

VALIDATION OF AN INSTRUMENT TO ASSESS BARRIERS TO CARE-SEEKING FOR FAECAL INCONTINENCE (ACCIDENTAL BOWEL LEAKAGE)

Hypothesis / aims of study

Faecal incontinence, or Accidental Bowel Leakage (ABL), affects approximately 10% of adult women monthly and significantly negatively impacts mental health and quality of life (1). Despite the existence of effective treatments, fewer than 30% of women with ABL seek care (1). Care-seeking is associated with symptom severity and duration, knowledge of the condition, and access to a primary care physician (1), but little is known about barriers that prevent women with ABL from seeking care. We previously used qualitative methods to ascertain 12 domains for ABL care-seeking barriers and to confirm content validity of an instrument with 42 potential items mapping to those 12 domains: the Barriers to Care-seeking for Accidental Bowel Leakage Questionnaire (BCABL). Our aims with this study were to:

- 1) Evaluate test-retest reliability of the BCABL instrument
- 2) Evaluate criterion validity of the BCABL instrument

Study design, materials and methods

We invited adult women with ABL to complete an electronic survey that collected information regarding condition severity and impact, patient activation, prior care-seeking, and demographics, as well as the BCABL instrument, and invited them to complete the BCABL again two weeks later. Condition severity was assessed via the Vaizey scale (2). The well-validated Patient Activation Measure (PAM) assessed knowledge, skill, and confidence to manage one's health and healthcare (3). Descriptive analyses were conducted to characterize the sample. Paired t-tests with Bonferonni correction when appropriate were used to evaluate test-retest reliability, excluding respondents who completed the BCABL for the second time more than 3 weeks after their first response. Iterative principal components analysis and factor analysis were used to identify a simple factor structure, using several criteria for factor and item selection and retention: the Kaiser-Guttman rule (Eigenvalues > 1.0), loading thresholds of 0.60/.40, scree plots, residuals and partial correlations, and Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy > 0.75. Orthogonal (Varimax) and oblique (Promax) rotation were performed to evaluate the factor structure. Internal consistency was evaluated using Cronbach's alpha. Within factor item means and across factor means were used to generate a summary BCABL score. This summary score was used to evaluate scale validity using six external criterion measures: 1) history of care-seeking; 2) immediacy of care-seeking; 3) length of time with ABL; 4) ABL severity per Vaizey score (2); 5) access to a primary care physician; and 6) Patient Activation Measure (PAM) score (3).

Results

A total of 455 completed surveys were received from 458 eligible women with ABL. Median age was 62 years (range 27-89) and mean Vaizey score was 13.5 (sd=5.3), indicating moderate condition severity. Fifty-three percent (230/437) had previously sought care for ABL. Item distribution was evaluated to detect floor and ceiling effects and two items not meeting threshold were removed. Test-retest reliability was excellent for all items in the BCABL item pool. Following factor extraction using an oblique rotation, the final factor structure that emerged contained 6 domains with a total of 16 items retained (Table 1). Internal consistency of items within each domain was high, with Cronbach's alpha values ranging from .59 (Access Limitations) to .89 (Shame/Stigma). The Access Limitations and Fear of Treatment domains were retained despite not meeting the .70 threshold due to their theoretical and clinical relevance. All six external criterion measures were significantly correlated with overall BCABL score (Table 2).

Interpretation of results

The Barriers to Care-seeking for Accidental Bowel Leakage (BCABL) questionnaire, consisting of 16 items mapping to 6 domains, has excellent criterion validity and test-retest reliability when administered electronically in women with ABL. The strongest barriers to care-seeking for ABL are related to shame/stigma, life impact, and normative thinking. Having never sought care and not having a primary care provider are positively correlated with BCABL score (indicating greater perceived barriers to care-seeking). Having ABL for a longer duration of time and having more severe ABL are negatively associated with BCABL score (indicated fewer perceived barriers to care-seeking), as are history of immediate care-seeking and higher level of patient activation.

Concluding message

We present the first validated, condition-specific instrument to assess barriers to care-seeking among women with ABL: the BCABL questionnaire. This instrument can be used to ascertain barriers in specific populations at risk, to inform development of targeted interventions to promote care-seeking, and to measure subsequent effectiveness of these interventions. Four of the six domains retained in the final factor structure (shame/stigma, normative thinking, lack of knowledge about treatment, fear of treatment) may be addressed through dissemination of information about the prevalence, causes, and treatments available for this condition.

Table 1. Final factor loadings and internal consistency for scale dimensions and items

<i>I don't want to talk to my health care provider about my ABL because:</i>	Cronbach's Alpha	Score Mean (SD)	Factor loading
Shame/Stigma (SS)	0.89	2.19 (0.97)	
It makes me feel bad about myself			0.9033
I don't want it to be part of the way a health care provider thinks about me			0.8640
I feel ashamed			0.8782
It is a taboo topic			0.8287
Life Impact (LI)	0.77	2.06 (0.72)	
It does not interfere with my life			0.8749
I have my symptoms under control			0.7641
It only happens once in awhile			0.7932
I worry about having an accident if I leave home			0.6526
Normative Thinking (NT)	0.80	2.07 (0.83)	
It is a typical bodily change for women			0.9064
It is just another part of aging			0.8983
Lack of knowledge about treatment (KT)	0.70	2.38 (0.82)	
It cannot be treated			0.8727
There really isn't anything a health care provider can do to help me			0.8639
Fear of treatment (FT)	0.65	2.95 (0.84)	
I am afraid to have surgery for ABL			0.8500
I am worried about the side effects of treatments for ABL			0.8404
Access limitations (AL)	0.59	1.84 (0.90)	
The cost of seeing a health care provider for ABL is a concern			0.8266
Transportation to see a health care provider for ABL is a concern			0.8272

* all scales and scale items have value range of 1 to 4, with a higher score indicating greater perceived barriers to care seeking

Table 2. Criterion validity Spearman's rank order correlations

Criterion	Correlation	p-value
Has never sought care	.2295	<.0001
History of immediate care-seeking	-.2165	<.0001
Longer duration of time with ABL	-.1765	.0002
More severe ABL (Vaizey score >12)	-.0993	.0356
No primary care provider	.1914	.0001
Higher Patient Activation Measure score	-.1106	.0192

References

1. Female Pelvic Med Reconstr Surg. 2013 Mar-Apr;19(2):66-71
2. Gut 1999;44:77-80
3. Health Serv Res. 2005 Dec;40(6 Pt 1):1918-30

Disclosures

Funding: WI Multidisciplinary K12 Urologic Research Career Development Program (NIH K12DK100022) **Clinical Trial:** No **Subjects:** HUMAN **Ethics Committee:** University of Wisconsin-Madison Minimal Risk Health Sciences Institutional Review Board 2015-0786 **Helsinki:** Yes **Informed Consent:** Yes