symptoms. Because the goal was to model care-seeking as a function of the woman's characteristics at her prior visit, women who completed two consecutive visits were included. The population was randomly divided into "training" (model development) and "testing" (model validation) sets. The predictive model was developed in the training set. For SUI and OAB bother scores, we identified thresholds to define statistically distinct probabilities of care-seeking. A multivariable model was created, including SUI and OAB bother categories as well as characteristics associated with care seeking at the $P < 0.05$ level. The resultant prediction model was then applied to the "testing set"; predicted and observed care-seeking frequencies were compared.

RESULTS—Care-seeking was strongly associated with SUI and OAB bother. We defined three categories for OAB score and four categories for SUI score. The resulting twelve risk categories were then collapsed into five distinct risk-groups. These groups accurately predicted care-seeking in the testing set (area under the receiver-operating curve 0.760 (95% confidence interval 0.713, 0.807). Inclusion of other risk factors did not improve the model.

CONCLUSIONS—Symptom bother is a strong determinant of care-seeking in the first two decades after delivery. These results define five ordinal categories that predict seeking-care for urinary symptoms in a community population.

Keywords

Urinary Incontinence; pelvic floor disorders; Care-seeking

INTRODUCTION

Urinary incontinence is highly prevalent in adult women¹²⁻⁵. However, less than 50% of women with incontinence seek medical care for their symptoms⁶⁻⁸. Incontinence severity appears to be significantly associated with care-seeking for urinary symptoms.⁹ Prior studies have shown that perceived severity determines whether or not affected women desire treatment¹⁰.

Although it is not surprising that women with more severe urinary symptoms are more likely to seek treatment, this raises the question whether there is a specific threshold for symptom bother that predicts care-seeking. The identification of such a threshold could be useful in epidemiologic research (to define clinically-significant urinary symptoms), in public health (to anticipate the demand for incontinence treatment across a population), and in clinical trials (to define treatment success). This is a significant and recognized need; in 2010, it is estimated that 1.2 million new patient visits for pelvic floor disorders took place in the US and 1.6 million are predicted by 2030¹¹.

The goal of this investigation is to study the relationship between urinary symptom bother and care-seeking. We utilized data from the Mothers' Outcomes after Delivery study, a longitudinal study of pelvic floor disorders among parous women. Participants are annually assessed for urinary symptoms using the Epidemiology of Prolapse and Incontinence Questionnaire (EPIQ) and are also questioned annually about care-seeking for urinary symptoms over the prior interval. Using these data, we sought to estimate the extent to which care-seeking is a function of symptom bother, and to identify the bother-score thresholds that predict care-seeking. Our goal was to develop a model that would predict care-seeking for urinary symptoms among symptomatic women using established tools in the field.

MATERIALS AND METHODS

This analysis was based on data collected for the Mothers' Outcomes after Delivery study, a prospective longitudinal cohort study of pelvic floor disorders in parous women. Women were eligible to enroll in this study 5 to 10 years after their first delivery and are followed annually; recruitment began in 2007 and continued until 2012. Recruitment methods, selection criteria, and exclusion criteria have been previously described^{12,13}.

The outcome of interest in this investigation was care-seeking for urinary symptoms. Care-seeking is assessed at each study visit. Specifically, participants reporting any urinary symptoms are asked "Since your last visit, have you talked to a doctor, nurse, or other healthcare professional for help with urine leakage?" In our analyses, care-seeking at any point in time was evaluated as a function of the woman's characteristics at her *prior* visit. As such, our unit of observation in this analysis was a *visit-pair*, with exposure data measured at the first of the paired visits, and our primary outcome (incontinence care-seeking in the past year) assessed at the follow-up visit. Therefore, women who completed at least two consecutive annual visits were eligible for inclusion in this analysis. Women with three or more visits contributed multiple visit-pair observations to the analysis.

The primary independent variables of interest in our analyses were urinary symptom bother scores, derived from self-report using the Epidemiology of Prolapse and Incontinence Questionnaire (EPIQ)¹⁴. This questionnaire is designed to identify and quantify the severity of pelvic floor disorders in community populations. Individual EPIQ items are used to calculate summary scores of bother severity for stress urinary incontinence (SUI) and overactive bladder (OAB). Each summary score ranges from 0, representing no symptoms or symptoms with no bother, to 100, representing symptoms with the highest possible level of bother. In validating the EPIQ scores, a score of >47.3 on the SUI scale was found to predict a clinical diagnosis of SUI with sensitivity 80% and specificity 92%. A score of >59.6 on the OAB scale was found to predict a clinical diagnosis with sensitivity and specificity of 77% and 90%¹⁴.

To develop and test a model to predict care-seeking, we randomly divided the study population into “training” (model development) and “testing” (model validation) sets, applying a 2:1 ratio. For each visit-pair in the “training set”, we compared demographic and clinical characteristics for women who reported care-seeking for urinary symptoms to those who had not sought care. Characteristics of interest included: SUI and OAB scores, current age, body mass index (BMI), age at first delivery, self-reported race, educational attainment, self-reported history of depression, self-reported plans for future pregnancies, and history of vaginal birth (versus all deliveries via cesarean birth). BMI was calculated at each visit (weight and height were measured and BMI calculated as $\text{weight (kg)} / [\text{height (m)}]^2$).

In developing the predictive model, we hypothesized that incontinence care-seeking behavior could largely be anticipated from symptom bother (SUI and OAB bother scores). Using the “training” set, we used a recursive-partitioning approach¹⁵ to identify score thresholds above which the probability of care-seeking was greater. Specifically, each observation’s bother score was dichotomized as being greater than or less than or equal to some threshold value, c ; the threshold value, c , was allowed to take on all integer values on the bother score range (e.g., 0 to 100). Univariable logistic regression models with a robust variance estimator to account for repeated measures (visit-pairs) from a given participant were run to model care-seeking as a function of bother score greater than or less than or equal to c for each value of c . The model producing the test statistic of greatest magnitude for the independent variable was considered to yield the best threshold value, c , for discriminating the likelihood of care-seeking. To be considered a valid cut point, the test statistic must be significant at the $\alpha=0.001$ level. This process was repeated within sub-ranges of the data to identify additional cut points, thus allowing for multiple cut points along the symptom bother score continuum. Once identified, cutoffs were rounded to the nearest integer value ending in zero or five. This process was carried out for the SUI symptom bother score and the OAB symptom bother score separately. This process resulted in four distinct care-seeking risk groups along the SUI symptom bother scale and three groups along the OAB scale.

Following the recursive partitioning analysis described above, the joint contribution of SUI and OAB bother symptoms on care-seeking was considered. Because we identified four categories of SUI severity and three of OAB bother, we began with twelve unique OAB- and SUI-specific levels. We then used a recursive amalgamation algorithm whereby SUI- and

OAB-specific symptom bother profiles with similar risks for seeking care were combined iteratively. Combinations of categories with the most similar risk for care-seeking were amalgamated and the process was repeated until no further amalgamation was warranted as determined by a comparison of nested models (model of n risk categories vs. models of all possible $n-1$ risk categories). Models being compared were generalized estimating equations of a binomial outcome (care-seeking) with the statistical criteria for an improved goodness of fit of the data being the Quasi-Akaike Information Criterion (QIC). This analysis identified five statistically distinct care-seeking risk groups. Models adjusting for other *a priori* risk factors assessed the strength of association between urinary symptom bother level and care-seeking in the multivariable setting.

The urinary symptom bother categories for predicting care-seeking were then applied in the testing data set. Specifically, the *observed* care-seeking frequencies were compared to the *predicted* (from the test data set) frequencies using a Chi-square statistic. Model discrimination strength was assessed using the areas under the receiver-operator curve (AUC).

The recursive partitioning and amalgamation modeling was performed using SAS 9.3 statistical software (SAS Institute, Cary, NC). Validation analysis was performed using STATA SE 12.1 statistical software (StataCorp LP, College Station, TX)

RESULTS

This research includes data for 1128 women who contributed a total of 3217 visit-pairs to this analysis. The training data set was a random subset of visit-pairs, consisting of 2145 visit-pairs from 998 women; the testing set included 1072 visit-pairs from 731 women. Because randomization took place at the visit-pair level, some women with multiple visit-pairs contributed observations to both the training data set and the testing data set. The characteristics of the women in the “training” and “testing” sets were similar with respect to demographic, clinical and obstetric characteristics (see appendix).

In the training set, there were 199 (9%) reports of care-seeking (Table 1). Care-seeking was strongly associated with higher SUI and OAB bother scores, a history of a prior vaginal delivery, and self-reported history of depression. Age, obesity, and educational attainment were not significantly associated with care-seeking.

Care seeking as a function of SUI and OAB bother scores are shown in table 2. As noted, 37% (801/2145) reported no symptoms or very mild symptoms. In the remaining cases, mixed SUI and OAB was common. Considering care-seeking as a function of SUI score, we noted the highest probability of care-seeking for women with an SUI score greater than 55. Among women with an SUI score greater than 55, 39% (61/157) reported seeking care at the next annual visit. A lower probability of care-seeking was found for women with an SUI score between 20 and 55 (16%), still lower for those with a score between 5 and 20 (7%) and lowest overall for those with a score less than or equal to 5 (2%). Similarly, when considering OAB score, we identified three distinct score categories - 15, 15–50, and >50 – with observed rates of care-seeking of 5%, 10%, and 34%, respectively.

Considered jointly, the four SUI score categories and the three OAB score categories formed twelve bother categories. Among women who reported the highest category of bother for one symptom type, very few reported the lowest category of bother for the other symptom type. For example, only seven women reported an OAB score greater than 50 but an SUI score less than 5. As such, cells containing less than 20 observations each were merged, yielding 11 unique SUI-OAB categories.

Using the amalgamation algorithm, these categories were then collapsed into five distinct risk-groups (Figure 1). Those with no SUI or mild SUI (SUI ≤ 5) and no OAB or mild OAB (OAB ≤ 15), were least likely to seek care (1.2%). Women who reported either extreme SUI bother (>55) or severe SUI bother (20 to 55) combined with severe OAB bother (>50), had the highest probability of care-seeking (shown in the figure as two distinct levels: 30.6% and 42.9%). Women with low to moderate levels of bother of either SUI or OAB, exhibited rates of care-seeking at two other unique levels: 5% and 12%.

Urinary symptom care-seeking was modeled multivariately as a function of the five unique SUI-OAB risk categories as well as age, years from 1st delivery, history of vaginal birth, obesity, and self-reported history of depression. The five SUI and OAB risk categories (as described in Figure 1) were significantly associated with care-seeking in a strong dose-response manner. Specifically, compared to the reference category (e.g., with the lowest bother for both SUI and OAB), the relative odds for care-seeking was 4.06 (95% confidence interval (CI) 2.00, 8.23) for the second category, 10.22 (95% CI 5.44, 19.20) for the third category, 30.77 (95% CI 15.21, 62.23) for the fourth category, and 50.79 (95% CI 25.07, 102.91) for the highest risk category. At the same time, none of the demographic or obstetrical risk factors remained significantly associated with care-seeking in the multivariable setting.

The 5-category model was applied to the testing set; the predicted frequencies of care-seeking were compared to those observed (Table 3). Overall, the rate of incontinence care-seeking in the testing set was similar to that seen in the training set (10% vs. 9%, $p=0.84$). The 5-category risk model accurately predicted the number of care-seeking events in the testing data set ($p=0.273$ based on chi-square test). Additionally, the 5-category risk model was able to discriminate probability of care-seeking in the testing set with an area under the receiver-operating curve (AUC) for the 5-category model of 0.760 (95% CI 0.713, 0.807). Inclusion of the other *a priori* risk factors in the multivariable model did not significantly improve the models strength of discrimination for care-seeking (AUC: 0.787, 95% CI: 0.741, 0.834).

DISCUSSION

This research demonstrates that the degree of bother related to urinary symptoms has a significant and powerful association with the probability a woman will seek care in the first two decades after delivery. In the 5-category model we developed, the odds of seeking care was 50 times higher among women in the highest bother group versus those in the lowest group, indicating the dramatic magnitude of the differences between groups. While others have observed an association between incontinence severity and care-seeking⁹ as well as

coping mechanisms among patients with significant bother¹⁶, this research is unique in that we identified specific thresholds for symptom bother associated with care-seeking. Prior research has considered care-seeking as a function of a priori categories (such as the frequency or volume of urine leak⁹); in contrast, this research established thresholds that describe care-seeking behavior. The identification of such thresholds and the resultant 5-category model could facilitate the identification of clinically-significant urinary symptoms for epidemiologic studies. This model can also be used for ascertaining, communicating and planning a woman's future clinical service demand, particularly of interest as we know that clinical service demand for pelvic floor disorders continues to rise at an unprecedented rate¹¹.

As mentioned above, we were able to identify several thresholds for care-seeking risk across the full spectrum of symptom bother. In the original validation of the EPIQ, the investigators identified a single threshold for SUI and OAB score to maximize positive predictive value for a clinical diagnosis. For example, a threshold SUI score of >47.3 maximized positive predictive value for a clinical diagnosis of SUI¹⁷. In contrast, we identified four categories for SUI bother, indicating four distinct levels of probability for care-seeking. Our model suggests that the previously published threshold (47.3) would distinguish women with extreme bother (>55 , in this research); however we found that meaningful and significant distinctions of risk can be made among bother scores below that level. A two category model (e.g., 47.3 versus >47.3) is likely to be less useful than a four category model for describing risk across a spectrum or for following bother over time.

Our model suggests that SUI and OAB bother are two independent contributors to the probability of care-seeking. In this study population, mixed symptoms (SUI and OAB) were quite common. There were relatively few women who described pure SUI or OAB. This allowed us to assess the contribution to care-seeking of both symptom types. Prior research has compared care-seeking to a more global measure of incontinence severity without regard to incontinence subtype^{9,18}. Other recent studies have not used the EPIQ questionnaire and have only evaluated UI as an umbrella term and not the spectrum of mixed urinary continence, for which our model provides a snapshot.¹⁹ Our findings demonstrate that SUI and OAB bother each contribute to the probability a woman will seek care for urinary symptoms.

With respect to other predictors of care-seeking, we found that women who sought care were more likely to have a history of depression and were more likely to have delivered at least one baby vaginally. We found an association (although not significant) for women who were older. Our predictive model was not improved by controlling for age, obesity, or history of vaginal birth. The implication is that these other characteristics are not important determinants of care-seeking after considering SUI and OAB score.

The additional advantage of our model is that SUI <55 contains the majority of the observations (93%); therefore having the ability to assess risk in this range of the bother spectrum is relevant to the majority of the population. Other strengths of this study include the size of the database and the use of a validated tool to measure symptom bother. In addition, the longitudinal design allowed a unique and valuable opportunity to prospectively

consider the relationship between symptom bother and care-seeking. Clinically speaking, the distribution of the data allowed our study to identify statistically significant categorical cutoffs that can be practically used to predict care-seeking behaviors in an ambulatory population of adult women.

A limitation of our data is that few women reported a very high level of bother for one symptom type and a very low level of bother for the other symptom type. Thus, most women in this population who described bother associated with urinary symptoms had a mixed picture. The relatively small number of women with severe bother related to either pure SUI or pure OAB symptoms may limit the precision of our estimates for care-seeking among these women.

An additional limitation of our research is that our study population is largely pre-menopausal and highly educated, as well as overall compliant. Because our population is relatively young compared to the traditional UI care-seeking population, our results may not be generalizable to older and less educated women. Studies have shown that women with more preventive health visits were more likely to seek care²⁰, and to that point our population is self-selected to be a part of a longitudinal study and by definition followed closely. Also, we did not collect data about health insurance or other factors that might impact access to care. Finally, we also do not explicitly know “why” some symptomatic women did not seek care. For example, among 78 women in the “test” set with the highest level of bother related to both SUI and OAB, only 34 (44.6%) sought care in the subsequent year. It is somewhat surprising that care-seeking was not universal in that group, however given the small number of women with the most severe symptoms, it is difficult to extrapolate the behavior of this group of women to predict why they did or did not seek care. We did not collect information about women’s perception of care-seeking or the reasoning behind her decision.

The present research has extended the value of the EPIQ by identifying categories of SUI and OAB symptom bother with clinically unique burden levels of seeking care for urinary symptoms. We describe a simple 5-category model that defines ordinal categories of severity for urinary symptoms. We believe this model could be used not only to describe UI severity in a population but also in clinical research as an outcome measure. Additional testing in the setting of a clinical trial would be valuable to establish whether this model could be used to describe treatment impact or to define treatment failure.

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Appendix

Comparison of study participants in training (model development) and testing (model validation) data sets

	Data Set		
	Training Set	Testing Set	p-value for difference ^c
Bother reporting	N=2145	N=1072	
Urinary symptoms			
Self-Report of SUI bother ^a	73% (1573)	73% (782)	0.81
Level of SUI bother ^d	16 [5, 35]	17 [5, 38]	0.21
Self-Report of OAB bother ^b	88% (1879)	89% (956)	0.19
Level of OAB bother ^e	11 [3, 29]	12 [3, 31]	0.65
Sought care for UI symptoms	9% (199)	10% (102)	0.84
Participant characteristics			
Age, years	41 [37, 45]	41 [37, 44]	0.11
Obese, BMI ≥ 30 kg/m ²	27% (565)	27% (283)	0.98
Primary race			
Caucasian	84% (1796)	84% (899)	ref.
African-American	12% (254)	11% (120)	0.62
Other	4% (95)	5% (53)	0.47
History of depression	19% (402)	16% (170)	0.048
Education			
Did not graduate from college	19% (410)	20% (219)	0.29
College graduate	43% (928)	42% (447)	ref.
Graduate Degree	38% (807)	38% (406)	0.60
Reproductive characteristics			
Parity			
1	27% (580)	27% (291)	ref.
2	56% (1211)	56% (604)	0.95
3+	17% (354)	17% (177)	0.97
Age at 1 st delivery, years	32 [29, 36]	32 [29, 35]	0.33
Years from 1 st delivery	9 [7, 11]	9 [7, 10]	0.094
At least one prior vaginal birth	50% (1064)	51% (549)	0.39
Planning more children	5% (80)	6% (54)	0.44

Missing data: BMI, n=64; Depression, n=66; Planning more children, n=587

^aDefined as having an SUI score > 0

^bDefined as having an OAB score > 0

^cDerived from univariate generalized estimating equations modeling the dataset (training or testing) as the outcome to account for repeated observations from some women.

^dAmong observations with SUI scores > 0

^eAmong observations with OAB scores > 0

n=3217 visit pairs among 1128 women

		SUI bother score				
		None/Mild [0,5]	Moderate [5,20]	Severe [20,55]	Extreme >55	
OAB bother score	None/Mild [0,15]	1.2% (10/801) (1)	4.9% (24/488) (2)			4.9% (66/1335)
	Moderate [15,50]	4.9% (24/488) (2)	12.1% (72/597) (3)		30.6% (45/147) (4)	10.4% (63/606)
	Severe >50			30.6% (45/147) (4)	42.9% (48/112) (5)	34.3% (70/204)
		2.1% (21/993)	7.0% (32/459)	15.9% (85/536)	38.9% (61/157)	9.3% (199/2145)
Outcome: care-seeking at next visit; n=2145 training set (model development) observations						

Figure 1.

Statistically distinct care-seeking risk groups, across categories of stress urinary incontinence (SUI) and overactive bladder (OAB) symptom bother

Table 1

Characteristics of study participants by incontinence care-seeking status, by visit-pair in the training (model development) data set

	Sought Incontinence Care During Follow-up		
	No	Yes	p-value for difference ^c
Bother reporting	N=1946 (91%)	N=199 (9%)	
Urinary symptoms			
Any bother associated with stress urinary incontinence (SUI) ^a	71% (1382)	96% (191)	< 0.001
SUI bother score ^d	14 [5, 30]	38 [22, 61]	<0.001
Any bother associated with overactive bladder (OAB) ^b	87% (1691)	94% (188)	0.007
OAB bother score ^e	10 [3, 26]	35 [12, 59]	<0.001
Participant characteristics			
Age, years	41 [37, 45]	42 [38, 46]	0.13
Obese, Body Mass Index ≥ 30 kg/m ²	26% (499)	34% (66)	0.45
Primary race			
Caucasian	84% (1632)	82% (164)	ref.
African-American	12% (226)	14% (28)	0.39
Other	5% (88)	4% (7)	0.71
History of depression	18% (350)	26% (52)	0.007
Education			
Did not graduate from college	19% (361)	25% (49)	0.076
College graduate	44% (852)	38% (76)	ref.
Graduate Degree	38% (733)	37% (74)	0.34
Reproductive characteristics			
Parity			
1	27% (525)	28% (55)	ref.
2	57% (1101)	55% (110)	0.96
3+	16% (320)	17% (34)	0.94
Age at 1 st delivery	32 [29, 36]	34 [30, 37]	0.21
Years from 1 st delivery	8.7 [6.8, 10.7]	9.1 [7.1, 10.6]	0.30
At least one prior vaginal birth	48% (941)	62% (123)	0.006
Planning more children	5% (75)	3% (5)	0.44

Missing data: Body mass index, n=46; Depression, n=42; Planning more children, n=395

^aDefined as having an SUI score > 0

^bDefined as having an OAB score > 0

^cDerived from univariate generalized estimating equations modeling the care-seeking (yes vs. no) as the outcome to account for repeated observations from some women.

^dAmong observations with SUI scores > 0

^e Among observations with OAB scores > 0

Total: n= 2145 visit pairs among 998 women

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Observed care-seeking in the training (model development) data set, across categories of stress urinary incontinence (SUI) and overactive bladder (OAB)

Table 2

		SUI bother score			
		None/Mild [0,5]	Moderate [5,20]	Severe [20,55]	Extreme >55
OAB bother score	None/Mild [0,15]	1.2% (10/801)	5.3% (16/303)	13.2% (26/197)	41.2% (14/34) 4.9% (66/1335)
	Moderate [15,50]	4.3% (8/185)	10.8% (15/139)	11.4% (27/237)	10.4% (63/606)
	Severe >50	42.9% (3/7)	5.9% (1/17)	31.4% (32/102)	34.3% (70/204)
		2.1% (21/993)	7.0% (32/459)	15.9% (85/536)	38.9% (61/157) 9.3% (199/2145)

SUI and OAB bother scale [0–100]¹⁴, n=2145 visit pairs

Table 3

Observed vs. predicted care-seeking in the testing (validation) set, based on the 5 category model

Risk group (n)	Number of care-seekers in validation set	
	Observed	Predicted*
1 (388)	9 (2.3%)	4.8 (1.2%)
2 (225)	13 (5.8%)	11.1 (4.9%)
3 (327)	38 (11.6%)	39.4 (12.0%)
4 (75)	18 (24.0%)	23.0 (30.7%)
5 (57)	24 (42.1%)	24.4 (42.8%)
OVERALL (1072)	102	102.7

* Derived from predicted probabilities for each risk group modeled from the training data set and applied to the validation data set.