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Written versus oral disclosure of fecal and urinary incontinence in women with dual incontinence

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Abstract

Introduction and Hypothesis—To compare fecal incontinence (FI) and urinary incontinence (UI) disclosure in women with dual incontinence (DI), and to assess UI disclosure in DI subjects compared to women with UI alone. We hypothesized that women with DI would be less likely to disclose fecal incontinence (FI) in comparison to urinary incontinence (UI) and as likely to disclose UI as women with UI alone.

Methods—We performed a retrospective chart review of new patient visits to an academic Urogynecology clinic from 2007–2011. Clinical records were reviewed; demographic data and responses to the ISI and Wexner scales were recorded. Patients' written responses to the ISI and Wexner were compared to the diagnoses obtained from oral history by the physician.

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Results—Of 1899 women in the database, 557 women were diagnosed with dual incontinence (DI) and 447 women were diagnosed with UI alone. Women with DI were less likely to orally disclose FI than UI (135/557 (23%), vs 485/557(87%), $p<0.001$) but were as likely as women with UI alone to disclose UI (385/447(86%) vs 485/557(87%), $p=0.66$). In the multivariable analysis, DI subjects had greater odds of disclosing FI to their physicians if they had private insurance (OR 1.9, 95% CI [1.2, 3.0]) or Wexner score > 7 (OR 9.0, 95% CI [5.4,14.8]) and lower ISI score (OR 1.5, CI [1.4, 1.6]).

Conclusions—Women with DI were less likely to report FI in comparison to UI. Patients were more likely to orally report FI when the symptoms were severe.

Keywords

Dual Incontinence; Oral Disclosure; Written Disclosure

Introduction

A physician is only able to treat functional complaints that a patient demonstrates or acknowledges; unspoken problems often perpetuate despite available treatment options. Epidemiologic studies indicate people suffering from fecal incontinence and/or urinary incontinence may conceal these conditions from their physicians because of embarrassment, a belief their symptoms are a normal part of aging, or because they assume treatments do not exist. (1–4)

Fecal incontinence (FI) is defined as the involuntary passage of solid or liquid stool with prevalence estimates ranging from 4.2% to 24% among community based women and that prevalence increases with age. (5, 6) Patients with FI often do not discuss this condition with their physicians until symptoms are severe. (1) It has been estimated that 71% of women with accidental bowel leakage do not seek care. (7) Even when patients are directly questioned they are unlikely to report FI, although direct questioning from the physician does increase the number of patients willing to discuss these symptoms (12% with direct questioning vs 2% of women spontaneously disclosing symptoms). (8)

Urinary incontinence (UI), whether it is related to urgency or stress incontinence, is also underreported to physicians even when it results in significant bother, depression and isolation. (9) Cross-sectional data suggests that only 40–50% of individuals with urinary urgency incontinence discuss their symptoms with a provider (3, 4). Stress incontinence seems to have the highest rate of reporting to physicians, but only when symptom severity is high. (10, 11)

About 7% of community dwelling women report urinary and anal incontinence or double incontinence (DI) and it is associated with advanced age (>80), depression and decompensating medical conditions. (12) Women with DI tend to report greater FI symptom severity than women with FI alone. (13) It would seem that higher symptom severity would result in similar disclosure between FI and UI for women with DI; however one study indicates DI patients are unlikely to voluntarily disclose their anal incontinence symptoms. (14)

Given poor disclosure by patients of UI and FI, we sought to compare UI and FI disclosure patterns of women with DI on written and oral history and sought to explore how disclosure mode impacts report rates. We also compared oral and written history disclosure rates of UI between women with DI and UI alone. We hypothesized women with DI would be less likely to disclose FI than UI on oral history and as likely to disclose UI as women with UI alone. To do this, we compared each patient's written responses on the Incontinence Severity Index (ISI) (15) and Wexner scales with the oral history obtained by the physician.

Materials and Methods

This study was approved by the Institutional Board Review at the University of New Mexico Health Sciences Center. We conducted a retrospective chart review of all new patients presenting to the Urogynecology Clinic at the University of New Mexico from January 2007 to October 2011. We have previously reported on the impact of FI on sexual function from this database. (16) Starting in 2007, all new Urogynecology patients were interviewed by a physician using a standardized intake questionnaire that included basic demographic and clinical information as well as specific questions regarding UI and FI symptoms. Specific questions regarding urinary and fecal incontinence included: Do you accidentally lose stool? Do you have fecal incontinence? Do you have urinary leakage? Four attending physicians and 3 fellows were responsible for all new patient care during the study period; all physicians were trained to ask questions about FI of every new patient. Data collected from the chart review included age, BMI, ethnicity/race, exam findings, responses to the ISI and Wexner scales, and the patient's urogynecologic diagnosis(es) as outlined in the attending physician's dictation of the new patient encounter. The Oxford grading scale was used to assess vaginally pelvic muscle contraction strength. In this scale 0=no contraction, 1=flicker, 2=weak, 3=moderate 4= good and 5=strong contraction. We used the urogynecologic diagnosis(es) from the attending physician's dictation as representative of the oral history obtained by the physician. In addition to the oral history, all women completed the ISI and Wexner Fecal Incontinence Scale prior to their interview by the physician. While physicians had access to the questionnaires, during the study time the purpose of the questionnaires was research driven rather than to guide the physician interview. Physicians did not routinely reference the questionnaires prior to conduction of the interview. The ISI and Wexner were defined as the patient's written disclosure of UI or FI.

The ISI is well validated (15) and contains 2 questions asking about urinary leakage; frequency of urinary leakage (less than once per month, 1–3 times per month, once per week, once per day) is multiplied by the amount of leakage (drops, small splashes, more). Frequency is assigned a value of 1–4 to and leakage a value of 1–3, with higher numbers indicating higher severity. Typically a score of 1–2 indicates leakage of a few drops once per month, 3–4 indicates weekly leakage and 6 indicates large amounts of leakage daily or weekly. We used a score 1 as identifying UI.

We defined FI based upon patient responses to the Wexner scale; women who affirmed leakage of solid or liquid stool with or without the use of pads or lifestyle alterations were defined as having FI. Because the first question of the Wexner scale refers to gas only

incontinence, patients who only answered affirmatively to this question were excluded from the FI group. The Wexner scale consists of 5 questions, each scored 0–4; a score of 0 indicates perfect continence and 20, total incontinence. (17) A Wexner score >9 correlates to patients confining themselves to home. (18) We used a score >9 in our initial analysis as defining severe fecal incontinence, but subsequently found that a score >7 was more sensitive and specific and therefore used this to define severe FI.

The primary outcome was comparison of FI and UI disclosure to the physician on oral history versus written questionnaires in women with DI. We also compared oral history disclosure rates of UI between women with UI alone versus those with DI.

Descriptive statistics were used to describe the patient population. Categorical variables were compared using Fisher's exact test, and continuous variables were evaluated with paired t tests. Logistic regression was used to determine the characteristics independently associated with FI oral disclosure to physicians. A Receiver Operator Curve (ROC) was used to define a Wexner cut-score for oral disclosure and to generate sensitivity and specificity estimates in predicting oral disclosure of FI to the physician. After the Wexner cut-score was defined, it was used to identify the odds ratio of oral disclosure. A ROC was also used to define an ISI cut-score predicting oral disclosure of UI to the physician. Data were analyzed using SAS 9.3. Significance was set at $P < .05$.

Results

During the study period, 1899 women presented for new patient evaluation. We excluded one hundred and two women (5%) for missing Wexner or ISI scores, 31 (<1%) women with FI only and 762 women who did not have UI or FI, leaving 1004 women for analysis. (Figure 1) The thirty-one women with FI only were excluded from comparative analysis because the group size was too low for meaningful evaluation. The DI subgroup included 557 and the UI sub-group 447 women respectively. Women with DI were less likely to disclose FI than UI on oral history (135/557(23%) vs 485/557 (87%), $p < 0.001$). Age, BMI, ethnicity/race, parity, sexual activity, frequency urinary incontinence, and stage of prolapse did not differ between the FI disclosure and non-disclosure groups; although women who disclosed FI on oral history were more likely to have private insurance and have a lower ISI score. (Table 1)

Significant findings from the univariate analysis were placed in a multivariable logistic regression model. Disclosure of FI was independently associated with private insurance (OR 1.9, 95% CI [1.2, 3.0]), Wexner score > 7 (OR 9.0, 95% CI [5.4, 14.8]) and lower ISI score (OR 1.5, CI [1.4, 1.6]). (Table 2) When evaluating Wexner as a continuous variable, for each 1 point increase in Wexner score, odds increased 1.26 [CI 1.2, 1.3] that a patient would disclose FI to the physician. In the DI group for each point increase in ISI the OR of non-disclosure of FI was 1.5 [CI 1.4, 1.6]. Wexner score and ISI score increases and their subsequent effect on oral disclosure of FI were independent of each other. An ROC curve demonstrated that Wexner score >7 (solid or liquid stool leakage with changes in lifestyle and/or pads) gave good sensitivity and specificity (0.80 and 0.68 respectively) for disclosure of FI on oral history (Supplemental figure 1).

Women with DI when compared to women with UI were older, heavier, less likely to have private insurance, more likely to have prolapse, and poorer pelvic floor muscle strength on the Oxford grading scale than women with UI, but were as likely as those with UI alone to disclose UI (385/447 (86%) vs 485/557 (87%), $p = 0.66$). (Table 3)

We further analyzed disclosure of FI or UI based on symptom severity. After separating women with UI or DI into groups based on ISI score, women with one leak per month or ISI score ≤ 2 were less likely to orally disclose UI symptoms than those women with daily leakage or ISI score ≥ 6 , (41% vs 96% respectively). (Table 4) An ROC curve demonstrated that an ISI score of ≥ 3 (weekly leakage or moderate severity) gave good sensitivity and specificity (0.84 and 0.61 respectively) for UI disclosure on oral history (Supplemental Figure 2). Similarly, as FI severity increased, reporting to the physician increased. (Table 5) In contrast to high disclosure rates for UI at relatively less severe symptoms, of women with severe FI (Wexner scores ≥ 7) only 43% reported FI to their physician.

To verify that we had correctly chosen written history as the standard we looked at the reverse and evaluated how many women denied UI or FI on questionnaires but provided an oral history of these disorders to the physician. 17 women (3.23% of the total women with FI symptoms) told the physician about FI symptoms but did not report symptoms on Wexner. No women told the physician about UI symptoms that were not reported on ISI.

Conclusions

We found that women with dual incontinence were less likely to report FI than UI on oral history while they were as likely as women with UI alone to discuss symptoms of UI. Oral history disclosure rates of FI were extremely low even among women with severe symptoms compared to written history; while women were much more likely to disclose even mild UI symptoms. In our study, women with DI who disclosed their FI were more likely to have private insurance, and had more severe symptoms.

Barriers to care seeking for FI have been explored by others. Bharucha et al found that only 48% of women with severe FI consulted a physician. (1) Brown et al found that FI was more severe and of longer duration for those who do seek care. (7) The patients in our current report were already seeking care for pelvic floor dysfunction, however, remained reluctant to disclose their FI symptoms. UI and FI are both considered socially unacceptable, yet these patients were more apt to disclose UI than FI. We assume that this is because, as noted by others, accidental bowel leakage is a source of disgust and carries more stigma than UI. (19, 20) It is also possible that patient's gave greater priority to addressing their urinary incontinence with the physician. This is also indicated by the decreasing likelihood of discussing FI with increasing ISI score in our cohort of women with DI. However this is still independent of Wexner score, so it may also be that a certain threshold of bother or impairment in quality of life for FI needs to be reached prior to patient oral disclosure.

Like others, we found that FI disclosure increased as FI severity increased. Based on the Wexner scores, the ROC identified a score ≥ 7 as sensitive for predicting oral disclosure to the physician. This score indicates, at a minimum, some solid or liquid stool leakage that

results in alterations in lifestyle and/or pad usage. The ROC curve for UI indicated that the cut-score for oral disclosure of UI occurred with milder severity than that which was found for FI. Again, this may indicate that UI is more socially acceptable than FI and that patients are only willing to discuss FI when severity becomes unbearable.

In our clinical setting during the study period, questionnaire responses were collected for the purpose of patient research rather than guiding the physician during the oral interview. We specifically evaluated the patient's chart for the term "fecal incontinence" and a plan of care for that complaint. While physicians asked women about their incontinence, women remained unlikely to reveal FI symptoms on oral history despite severe FI symptoms on questionnaire responses. There are several possibilities for this finding. One possibility would be that patients voiced another complaint as a surrogate for FI, resulting in lack of physician understanding of the specific problem. One study previously found that in patients complaining of "diarrhea" were actually seeking care for FI. (21) Others have reported that women prefer the term "accidental bowel leakage" when referring to FI, rather than the terms "fecal" or "anal" incontinence.(7) Our study may highlight the problem of patient's reluctance to disclose FI when certain terms are used to ask this question. We did not obtain physician specific data and it is possible that one or two physicians asked these questions better than the others. Another possibility is that subjects verbalized that they had FI and that their physician chose to disregard this problem. We believe that the latter is less likely in the Urogynecologic setting when a standardized interview outline is followed. FI is commonly cared for by physicians in our subspecialty and lack of knowledge about the problem, the usual reason for overlooking complaints, is unlikely (22).

This study is innovative in that this was a large cohort of women with dual incontinence who have taken the initiative to seek care for pelvic floor disorders. Yet, despite this, they remained reluctant to disclose their FI compared to UI to their physician on oral history. It would seem that this cohort of women would be more willing to discuss any pelvic floor disorders because they were seeking care in a clinic with that focus; nevertheless there was preferential disclosure of UI in comparison to FI.

Weaknesses of this study stem from its retrospective design. It is possible physicians discussed FI with patients and failed to note the disclosure in the new patient encounter. While this is possible, it is unlikely to explain the nearly 80% of women that did not disclose FI on oral history obtained by the physician. Also, we were only able to explore the variables we collected as possible predictors of disclosure. It is possible other variables, such as flatus or fecal incontinence during the pelvic exam, previously seeking care for FI and or patient comfort with the provider may have contributed to disclosure rates. Ideally, we would have had a comparable number of women with FI-only to compare FI disclosure rates with the DI group. Additionally as patients became more comfortable with our clinic and physicians they may have chosen to discuss FI at a follow-up appointment. Our clinic population also represents women who sought care at an academic tertiary referral setting and may not be generalizable to the population. It is also possible patients misunderstood the Wexner questionnaire and responded affirmatively in writing but then when directly questioned had better understanding and did not report FI. Last, patients may have assumed

that by the physician title “Urogynecology” that we do not treat FI and therefore thought it was not worth discussing during their visit.

Strengths of this study include the large sample size and the use of validated questionnaires as well as a standardized intake form for taking the oral history. The results of this study have changed our clinical practice. Because it seems that FI questionnaires represent a more acceptable way for patients to initially report symptoms, we are now asking questions differently. For example, instead of asking, “Do you have accidental bowel leakage or fecal incontinence?” we instead ask, “We noticed on your form that you checked that sometimes you are incontinent (accidentally losing) stool, does this bother you and would you like to talk about this today?”

FI was called a “silent affliction” in the *Lancet* in 1982. (21) Research continues to argue that FI is common and FI symptoms remain unspoken. Further research should pursue tactics and avenues to help patients overcome their silence.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Patient Breakdown

Table 1

Patient Characteristics between Oral Disclosure and Non-Disclosure of FI

Dual Incontinence N=557	Told Physician about FI N= 127	Did not tell Physician about FI N=430	P value
Age(Mean +/- SD*)	58.5 ± 12.6	58.5 ± 13.0	0.29
BMI (kg/m2) (mean +/- SD)	31.2 ± 8.0	31.8 ± 8.0	0.46
Parity(mean +/- SD)	2.7 ± 1.6	2.7 ± 1.8	0.66
Insurance (%)			0.01
None	3 (2.4)	7 (1.7)	
Private	54 (42.9)	130 (30.1)	
Public	70 (54.8)	293 (68.2)	
Ethnicity/Race (%)			0.39
Hispanic	43 (33.5)	138 (32.2)	
Non-Hispanic White	58 (45.8)	227 (52.8)	
American Indian	16 (12.6)	31 (7.1)	
African American	3 (2.3)	14 (3.2)	
Other	7 (5.9)	20 (4.7)	
Sexually Active (%)	51 (40.1)	182 (42.3)	0.63
Stage prolapse on POP-Q (%)			0.73
2	78 (64.5)	249 (58.9)	
3	21(17.4)	84 (19.9)	
4	4(3.3)	19 (4.5)	
Wexner >7 (%)	108 (42.9)	27 (8.1)	<0.001
ISI Score (mean±SD)	6.9 (3.9)	7.5 (3.8)	0.04

Table 2

Factors associated with oral disclosure of FI on Multivariable Analysis

Characteristic	OR[CI]
Wexner score >7	OR 9.0 [CI 5.4, 14.8]
Private Insurance	OR 1.9 [CI 1.2, 3.0]
Decreasing ISI Score	OR 1.5 [1.4, 1.6]

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Table 3

Patient Characteristics between women with Urinary Incontinence alone (UI-only) and Double Incontinence (DI)

	UI-only N= 447	DI N=557	P value
Age(Mean +/- SD*)	53.8 ± 15.4	58.2 ± 12.9	<0.01
BMI (kg/m2) (mean +/- SD)	30.1 ± 7.5	31.7 ± 7.9	<0.01
Parity(mean +/- SD)	2.5 ± 1.7	2.7 ± 1.8	0.10
Insurance (%)			
None	12 (2.7)	10 (1.8)	0.03
Private	179 (40.1)	184 (33.0)	
Public	256 (57.2)	363 (65.2)	
Ethnicity/Race (%)			
Hispanic	173 (38.7)	185 (33.2)	0.34
Non-Hispanic White	191 (42.7)	264 (47.4)	
American Indian	50 (11.2)	63 (11.3)	
African American	7 (1.6)	14 (2.5)	
Other	26 (5.8)	31 (5.6)	
Pelvic Muscle Contraction Strength (out of 5)	2.5± 1.1	2.2±1.1	<0.01
+ Empty Supine Cough Test (%)	103 (23.0)	113 (20.2)	0.32
Sexually Active (%)	238 (53.2)	236 (42.3)	<0.01
Stage 2,3,4 prolapse on POP-Q (%)	330 (73.8)	455 (81.7)	<0.01
Urinary Incontinence Disclosure (%)	385 (86.1)	485 (87.1)	0.66

Table 4

Urinary Incontinence disclosed to the physician grouped by ISI score combining UI and DI patients

ISI Score Category	Number of Patients in each ISI Category	% Disclosure of UI to the physician	Post-hoc comparisons *
ISI=1–2	65	40%	C
ISI= 3–6	246	83%	B
ISI= 7–9	267	96%	A
ISI= >9	262	98%	A

* Post-hoc pairwise comparison in order to determine where differences might be.

Letters that are different represent significant differences in disclosure of UI between groups. Overall p value is <0.001.

Table 5

Fecal Incontinence disclosed to the physician grouped by Wexner score for DI-only group

Wexner Score Quartile	Number of Patients in each quartile	% Disclosure of FI to the physician	Post-hoc comparisons *
Wexner= 1–7	217	7%	C
Wexner= >7–9	188	19%	B
Wexner= 10–14	114	50%	A
Wexner= 15–20	35	57%	A

* Post-hoc pairwise comparison in order to determine where differences might be.

Percent disclosure of FI with different letters are significantly different. Overall p value is <0.001.