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Comparison of Recall and Daily Self-Report of Fecal Incontinence Severity

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Fecal incontinence (FI), the inability to control stool loss, affects 2–5% of the general population and up to 15% of older adults living in the community.[1] It is important to study FI management since it is known that FI significantly lowers quality of life in many areas, including relationships, employment, travel, and physical exercise.[2] Knowing the severity of FI is important for researchers and clinicians studying incontinence to determine appropriate management strategies and to gauge the degree of effectiveness of interventions. The standard method for measuring FI and its severity is self-report. There is little research about the ways FI severity is reported or about the topic of FI severity itself. Although recall has not been extensively studied in the area of FI severity, several studies have evaluated recall in reports of urinary incontinence (UI) severity, which may have factors in common to FI. Researchers found that when comparing a 14-day daily urinary diary with recall data from the same period, participants reported more frequent occurrences of UI than what was actually recorded on the diary.[3] This result is consistent with earlier findings that found that participants reported a higher incidence of UI during a health history than they recorded on a subsequent daily urinary diary.[4] Although UI and FI are both types of incontinence, there are several differences that support the need to investigate this question with a specific focus on FI. FI typically occurs less frequently than UI. An episode of FI may be more noticeable and upsetting due to the distinct odor and color of leakage on clothing.[5] Therefore, it is possible that recall of FI severity may be different than UI severity recall and perhaps more comparable to daily reporting.

The specific aims of this study were:

1. To compare the severity of FI episodes as recorded on daily stool diaries during the baseline or "usual" period of bowel function to the severity of FI episodes reported by participants on a recall bowel history form completed just prior to the baseline period.
2. To examine possible covariates of the differences between data reported on daily baseline stool diaries and recall data on the bowel history in terms of demographic and health information.

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Review of Literature

Several tools or scoring systems have been developed to characterize or measure FI severity. Many of the tools used in the clinical setting rely on recall of FI symptoms such as frequency, type and/or consistency of leakage; some add a rating of the strength of the anal sphincters while others include lifestyle alterations.[6] A few use simple categories such as the outcome (e.g., continent, partially continent, totally incontinent)[7] while others calculate a numerical score using several variables. The Continence Grading Scale of Jorge and Wexner,[8] for example, calculates a score based on recall of 4 levels of frequency (never to always) of solid or liquid stool, gas, wearing a pad and lifestyle alteration.

Although no studies have compared recall and daily self-report of FI severity, researchers have evaluated patient-physician agreement on FI symptoms reported by patient recall. In developing and testing the Fecal Incontinence Severity Index, a tool used to rate the severity of FI, researchers found that patients and surgeons agreed on the severity of FI symptoms for most types of FI. A main difference in severity ratings related to the loss of solid stool.[9] Patients rated incontinence of liquid stool as more severe while surgeons considered incontinence of solid stool more severe. These findings suggest that a patient's report of FI severity is an important factor to consider. Bharucha, Locke, Seide, and Zinsmeister[10] tested the validity and reproducibility of the Fecal Incontinence and Constipation Assessment tool in a sample of 83 women with FI and/or constipation. Each subject completed the tool, and a gastroenterologist independently completed the tool for each of the participants after performing a clinical assessment. The investigators found that patients and the physician agreed on symptoms of FI severity in 77% of the cases. The investigators point out that further research should test various severity scales used by physicians against criterion such as bowel diaries completed by patients with FI.

In patients with UI, researchers comparing an individual's report of UI severity on a health history to a daily urinary diary found that participants reported more frequent episodes of UI on the health history than what they recorded on the daily urinary diary.[4] It is possible that FI recall may differ from UI severity recall. If so, factors influencing recall of FI severity should be investigated. The current study provided a unique opportunity to compare recall of FI severity on a bowel history with daily report of FI severity symptoms on a stool diary during a period before any intervention was implemented. The components of FI severity that were compared were frequency, consistency, and amount.

Methods

Study Design

This was a comparative analysis in which existing data from a parent study were analyzed. The parent study, The Impact of Fiber Fermentation on Fecal Incontinence, is the first randomized controlled clinical trial to study FI symptom management in a large sample of community-living adults (Bliss, D.Z. NINR, NIH RO1-NR07756). Participants reported their bowel pattern, diet, and physical symptoms for a 14-day baseline period. They then received one of three types of a soluble dietary fiber supplement or a placebo supplement for the remaining 38 days of the 52-day protocol. During the supplement period, participants reported the same data as during the baseline period. For this analysis, only data from the baseline period in which participants did not receive any intervention were utilized.

Sample

The sample of participants met specific eligibility criteria for inclusion into the parent study. All the participants were at least 18 years of age, lived in the community, were able to toilet independently, and experienced episodes of FI at least once per week. The first 105 participants to complete the study were eligible for inclusion in this analysis. Eligibility criteria for this analysis were completion of the parent study protocol and having data entered into a Microsoft Access database. Nine of the participants were excluded because of incomplete or unclear data for one or more of the variables used for this analysis, leaving a total of 96 participants.

Data Collection Instruments and Procedures

Three data forms were used in this analysis: a Demographic form, a Bowel History form, and a Stool Diary completed daily during the 14-day baseline period of the study. During the initial study visit prior to the baseline data collection period, the data collector interviewed participants about descriptive characteristics such age, gender, relationship status, living situation, employment status, income, level of education, self-care status, and caregiver status. The data collector reported these data on the Demographic form. Data collectors also administered the Mini Mental Status Exam[11] at the initial study visit and recorded the subject’s score on the Demographic form. The Bowel History form was completed by the data collector at the initial visit also. Participants were asked to recall their usual severity of FI in terms of frequency, consistency, and amount, and these data were reported on the Bowel History form. Participants were also used asked about the presence or absence of concurrent UI. During the 14-day Baseline data collection period, participants reported characteristics about their stools and incontinence episodes on the Stool Diary every day. Frequency, consistency, and amount of involuntary FI leakage were included among the characteristics. Participants were trained by the data collectors to use the Stool Diary independently.

Statistical Analysis

The frequency, consistency, and amount of stool data reported by participants on the Bowel History form and Stool Diary were converted into numeric codes. For example, “soft but formed” stool was coded as 2, and “loose and unformed” stool was coded as 3. A single weighted score was obtained for each subject’s FI severity reported on the Bowel History form by multiplying the individual numeric codes for frequency, consistency, and amount of FI. All Bowel History scales were measured on a 4-point scale. Similarly, weighted scores were computed for each event on the Stool Diary, and an average FI severity score was obtained from data on each of the 14 daily Stool Diaries. Originally, the measure of amount on the Bowel History form had 4 categories, while the same measure on the Stool Diary had 5 categories. Collapsing categories 2 and 3 on the stool diary resulted in the same definition as the Bowel History form.

A score difference in FI severity scores was found by subtracting the daily FI severity score (from the Stool Diary) from the recall score (from the Bowel History form). A Spearman's correlation was used to determine if recall and daily self-report of FI severity were significantly correlated. A Wilcoxon Matched-pairs Signed-rank test was used to determine if the difference between recall and daily self-report was significantly different.

T-tests or Spearman's correlations were used to assess the impact of demographic and health variables including age, gender, relationship status, living situation, employment status, MMSE score, income, level of education, self care status, caregiver status, and concurrent presence of UI was accomplished using. A T-test was used to compare the mean difference in recall and daily FI severity scores between groups defined by categorical demographic or health characteristics; a correlation was used to determine associations between differences in recall and daily FI severity scores and interval demographic variables. Data analysis was performed using SPSS (Chicago, IL), version 13.0.

Results

Description of Sample

The 96 participants in this sample had a mean age of 59 years (SD=13.4); 78 percent were women, 95 percent were Caucasian, and 45 percent had a college-level education or beyond (see Table 1). The vast majority (96 percent) was independent in self-care, and 25 percent were caregivers for another person such as a child, grandchild, or spouse. Fifty-five percent were employed or self-employed, and 47 percent had an annual income of at least 50,000 U.S. dollars.

Comparison of Severity Scores—Recall and daily FI severity scores were significantly and moderately correlated (rho=.29, p=.004). There was a significant difference between the mean recall and daily severity scores (z= −2.82, p=.005). A negative mean score difference of −0.99, indicated that participants under-reported FI severity on the recall Bowel History form compared to their report on the Stool Diary.

The median recall severity score (from the Bowel History form) was significantly lower than the median daily severity score (from the Stool Diary) (see Table 2). The individual components of both severity scores were also significantly different. These results indicate that participants under-reported the frequency of FI on the Bowel History form and over-reported the severity of consistency and amount on recall.

Influence of Demographics and Health Characteristics on Severity Score Difference

The mean severity score difference did not significantly vary with any of the following demographic, cognitive, or health characteristics: age, gender, relationship status, living situation, MMSE score, income, level of education, self-care status, ethnicity or race, year FI began, consistency of FI, and amount of FI.

The FI severity score differences of participants who had UI and FI and those who had FI only were significant. Participants with UI and FI had a higher (more positive) difference in the mean FI severity score between recall and daily self-report. This meant the participants under-reported FI symptoms on recall. There was also a significant difference between the mean FI severity scores of participants who were caregivers for another person and those who were not. Participants who were caregivers had a significantly higher (more positive) mean FI severity score difference, indicating under-reporting of FI symptoms on recall. Frequency of FI events (as measured by recall) was significantly and negatively correlated with a lesser FI severity score difference, indicating that recall and daily reporting of FI severity were more similar in participants who had more frequent FI episodes. Consistency of FI (as measured by the daily Stool Diary) was significantly correlated with a greater FI severity score difference, indicating that participants having more liquid leakage had a greater difference between recall and daily report of FI severity.

Discussion

To our knowledge, this is the first study to compare recall and daily report of FI severity symptoms. The results show that individuals with FI tend to under-report the severity of their symptoms on recall. Those who are caregivers for another person tend to under-report FI severity when asked to recall their symptoms compared to those who are not caregivers. It may be possible that those who have others relying on them for care are reluctant to acknowledge health problems of their own. In addition, previous studies have shown that those with FI often feel embarrassed or shamed by their problem and use denial as one of many coping strategies.[12]

The results of this study are consistent with previous research in that 42 percent of those with FI had UI also. Bliss, Fischer, Savik, Avery, and Mark[1] found that up to 50 percent of adults living in the community who have FI also have UI. Since there is no previous examination of the factors influencing FI recall, it is difficult to know for certain why those with UI and FI under-report their FI symptoms and those with FI only do not. It may be possible that those with FI only pay more attention to episodes of incontinence because they occur less frequently than UI episodes, and, therefore, they can more accurately recall their symptoms. It is also possible that those who have both UI and FI are more bothered or stressed and pay more attention to UI, which usually occurs more often than FI. Qualitative studies that explore how participants perceive the stress of having one versus both types of incontinence would be helpful in revealing why FI severity may be under-reported in those with double incontinence.

Interestingly, recall and daily report of FI severity are more similar in those who have a greater frequency of FI. This may due to the fact that those with frequent FI episodes are more aware of or pay more attention to their bowel pattern than those who have infrequent episodes of leakage. Participants who reported a more solid consistency of leakage on the daily Stool Diary had more similar recall and daily FI severity scores as opposed to those who had more liquid FI. Unlike the findings of Rockwood et al.[9] in which patients perceived liquid stools as being more severe, these findings suggest that participants perceived the leakage of solid stool as more severe; this perception may have made leakage of solid stool more memorable than the leakage of liquid stool. An area for future research is what facilitates recall of different components of incontinence severity.

FI severity score difference between recall and daily report did not vary significantly with participant characteristics that might be expected to influence symptom recall such as age, gender, level of education, cognitive ability as measured by the MMSE, or length of time the participant had had FI. Severity score differences between recall and daily report of FI severity varied significantly with individual components of incontinence severity, as well as with significant life stressors (such as being a caregiver) rather than with characteristics of the participants themselves.

A limitation of this study is that there is no standard, practical objective measure of FI severity. The natural course of FI for an extended time is unknown and likely varies within individuals. It is possible that the severity of FI might have decreased during the period subjects reported their bowel pattern on the daily Stool Diary, thus influencing the difference from recall.

Clinical Implications

The findings of our study show that persons with FI tend to under-report their symptoms on recall questionnaires. Under-reporting FI symptoms is most significant in those who have both UI and FI, are caregivers for another person, or have greater frequency of incontinent episodes. The findings suggest there may be denial, stigma, or embarrassment about having FI, especially by those who have others relying on them for care, which could prevent seeking help from a provider. Denial can cause patients with FI to be less likely to seek care or to report their symptoms to a clinician even if directly asked.[5] The continence nurse should inquire about incontinence symptoms with a discerning and sensitive approach, keeping in mind that patients may be reluctant to disclose this information because of the social stigma associated with incontinence[13] and need to appear capable of caring for a dependent family member. Since patients may be likely to under-report the severity of their FI symptoms for a variety of reasons, the continence nurse should ask focused questions about the severity of symptoms in order to obtain a realistic assessment of the patient’s condition and implement appropriate continence management. For research purposes, it is recommended that daily bowel diaries continue to be used on order to obtain information about the severity of FI symptoms accurately.

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Table 1

Description of Sample

	N (%)[*]
Age (years)	59.4 (13.4) Mean (SD)
Sex Female Male	75 (78) 21 (22)
Live alone	14 (15)
Live with Spouse	68 (71)
Employed	46 (48)
Self-employed	7 (7)
Caucasian	91 (95)
Black	3 (3)
Asian	1 (1)
Other racial background	1 (1)
High school graduate or equivalent	8 (8)
College graduate	15 (16)
Master’s degree	10 (10)
Doctoral degree	3 (3)
Income ≤ 19,999 (U.S. dollars)	9 (9)
Income 20,000–34,999 (U.S. dollars)	16 (17)
Income 35,000–49,999 (U.S. dollars)	17 (18)
Income 50,000–74,999 (U.S. dollars)	25 (26)
Income 75,000–99,999 (U.S. dollars)	10 (10)
Income ≥ 100,000 (U.S. dollars)	10 (10)
Independent in self care	92 (96)
Caregiver for another person	24 (25)

[*] % except where indicated

Table 2

Recall and Daily FI Severity Scores

	Recall score median (range)	Daily score median (range)	*Z* score	*P* value
Frequency	.43 (.1–5.5)	1.4(1–3.25)	−5.3	<.001
Consistency	3.0 (1.5–4.0)	2.8 (.67–4.0)	−4.7	<.001
Amount	2.0 (1.0–3.5)	1.4 (1.0–3.3)	−4.8	<.001
Total Score	2.7 (.36–24.0)	5.0 (1.2–15.5)	−2.8	.005

Table 3

Comparison by Demographic Variables of Mean FI Severity Score Differences Between Recall and Daily Self-Report

	Mean score difference (SD)	**Statistic and d.f.**	***P* value**
Caregiver			
Yes	3.8 (2.9)	t=−.34, df=94	P=.001
No	.06 (5.1)		
Sex			
Male	2.2 (3.0)	t=1.2, df=94	P=.22
Female	.7 (5.3)		
Living situation			
Live alone	1.1 (4.8)	t=.52, df=94	P=.60
Live with others	.4 (5.6)		
Relationship status			
Married or partnered	1.2 (4.3)	t=−.79, df=94	P=.43
Single	.4 (6.3)		
Employed			
Yes	.71 (5.4)	t=.58, df=94	P=.56
No	1.3 (4.3)		
Caucasian			
Yes	1.0 (5.0)	t=.02, df=94	P=.98
No	1.0 (4.1)		
Have Caregiver			
Yes	.7 (2.8)	t=−.12, df=94	P=.91
No	1.0 (5.0)		

Table 4

Associations of Demographic Variables and Mean FI Score Difference Between Recall and Daily Self-Report and FI Severity Components

	Rho value	**P value**
Frequency of FI (recall)	−.72	<.001
Consistency of FI (recall)	.16	.11
Amount of FI (recall)	−.08	.42
Frequency of FI (daily)	.14	.18
Consistency of FI (daily)	.32	.002
Amount of FI (daily)	.13	.23
Age	−.08	.42
Level of education	.11	.31
MMSE score	.15	.16
Income	.06	.59
Years since FI began	−.001	.99