Published in final edited form as:

Int Urogynecol J. 2017 September ; 28(9): 1319–1328. doi:10.1007/s00192-016-3261-8.

Validation of an instrument to assess barriers to care-seeking for accidental bowel leakage in women: the BCABL questionnaire

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Abstract

Introduction and hypothesis—Fewer than 30% of women with accidental bowel leakage (ABL) seek care, despite the existence of effective, minimally invasive therapies. We developed and validated a condition-specific instrument to assess barriers to care-seeking for ABL in women.

Methods—Adult women with ABL completed an electronic survey about condition severity, patient activation, previous care-seeking, and demographics. The Barriers to Care-seeking for Accidental Bowel Leakage (BCABL) instrument contained 42 potential items completed at baseline and again 2 weeks later. Paired *t* tests evaluated test–retest reliability. Factor analysis evaluated factor structure and guided item retention. Cronbach’s alpha evaluated internal consistency. Within and across factor item means generated a summary BCABL score used to evaluate scale validity with six external criterion measures.

Results—Among 1,677 click-throughs, 736 (44%) entered the survey; 95% of eligible female respondents (427 out of 458) provided complete data. Fifty-three percent of respondents had previously sought care for their ABL; median age was 62 years (range 27–89); mean Vaizey score was 12.8 (SD = 5.0), indicating moderate to severe ABL. Test–retest reliability was excellent for

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Short Oral Podium: International Continence Society Annual Scientific Meeting, Tokyo, Japan, September 2016; Oral Podium: American Urogynecologic Society Annual Scientific meeting (PFD Week), Denver, CO, September 2016

Compliance with ethical standards

Financial disclaimers/conflicts of interest Heidi Brown serves as a consultant for Grand Rounds, Inc; Kelly Brezoczky is the founder and former Chief Executive Officer of Butterfly Health, Inc; and Rebecca Rogers is a paid author for UpToDate and receives royalties from McGraw Hill. Meg Wise, Danielle Westenberg, Nicholas Schmuhl, and Melissa Constantine have nothing to disclose.

Ethical committee/institutional review board Our protocol was deemed exempt by the Health Sciences—Minimal Risk Institutional Review Board (#2015-0785) at the University of Wisconsin-Madison and exempt category 4 (existing data) at the University of Minnesota IRB (#1509E78527).

all items. Factor extraction via oblique rotation resulted in the final structure of 16 items in six domains, within which internal consistency was high. All six external criterion measures correlated significantly with BCABL score.

Conclusions—The BCABL questionnaire, with 16 items mapping to six domains, has excellent criterion validity and test–retest reliability when administered electronically in women with ABL. The BCABL can be used to identify care-seeking barriers for ABL in different populations, inform targeted interventions, and measure their effectiveness.

Keywords

Accidental bowel leakage; Care-seeking; Barriers; Fecal incontinence; Validation; Help-seeking

Introduction

Accidental bowel leakage (ABL), also known as fecal or bowel incontinence, is a prevalent condition that affects one in five women aged 45 years and older and is associated with significant health care costs and a negative impact on the quality of life [1–3]. Despite the existence of minimally invasive, effective therapies, fewer than one-third of women with ABL seek care [4]. Women who have greater symptom duration and severity, increased knowledge about the condition and available treatments, higher depression scores, and access to a primary care provider are more likely to seek care, but ABL remains vastly underdiagnosed [4–7].

In December 2007, the US National Institutes of Health convened a State-of-the-Science conference to assess the available scientific evidence and define future research priorities regarding the prevention and treatment of fecal and urinary incontinence [8]. In conference proceedings, experts concluded: “Efforts to raise public awareness of incontinence and the benefits of prevention and management should aim to eliminate stigma, promote disclosure and care-seeking, and reduce suffering. Organized approaches to improving clinical detection of fecal and urinary incontinence are needed and require rigorous evaluation” [8].

In 2008, the Barriers to Incontinence Care Seeking Questionnaire (BICS-Q) was validated to measure barriers to care-seeking for urinary incontinence [9]. However, almost a decade later, a standardized instrument to assess barriers to care-seeking for fecal incontinence, or ABL, does not exist. A validated instrument that identifies and characterizes barriers will inform intervention development to minimize barriers and promote care-seeking, and measure intervention effectiveness.

In previous qualitative work, our research team explored barriers that may prevent or delay care-seeking through focus groups and cognitive interviews among community dwelling women with ABL with varied earlier care-seeking experiences [10]. The purpose of the current study was to evaluate the validity and reliability of an instrument informed by this work: the Barriers to Care-Seeking for Accidental Bowel Leakage (BCABL) questionnaire.

Materials and methods

After our protocol was deemed exempt by the Health Sciences Minimal Risk Institutional Review Board (#2015-0786) at the University of Wisconsin-Madison School of Medicine and Public Health, we conducted an electronic survey of community-dwelling women with ABL to evaluate the validity and reliability of potential items for inclusion in the BCABL instrument.

Recruitment and power calculation

The sampling frame for this validation study was a convenience sample of individuals who had registered on the website www.butterfly.com and had agreed to receive further informational emails. Butterfly Health, Inc. is a company that manufactures a paper product specifically created to help manage ABL. Butterfly Health, Inc. maintains an electronic mailing list of individuals who have registered on their website and have consented to receive further informational emails, and the company agreed to send our survey invitation to their electronic mailing list free of charge. We approached Butterfly Health, Inc. because we were not aware of any other comparable electronic lists of people likely to have ABL for which they may not have sought care. Butterfly Health, Inc. did not provide any funding for this study. An email was sent from the company on behalf of the research team inviting interested individuals to participate in a survey about barriers to care-seeking for ABL with an external link to the survey platform. Reminder emails were sent every other week up to three times to increase the response rate.

Informed consent was obtained electronically and screening questions confirmed eligibility (age 18, able to read and write English, and at least one experience with ABL within the last 3 months) before linking to the survey. Those who completed the initial survey were re-contacted via email starting 1 week after initial survey completion and invited to complete a portion of the survey a second time to assess the test-retest reliability of the BCABL items. No incentive was provided for participation.

The BCABL included 42 items for noncare-seekers. The standard requirement for psychometric item and scale evaluation is 10 respondents per item [11]; thus, our target sample size was 420 completed surveys.

Survey measures

Following confirmation of eligibility, respondents were directed to the BCABL questionnaire, which contained between 42 and 49 items depending on whether one had previously sought care. The 42 items asked of all respondents used a bipolar four-point Likert response format (for example: strongly agree, somewhat agree, somewhat disagree, strongly disagree). The seven items asked only of those who had previously sought care used a semantic differential format ranging from 1 = not at all helpful to 7 = extremely helpful. The final item pool had a Flesch-Kincaid readability of 5th grade.

Respondents were also asked to complete two validated questionnaires to assess condition severity and patient activation and to provide information about standard socio-demographic measures, relevant comorbid medical conditions, perceived general health status, previous

knowledge about ABL and ABL care-seeking behavior, and access to a primary care provider. The seven-item validated Vaizey incontinence score includes questions about the frequency of incontinence over the preceding 4 weeks, use of pads, use of constipating medicines, and ability to defer defecation, and was used to assess ABL severity [12]. The short form of the Patient Activation Measure (PAM) is a 13-item validated scale assessing the patient's knowledge, skill, and confidence in managing his or her health and health care [13]. PAM score values are categorized from 1 to 4, with 1 representing the lowest level of activation (patient does not recognize his or her active or important role in his or her own health) and 4 representing the highest level of activation (patient adopts and maintains self-care behaviors).

Analysis

Descriptive analyses were performed to characterize the sample and to compare those who had previously sought care with those who had not, using Chi-squared tests for categorical variables and *t* tests for continuous variables with $p = 0.05$. Item distributions were evaluated and those with floor or ceiling effects (10% or less of responses in one of the extreme response options) were flagged for further evaluation.

Construct validity addresses the extent to which a test measures what it is intended to measure. Construct validity of the BCABL item pool was evaluated using focus groups with 29 women and cognitive interviews with 10 women, during which we identified 12 barriers to care-seeking for ABL, and generated and revised potential items for inclusion in the BCABL questionnaire [10]. A survey with a list of potential items was used as a discussion tool for each focus group and cognitive interview; it was revised in an iterative process, informed by our study participants, to reflect their lived experiences. Upon completion of this qualitative work, we had generated and refined 49 items for potential inclusion in the BCABL questionnaire.

Test-retest reliability addresses the stability of question items over a time interval for the same subject. Paired *t* tests (uncorrected) were used to evaluate test-retest reliability with a threshold of $\alpha < 0.10$ to indicate a lack of response agreement over two points of measurement. Respondents who completed the retest questionnaire within 8–21 days of completion of the validation questionnaire were included in test-retest analysis.

Factor analysis (FA) is a standard approach used in scale development. FA is an item reduction approach with the assumption that a number of items that group together will represent a factor or dimension. FA uses correlation and co-variances to identify items that are interrelated and thus group together. Eigenvalues indicate the strength of a factor or grouping; factors with high eigenvalues (>1.0) are indicative of an underlying dimension or construct, whereas factors with low eigenvalues (<1.0) indicate that the items within that factor may not be interrelated. Items within factors that emerge are further evaluated by their factor loading scores, with each item having a unique loading on each factor. High loading scores (>0.60) for an item within a factor indicate that the item is strongly associated with the factor. Ideally, items are highly associated with only one factor and demonstrate low associations (<0.40) with other factors. Factor loading scores are primary considerations in

determining which items to retain to achieve a parsimonious, practical, and theoretically consistent group of items in the final instrument.

Iterative principal components analysis and iterative factor analysis were used to identify a simple factor structure, with orthogonal (Varimax) and oblique (Promax) rotation performed to evaluate a final factor structure. Orthogonal rotation assumes that factors are uncorrelated, whereas oblique rotation assumes and allows correlation between factors. An initial confirmatory model with a 12-factor solution was evaluated, with confirmatory models used if the exploratory model failed. Several criteria were applied to evaluate dimensions and factor retention: the Kaiser–Guttman rule (eigenvalues >1.0), factor loading thresholds of 0.60/0.40, scree plots, and Kaiser–Meyer–Olkin (KMO) residuals off-diagonal partial correlations measure of sampling adequacy >0.70 [14–16]. Internal consistency was evaluated with Cronbach’s alpha, a measure of how well a set of items measure a unidimensional latent construct, or “factor” [17].

Criterion validity addresses how well an instrument correlates with an expected outcome or another measure. Correlational analysis was performed using Spearman’s rank order correlations for categorical and ordinal variables and Pearson’s correlations for continuous variables to evaluate criterion validity between the score for the BCABL instrument overall and the individual scores of the six factors comprising the BCABL with multiple external criteria. Item means were used to generate individual factor scores and summated item means were used to generate a summary BCABL score. The summary BCABL and the final individual factors were evaluated against six external criterion measures:

1. Care-seeking history (yes/no)
2. Care-seeking immediacy/less than 1 year/1–5 years/longer than 5 years
3. Length of time with ABL (less than 1 month/1 month to 1 year/1 to 5 years/more than 5 years)
4. Having a primary care provider (yes/no)
5. Vaizey score (0 = asymptomatic; 24 = severe)
6. Patient Activation Measure (PAM) level (1 = does not grasp need to play a role in one’s own healthcare; 4 = has made most behavioral changes necessary to manage care)

Results

We sent email invitations to a total of 58,579 email addresses, resulting in 9,674 unique opens (16.5%) and 1,677 unique click-throughs (17.3%). This open rate is comparable to the typical open rate for other emails sent to this mailing list (15–20%), whereas the click-through rate is higher than the typical click-through rate of 5–10%. A total of 763 individuals entered the survey, with a total of 548 meeting the eligibility criteria: 437 women and 90 men. We were not able to compare the characteristics of responders and non-responders because no demographic data are collected or maintained on Butterfly Health, Inc.’s electronic mailing list. Owing to the low number of male respondents, we focused our

analysis on women only. Demographic and clinical characteristics of female respondents are presented in Table 1, stratified by care-seeking history. Just over half of the sample (230 out of 437, 52.6%) had previously sought care for their ABL. Among those who had previously sought care, 21% did so immediately, 32% sought care within 1 year, 36% waited between 1 and 5 years, and 11% waited longer than 5 years to seek care.

Five of the 42 BCABL items were flagged for reevaluation owing to skewed distributions. Three of these items demonstrated discriminatory power across sub-groups (care-seekers or noncare-seekers) and were retained. Two items were predicated on specific behaviors (use of laxatives and previous experience with anal sex) and were excluded from further analysis.

Of the 437 eligible women who completed the initial questionnaire, 190 completed the re-test version, a 43.5% response rate. Eight respondents who completed the re-test version more than 21 days after completing the initial survey were excluded, leaving data from 182 women available for reliability analysis. None of the BCABL items had different response distributions between test and retest administrations ($p = 0.05$), confirming test-retest reliability.

Psychometric analysis

Based on our initial identification of 12 barriers to care-seeking in our prior qualitative work [10], we initially attempted a confirmatory factor analysis using a forced 12-factor solution. In a forced factor solution, the model retains all factors regardless of whether or not they meet the pre-specified minimum criteria. Our forced 12-factor solution failed to meet criteria for a satisfactory factor solution. While eigenvalues for all 12 factors were > 1.0 , several items loaded on two or more factors with less than a 0.2 loading differential between factors, suggesting that some of the 12 factors might have been too closely related.

Iterative exploratory factor models were then run, allowing the statistical program to include and discard factors that optimize pre-specified criteria, and oblique rotation was used to arrive at a final simple structure containing six factors. Results of factor analysis, including final factors, are shown in Table 2. The final items retained for all six factors had factor loadings above 0.60 and no items had second factor loadings with a differential of less than 0.40, demonstrating that these six factors were distinct rather than interrelated. Item groupings based on these factors were consistent with the conceptual barriers identified when developing the scale. Factor grouping distributions are shown in Table 2 in addition to Cronbach's alpha for each factor, a reliability estimate of internal consistency. Higher Cronbach's alpha estimates are an indication that the set of items in the factor are measuring a single underlying dimension. Alphas for four factors fell within the acceptable to good range. The alphas for fear of treatment and access limitations (0.65 and 0.59 respectively) were lower than universally desirable values, which may be attributed in part to the presence of only two items within each of these factors. These two factors were retained in the final instrument because of their conceptual importance.

Table 3 displays the results of correlational analysis to evaluate external criterion validity. Statistically significant correlations were found between total BCABL score and all the external criterion measures selected, except for ABL severity. A higher BCABL score,

indicating a greater impact of barriers to care-seeking, correlated positively with having never sought care and not having a primary care provider. A higher BCABL score was negatively correlated with care-seeking immediacy, ABL duration and severity, and a higher patient activation level. When ABL severity was evaluated using the Vaizey score as a continuous variable, it did not statistically significantly correlate with the overall BCABL score, but did correlate statistically significantly with scores for five of the six factors included in the final factor solution. When ABL severity was evaluated as a dichotomous rather than as a continuous variable (Vaizey ≤ 12 or >12), total BCABL score correlated significantly with ABL severity (Spearman's rank order correlation coefficient -0.0993 , $p = 0.036$). Factor 1 (shame/stigma) correlated significantly with all six external criterion measures; factor 2 (life impact) with five; and factors 3 (normative thinking), and 4 (knowledge of treatment) with four, indicating high external criterion validity for items within these factors.

BCABL instrument and scoring

Figure 1 depicts the final BCABL instrument. The recommended scoring approach for the BCABL is a mean calculation. All items are scored with values of 1 = strongly disagree to 4 = strongly agree, with 4 representing the greatest impact of a barrier to care-seeking, with the exception of the last item, which is reverse-scored. The sum of scores for each response is calculated and then divided by the number of items for which responses were provided. This approach allows for some missing values. Future work will include an evaluation of the number of items with missing values that are allowable to calculate a valid BCABL score.

Discussion

We present a brief, valid, and reliable instrument for assessing barriers to seeking care for ABL in women. The items in this instrument, the Barriers to Care-Seeking for Accidental Bowel Leakage (BCABL) questionnaire, had been generated and refined in previous qualitative work with a sample of women with ABL in Wisconsin [10]. In the current study, we conducted an electronic survey of women with ABL across the USA and identified 16 items from the original item pool that constitute a brief, valid, reliable instrument. These 16 items map to six factors: embarrassment/shame, life impact, normative thinking, knowledge of treatment, fear of treatment, and access limitations.

The final BCABL questionnaire includes items that map to six factors that correspond to seven of the 12 barriers identified in our preliminary qualitative work with a separate sample of Wisconsin women [10]. Factor 1, shame/stigma (SS) encompasses two barriers previously identified: embarrassment/shame (E) and stigma (S). This combination is not surprising as our qualitative analysis revealed significant overlap among many of the 12 barriers identified. The other five factors addressed in the final BCABL questionnaire each address a single barrier identified in our previous qualitative work: Factor 2 addresses life impact (LI), factor 3: normative thinking (NT), factor 4: knowledge of treatment (KT), factor 5: fear of treatment (FT), and factor 6: access limitations (AL). The last two factors were retained, despite some suboptimal psychometric properties, because of their conceptual importance. Although physical and financial limitations may not fall within the control of a potential

care-seeker, from a practical and policy perspective, specific to community-based program interventions, it is critical to understand the magnitude of the potential role of this barrier to care-seeking behavior.

The other barriers identified in our qualitative work that are not addressed as distinct barriers in the BCABL instrument include knowledge of the condition (KC), avoidance/denial (AD), self-blame (SB), provider barriers (PB), and isolation(I). It is possible that using a sample derived from an email list from a company that markets a product to help with ABL self-management meant that women already possessed some KC and thus experienced less isolation (I), although many respondents still endorsed these barriers in their responses to individual items.

In our external criterion validity analysis, we hypothesized that a higher BCABL score (indicating a greater impact of barriers to care-seeking) would positively correlate with never having sought care or having delayed care-seeking, not having a primary care provider, and having a lower patient activation level, and would negatively correlate with ABL duration and severity. These directional relationships were observed and were statistically significant for all but ABL severity when measured as a continuous variable. Interestingly, factor 1 (shame/stigma) was statistically significantly associated with all six measures of external criterion validity selected, and was positively associated with all but duration of time with ABL, suggesting that perhaps the barrier of shame or stigma might be greater initially and decrease with time. Factor 2 (life impact) represents the minimal impact of ABL symptoms serving as a barrier to care-seeking, whereas factor 3 (normative thinking) represents the perception that ABL is something inevitable and “normal”; not surprisingly, both these factors were significantly negatively associated with symptom severity and duration. The finding that life impact was negatively associated with a lower level of patient activation is interesting and may suggest that those with a higher level of patient activation might be more seriously affected by their medical conditions. One participant in our previous qualitative work who had sought care immediately for her ABL, demonstrating a high level of patient activation, was so gravely affected by her ABL that she had ultimately undergone colostomy for resolution of her symptoms. Although we expected factor 4 (knowledge about treatment) to be associated with a delayed or never care-seeking history and lower patient activation, we were surprised to find it positively associated with ABL severity, for reasons that are unclear. We expected factor 5 (fear of treatment) to be associated with care-seeking history, condition severity, primary care provider status, and patient activation, but it was significantly associated only with not having a primary care provider. This finding, in conjunction with its relatively low Cronbach alpha, suggests that this factor may not be as robust as the others, and in future studies we will further evaluate whether this factor and its items should remain included in the BCABL. Finally, factor 6 (access limitations) was associated with not having a primary care provider and lower patient activation, as expected, but was also associated with ABL severity, which was unexpected. This association may be confounded by socioeconomic factors, but is retained, as it deserves further exploration.

We evaluated respondent demographics by care-seeking status because of its relevance to the overall topic of the questionnaire. Basic demographic characteristics did not differ significantly between care-seekers and noncare-seekers in this sample, with the exception

that a higher proportion of care-seekers had completed graduate school. Although the vast majority of respondents had health insurance, care-seekers in our sample were slightly more likely than noncare-seekers to have health insurance and a primary care provider. Consistent with our related research on factors associated with care-seeking for ABL [4], women who had experienced ABL for longer, in addition to women with greater symptom severity, as indicated by higher Vaizey scores, were more likely to be care-seekers. Notably, women with inflammatory bowel disease (IBD) were significantly more likely to be care-seekers, whereas women with obesity were significantly less likely to seek care. In a recent Slovakian study, obesity was a barrier to care-seeking for urinary incontinence in women but not men [18], and the association between obesity and care-seeking for both ABL and UI in women and men should be explored in future research.

The strengths of our study include its large sample size, inclusion of women with ABL from across the USA, and the use of rigorous psychometric methodology. Limitations include the inherent limitations of an internet survey and a survey that uses an existing registry. No physical examination was performed, but examination is not generally required for the diagnosis of ABL. The relatively low number of responses from men compared with women may be related to response bias and/or a disproportionate number of women on the electronic mailing list used. Women are more likely than men to respond to both written and on-line surveys [19]. Butterfly body liners were initially available only for women, and the company expanded their product line to serve men later. Therefore, it is likely that there are more women on the Butterfly Health, Inc. electronic mailing list. However, no demographic data exist on the constituents of the list; thus, we cannot confirm whether the list contains more women than men. Although the total number of respondents (763) seems low for the number of email addresses to which invitations were sent (58,579), the open rate of 16.5% was typical for such mailings, and the rates of click through (17.3%) and survey entry (44%) were higher than average [19].

This sample excludes women who do not have internet access and is biased toward women who have taken at least initial steps in the self-management of ABL, as indicated by their use of the Butterfly Health, Inc. website; therefore, there is an inherent selection bias in our sample. However, this strategy enabled us to efficiently identify a large number of women with ABL through a venue other than a health care setting, thus increasing the prevalence of noncare-seekers in the sample. Based on the variability in our sample composition (almost 25% do not think of ABL as a medical condition and over 47% had not discussed their ABL with a health care provider), the use of the Butterfly Health, Inc. electronic mailing list provided a satisfactory sample for this validation in women. Further, although this study was conducted electronically, self-report survey-based paper-and-pencil and internet data collection methods tend to be equivalent, suggesting that a paper-based version of the BCABL might have fared similarly [20].

Conclusion

The 16-item BCABL questionnaire presented in this paper provides a valid, reliable instrument to assess barriers to seeking care for ABL among adult women in the USA. This questionnaire can be used to characterize barriers in specific populations, to inform

development of interventions to minimize salient barriers for target groups, and to measure the impact of these interventions on key barriers. In subsequent work, we will further test the responsiveness of this instrument and determine the thresholds for a number of complete response items required to maintain valid scoring.

Acknowledgments

Funding This study was funded by the National Institutes of Health (NIH K12DK100022).

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Barriers to Care-Seeking for Accidental Bowel Leakage (BCABL) Questionnaire

In this survey, accidental bowel leakage refers to the unintended loss of mucus, liquid stool, or solid stool from the rectum. Stool is also called a bowel movement, BM, or poop. Accidental bowel leakage may refer to loss of large or small amounts of stool and may happen often or once in a while.

1. To what extent do you agree or disagree with the following statements?

	Strongly Agree (4)	Somewhat Agree (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Score
Accidental bowel leakage is just another part of aging.	☐	☐	☐	☐	_____
Accidental bowel leakage is a typical bodily change for women.	☐	☐	☐	☐	_____
Accidental bowel leakage cannot be treated.	☐	☐	☐	☐	_____

2. When thinking about potential treatments for accidental bowel leakage, please indicate how much you agree or disagree with each of the following statements.

	Strongly Agree (4)	Somewhat Agree (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Score
I am worried about the side effects of treatment for accidental bowel leakage.	☐	☐	☐	☐	_____
I am afraid to have surgery for accidental bowel leakage.	☐	☐	☐	☐	_____

People who experience accidental bowel leakage often hesitate to talk to a health care provider (like a doctor or a nurse) about it. We are interested in learning more about what makes it easy or hard to talk to a health care provider about accidental bowel leakage.

3. Please indicate how much you agree or disagree with each of the following statements.

	Strongly Agree (4)	Somewhat Agree (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Score
There really isn't anything a health care provider can do to help me with my accidental bowel leakage.	☐	☐	☐	☐	_____
The cost of seeing a health care provider about accidental bowel leakage is a concern for me.	☐	☐	☐	☐	_____
Transportation to see a health care provider about accidental bowel leakage is a concern for me.	☐	☐	☐	☐	_____

Total Score Page 1 _____

Please complete page 2 of this survey →

4. Thinking about your own experience, please indicate how much you agree or disagree with each of the following statements.

	Strongly Agree (4)	Somewhat Agree (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Score
I don't want to talk with a health care provider about my accidental bowel leakage because it does not interfere with my life.	☐	☐	☐	☐	___
I don't want to talk with a health care provider about my accidental bowel leakage because I have my symptoms under control.	☐	☐	☐	☐	___
I don't want to talk with a health care provider about my accidental bowel leakage because it only happens once in a while.	☐	☐	☐	☐	___

5. To what extent do you agree or disagree with the following statements?

	Strongly Agree (4)	Somewhat Agree (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Score
I do not want to talk to a health care provider about my accidental bowel leakage because I feel ashamed.	☐	☐	☐	☐	___
I don't want accidental bowel leakage to be part of the way a health care provider thinks about me.	☐	☐	☐	☐	___
Talking about my accidental bowel leakage with a health care provider would make me feel bad about myself.	☐	☐	☐	☐	___
I don't want to talk with a health care provider about my accidental bowel leakage because it is a taboo topic.	☐	☐	☐	☐	___

6. Thinking about your own experience, how much do you agree or disagree with the following statement?

	Strongly Agree (1)	Somewhat Agree (2)	Somewhat Disagree (3)	Strongly Disagree (4)	Score
I worry about having an accident if I leave home.	☐	☐	☐	☐	___

Total Score Page 2 _____

Total Score Page 1 ___ + Total Score Page 2 ___ = Total BCABL Score _____

Mean BCABL Score = Total BCABL Score _____ ÷ (# of items answered x 4) = _____

Fig. 1.
Barriers to Care-Seeking for Accidental Bowel Leakage (BCABL) Questionnaire.

Table 1

Sample characteristics

	Care-seekers <i>n</i> = 230 (52.6%)	Noncare-seekers <i>n</i> = 207 (47.4%)	Total <i>n</i> = 437
Age (mean years, SD)	61.3 (11.9)	61.1 (12.5)	61.2 (12.2)
Race, <i>n</i> (%)			
White	188 (81.7)	162 (78.3)	350 (80.1)
African-American	13 (5.7)	17 (8.2)	30 (6.9)
Native American	4 (1.7)	8 (3.9)	12 (2.8)
Asian	5 (2.2)	5 (2.4)	10 (2.3)
Other	3 (1.3)	4 (1.9)	7 (1.6)
Ethnicity, <i>n</i> (%) Hispanic/Latina	11 (5.4)	9 (4.8)	20 (5.1)
Education *, <i>n</i> (%)			
Less than HS	1 (0.5)	3 (1.6)	4 (1.0)
HS or GRE	35 (17.1)	43 (22.9)	78 (19.9)
Some college	83 (40.5)	88 (46.8)	171 (43.5)
Bachelors	39 (19.0)	29 (15.4)	68 (17.3)
Graduate school *	47 (22.9)	25 (13.3)	72 (18.3)
Marital status (married), <i>n</i> (%)	116 (56.6)	96 (51.1)	212 (53.9)
Has health insurance *, <i>n</i> (%)	199 (97.1)	174 (92.6)	373 (94.9)
Has primary care provider *, <i>n</i> (%)	189 (92.2)	160 (85.1)	349 (88.8)
General health status, <i>n</i> (%)			
Excellent	12 (5.9)	7 (3.7)	19 (4.8)
Very good	58 (28.3)	46 (24.5)	104 (26.5)
Good	72 (35.1)	75 (39.9)	147 (37.4)
Fair	51 (24.9)	54 (28.7)	54 (28.7)
Poor	12 (5.9)	6 (3.2)	3 (3.2)
Length of time with ABL **, <i>n</i> (%)			
Less than 1 month	15 (6.5)	11 (5.3)	6 (6.0)
1 month to 1 year	25 (10.9)	61 (29.5)	86 (19.7)
1 year to 5 years	108 (47.0)	94 (45.4)	202 (46.2)
More than 5 years	82 (35.7)	41 (19.8)	123 (28.2)
ABL severity * (Vaizey score mean, SD)	13.9 (5.1)	11.7 (4.8)	12.8 (5.0)
Co-morbidities, <i>n</i> (%)			
Diabetes	32 (13.9)	40 (19.3)	72 (16.5)
Irritable bowel syndrome	76 (33.0)	55 (26.6)	131 (30.0)
Inflammatory bowel disease *	24 (10.4)	10 (4.8)	34 (7.8)
Obesity **	65 (28.3)	82 (39.6)	147 (33.6)
Chronic diarrhea or constipation	74 (32.2)	52 (25.1)	126 (28.8)
Neurological disorder	20 (8.7)	9 (4.4)	29 (6.6)
Urinary incontinence	68 (29.6)	68 (32.9)	136 (31.1)
Previous vaginal delivery	115 (50.0)	86 (41.6)	201 (46.0)

	Care-seekers <i>n</i> = 230 (52.6%)	Noncare-seekers <i>n</i> = 207 (47.4%)	Total <i>n</i> = 437
Patient activation level, <i>n</i> (%)			
1: disengaged and overwhelmed	31 (13.5)	31 (15.0)	62 (14.2)
2: becoming aware	33 (14.4)	38 (18.4)	71 (16.3)
3: taking action	105 (45.7)	92 (44.4)	197 (45.1)
4: pushing further	61 (26.5)	46 (22.2)	107 (24.5)

Due to rounding columns, percentages may not total 100%

HS high school, *GRE* Graduate Record Examination, *ABL* accidental bowel leakage

*
p 0.05;

**
p 0.01 Chi-squared, *t* tests

Table 2

Final results of factor analysis: oblique rotation ($N = 369$)

	Factor 1 Shame/stigma	Factor 2 Life impact	Factor 3 Normative thinking	Factor 4 Knowledge of treatment	Factor 5 Fear of treatment	Factor 6 Access limitations
Mean score (standard deviation)	2.19 (0.97)	2.06 (0.72)	2.07 (0.83)	2.38 (0.82)	2.95 (0.84)	1.84 (0.90)
Cronbach's alpha	0.89	0.77	0.80	0.70	0.65	0.59
Questionnaire items:						
Talking about my ABL with a health care provider would make me feel bad about myself	0.9033	-0.0090	0.0947	0.3068	0.2934	-0.1875
I don't want ABL to be part of the way a health care provider thinks about me	0.8640	0.0007	0.0972	0.2338	0.2445	-0.2029
I do not want to talk to a health care provider about my ABL because I feel ashamed	0.8782	-0.0419	0.0605	0.3445	0.2798	-0.1799
I don't want to talk with a health care provider about my ABL because it is a taboo topic	0.8287	0.0306	0.2264	0.2723	0.2518	-0.1418
I don't want to talk with a health care provider about my ABL because it does not interfere with my life	-0.0196	0.8749	0.3400	0.0035	0.1153	0.0506
I don't want to talk with a health care provider about my ABL because I have my symptoms under control	0.0818	0.7641	0.2086	0.0240	0.1024	0.0090
I don't want to talk with a health care provider about my ABL because it only happens once in a while	0.0290	0.7933	0.3208	-0.0037	0.0437	-0.0262
I worry about having an accident if I leave home	-0.1444	0.6526	0.2001	-0.0973	-0.2248	-0.0677
ABL is a typical bodily change for women	0.1621	0.2775	0.9064	0.1151	0.1472	-0.0766
ABL is just another part of aging	0.0928	0.3632	0.8983	0.0417	0.0776	0.0977
ABL cannot be treated	0.2438	-0.0698	0.0784	0.8727	0.2339	-0.0779
There really isn't anything a health care provider can do to help me with my ABL	0.3482	0.0425	0.0697	0.8639	0.1550	-0.0786
I am afraid to have surgery for ABL	0.2295	0.0833	0.1091	0.1852	0.8500	-0.0445
I am worried about the side effects of treatment for ABL	0.2952	-0.0290	0.0976	0.1896	0.8404	-0.1984
The cost of seeing a health care provider about ABL is a concern for me	-0.1557	-0.0171	-0.0267	-0.0666	-0.1159	.8266
Transportation to see a health care provider about ABL is a concern for me	-0.2027	-0.0038	0.0335	-0.0911	-0.1178	.8272

Items containing the correlates are shown in bold

Table 3

Correlational analysis to evaluate external criterion validity

	BCABL overall score	Shame/stigma	Life impact	Normative thinking	Knowledge of treatment	Fear of treatment	Access limitations
Has never sought care	0.26 ^{**}	0.21 ^{**}	0.12 ^{**}	0.28 ^{**}	0.12 ^{**}	0.04	0.04
Delayed care-seeking	0.24 ^{**}	0.21 ^{**}	0.12 [*]	0.24 ^{**}	0.16 ^{**}	0.05	-0.01
Longer time with ABL	-0.18 ^{**}	-0.11 [*]	-0.16 ^{**}	-0.22 ^{**}	0.04	-0.06	-0.07
No primary care provider	0.19 ^{**}	0.16 ^{**}	0.08	0.07	0.02	0.16 ^{**}	0.13 ^{**}
ABL severity (Vaizey)	-0.08	0.12 [*]	-0.53 ^{**}	-0.23 ^{**}	0.16 ^{**}	0.05	0.10 [*]
Lower patient activation	0.11 [*]	0.11 [*]	-0.12 ^{**}	-0.04	0.10 [*]	0.06	0.12 [*]

All correlations are Spearman's with the exception of ABL severity (Vaizey), which is Pearson's because it is a continuous variable

* $p < 0.05$;** $p < 0.01$