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DEVELOPMENT AND VALIDATION OF A QUANTITATIVE MEASURE OF ADAPTIVE BEHAVIORS IN WOMEN WITH PELVIC FLOOR DISORDERS

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Abstract

Purpose—To establish validity for the Pelvic Floor Disorders Network (PFDN) self-administered Adaptive Behavior Index (ABI) and to assess whether ABI assesses known discordance between severity of pelvic floor symptoms and self-reported bother.

Methods—In addition to the ABI questionnaire, participants in one of 6 PFDN trials completed condition-specific measures of pre-treatment symptom severity (including Pelvic Floor Distress Inventory; PFDI) and health-related quality of life (Pelvic Floor Impact Questionnaire; PFIQ). The final survey was developed from an iterative process using subject and expert endorsement, factor analyses, and response distributions. Domains were created using a development cohort (n=304 women), reliability and validity was established using a validation cohort (n=596 women), and test-retest reliability was assessed (n=111 women).

Results—Factor analyses supported an 11-item Avoidance domain and a 6-item Hygiene domain. Cronbach's alphas were 0.88 and 0.68, respectively. Test-retest reliability was 0.84 for both domains. Construct validity was demonstrated in correlations between the ABI domains and baseline PFDI and PFIQ (r values 0.43 – 0.79 with all p values <0.0001). Moreover, the ABI

accounted for 8–26% of unexplained variance between the symptoms severity measure and the impact on HRQOL. Following treatment, Avoidance domain scores improved for urinary and fecal incontinence groups and Hygiene scores improved for the fecal incontinence group.

Conclusion—ABI is a reliable and valid measure in women with pelvic floor disorders. Adaptive behaviors account in part for discordance between pelvic floor symptom severity and bother.

Introduction

Pelvic floor disorders, including urinary incontinence (UI), fecal incontinence (FI), and pelvic organ prolapse (POP), are common conditions affecting one-quarter of women in the United States.[1] These disorders are associated with negative effects on quality of life, including social function, psychological well-being, body image, physical activity, and life satisfaction. [2], [3], [4],[5]

Women with pelvic floor disorders report adopting a range of behaviors to avoid embarrassment or mitigate their symptoms. In fact, those with UI or FI may be able to engage in their usual activities by resorting to behaviors with varying levels of complexity that may include wearing pads to absorb leakage, shopping only in stores with public restrooms, avoiding foods and beverages before going out, wearing only dark clothing, or carrying changes of clothes. [6] Some may avoid social or physical activities to limit their discomfort from a vaginal bulge or leakage of urine and/or stool.

Conceptually, these behaviors are the social manifestations of the human ability to adapt to various environmental and life challenges. Among these challenges are the often-embarrassing symptoms that arise from pelvic floor disorders in women and their negative impact on quality of life. While medical management options are available, they are not uniformly utilized leaving many to adapt to the effects of urinary and fecal incontinence as well as the disfigurement of pelvic organ prolapse. Moreover, these seemingly well-intentioned adaptive behaviors may have collateral consequences, such as social isolation, anxiety or the financial costs associated with absorbent products. To date, there have been no measures to quantify these adaptive behaviors among women with pelvic floor disorders.

Despite the prevalence of pelvic floor disorders, little is known about the extent or impact of adaptive behaviors used by women with UI, FI and/or POP. Some clinicians and researchers believe that adaptive behaviors may modulate a symptom's impact. If so, one would expect that greater symptom severity, as a measure of the weight of environmental challenge, should be associated with greater use of adaptive behaviors. Similarly, if a medical intervention successfully resolves the pelvic floor disorder, then one might observe a reduced reliance on adaptive behaviors.

To enable investigation of the use and effects of adaptive behaviors, a 7-site clinical trials network, the Pelvic Floor Disorders Network (PFDN) developed a 24-item draft adaptive behavior measure, initially titled, "Measure of Adaptations for Pelvic Symptoms (MAPS)." Development of this preliminary instrument included extensive literature review, input from clinical experts, telephone-administered pilot study of 42 women, and six focus groups

composed of women with UI, FI and/or POP. [7] Analysis of the focus group data yielded eight adaptation themes (disclosure, seclusion, being prepared, planning, clothing considerations, sexuality, order and intensity and outlook) that were used to further refine the preliminary adaptation measure.

The overarching goal of this body of work is to identify important concepts that contribute to quality of life not captured by measuring symptom severity or other condition-specific patient reported measures.[7] The objective of the present study was to finalize and validate the resulting measure, now named the Adaptive Behavior Index or ABI. The ABI measures adaptive behaviors among women with pelvic floor disorders and may be useful in quantifying variations in symptom severity when compared with symptom bother, impact, and overall quality of life.

Methods

Study Sample

Six distinct study datasets were used to evaluate this instrument. The datasets were created from NIH-funded Pelvic Floor Disorders Network (PFDN) observational and interventional trials conducted between 2005 and 2013 (Appendix Table 1). These studies enrolled women with a variety of pelvic floor disorders including UI, FI, and/or POP. Details of each study have been published.[8–12] Depending on the period of enrollment, a convenience subset of women from these trials was also enrolled in this study, resulting in a total study population of 873 women. All participating clinical sites obtained IRB approval and each participant provided informed research consent for this project.

Instrument design

We developed a multi-scale, quantitative instrument that captured the major themes generated in our prior assessment of adaptive behaviors. Initially, we began with the list of 24 items in the MAPS, developed by Wren et al. [7] All participants completed the MAPS. For the subset of PFDN studies that involved an intervention, women completed the MAPS prior to and following the intervention. Only baseline responses were utilized for the purpose of instrument development. Post-intervention responses were utilized to examine the ABI's responsiveness.

In order to refine the domains for ABI, we divided the study population into an item selection/domain development subset and a validation/confirmatory factor analysis subset. At the time of the instrument development, the population from each of the six studies was comprised of 605 eligible cases. These were randomly selected for measure development ($n = 304$) and measure validation ($n = 301$). Subsequently, additional cases were accrued as the PFDN trials continued enrollment ($n = 268$), and were added to the validation subset, resulting in the final validation cohort of 569 subjects. A subgroup of 111 women that included those with primary problems of UI, FI, and/or POP, was assessed for 2-week test-retest reliability before any interventions (Appendix Table 1).

At the onset, our task was to select from the original 24 MAPS items those that contributed to one or more key concepts (ie potential domains) related to adaptation while eliminating

those that were poorly correlated to each other and their scale. From the development subset, we examined missing item responses and looked for ceiling and floor effects. Items with significant missing responses (greater than 20%) and those with that were highly skewed (greater than 90% responding in one direction), were eliminated. We then performed exploratory factor analyses to discover underlying domains, keeping factors with an eigenvalue greater than 1.0. We then examined the factor loading to identify items that loaded poorly or loaded on multiple domains. Item-scale correlations, with item deletion, were used to check for internal consistency during development and any items were eliminated if the Pearson r was less than 0.20. Confirmatory factor analyses with varimax rotation, correlations as measures of construct validity and responsiveness, and measures of reliability (both internal consistency and test-retest) were then carried out in the validation subset. The final instrument and scoring instructions are included as Appendix Tables 2 and 3.

Domain Scoring

Five response options (never, rarely, sometimes, often, always) were used for each item in the ABI questionnaire. Each item was weighted equally. We linearly transformed these frequency responses into a 0–100 scale, then averaged to comprise the composite score for each domain. Thus, a higher domain score represented greater use of adaptive behaviors.

Construct Validation studies

As there are no pre-existing measures of adaptive behaviors for pelvic floor disorders, it was not possible to establish criterion validity. We did assess construct validity by co-administration of condition-specific measures with the ABI. Based on our concept of adaptive behaviors, we hypothesized that women with the greatest degree of symptom severity and HRQOL impact would report the highest use of adaptive behaviors. We measured the severity of symptoms due to pelvic floor disorders using the validated Pelvic Floor Distress Inventory (range 0–300 for UI and POP subscales and 0–400 for colo-rectal anal subscale, with higher scores indicating more symptoms)[13] and condition-specific HRQOL using the Pelvic Floor Impact Questionnaire (range 0–400, with higher scores indicating greater impact)[13]. Face and content validity of these items have been established previously for MAPS, and were not repeated in the current study.[7]

Responsiveness

Given that a subset of our validation cohort underwent discrete interventions to treat UI, FI and/or POP and our concept that adaptive behaviors should lessen with adequate treatment of the underlying pelvic floor disorder, we hypothesized that the ABI would be responsive to symptom changes following intervention. We chose this approach as it is well accepted that not all women will respond equally to such interventions, even those that are surgical in nature. Thus rather than assuming that a non-zero change would be significant, we evaluated responsiveness of each domain by measuring the relationship between changes in the individual domain scores for the ABI and changes in symptom severity at 3 months and 12 months after treatment using Pearson correlation. Severity of UI was measured using the Incontinence Severity Index (range 1–12 with higher score indicating more incontinence). [14] FI was measured with the Fecal Incontinence Severity Index. [15] POP was

characterized using the validated Pelvic Organ Prolapse Quantification system, in which ordinal categories describe the extent of vaginal prolapse, ranging from stage 0 (perfect uterovaginal support) to stage 4 (complete vaginal eversion)). [16]

We further hypothesized that adaptive behavior could account for some degree of variance explained by symptoms as measured by the PFDI upon condition-specific HRQOL as measured by the PFIQ. In order to assess this, we constructed two regression models based upon the validation sample. In Model set I, single domains of the PFDI were correlated to the corresponding disease domains of the PFIQ. In Model set II, both individual PFDI domains and the ABI domains were regressed upon PFIQ domains (in other words, the 2 ABI domains were added to each model from Model set I).

Symptoms, HRQOL, and ABI data were collected via telephone interviews conducted from a centralized location with trained staff that specialized in HRQOL telephone interviewing methodology.

All analyses were performed using SAS version 9.12 (Cary, NC). Statistical testing was two-sided and a P-value <0.05 was considered statistically significant.

Results

Participant characteristics

Participant characteristics and a brief description of each trial are summarized in Table 1. While each clinical trial focused on a particular pelvic floor disorder, women often had a combination of these disorders and treatments varied widely between studies. For the purpose of description, participants are enumerated according to the trial in which they participated. No woman participated in more than one trial.

Item endorsement and development of discrete domains

The items from MAPS were examined for missing responses and distribution using the current study population. There were minimal missing responses (<2%) except for a single item that, by design, was meant to be endorsed only by sexually active women. Several items were skewed towards 'never' such that 72% to 79% of women responded 'never' to wearing protective undergarments, using products to control odor, avoiding eating, limiting travel, holding in prolapse, avoiding sitting for long periods, and planning/scheduling around problems. As these floor effects were not extreme, all items were included in the exploratory factor analysis.

Exploratory factor analysis using the development sample of 304 women revealed three factors explaining more than 50% of the variance. Three of the 24 items failed to load on any of the three domains (items 10 "limiting foods that irritate," 18 "holding in prolapse," 24 "limiting sexual activity"), while three loaded on more than one domain (items 5 "wearing dark/long clothing," 6 "urinating whenever possible," 8 "limiting fluid intake"). These six items were then excluded and a second exploratory factor analysis performed with the remaining 18 items. This analysis demonstrated a 3-factor solution. However, item 12 "bathe/shower more than once a day" loaded on two factors. Subsequently, this item was

also excluded, leaving the preliminary index with 17 items and three domains: Avoidance, Hygiene, and Disclosure.

Using the development sample, the initial assessment of internal consistency revealed that factor three, the Disclosure domain (items 22 and 23 “dealing with problems with/without telling people”), had an unacceptably low reliability with a coefficient of 0.59. Based on the lack of sufficient homogeneity, the Disclosure domain was eliminated, resulting in the final ABI measure (Appendix Table 2), which consists of 17 items within two domains – Avoidance (11 items) and Hygiene (6 items). Using the validation subset, confirmatory factor analysis revealed 2 domains with items separated as expected into either the Avoidance or Hygiene domains.

Reliability

Internal consistency—Internal consistency was assessed in the validation subset. The Cronbach’s alpha coefficients for the Avoidance and Hygiene domains were 0.88 and 0.68, respectively.

Test – retest reliability—Analysis of test-retest reliability in the validation subset of 111 women revealed an intraclass correlation coefficient of 0.84 for both the Avoidance and Hygiene domains.

Validation studies

Construct validity—Correlation coefficients for relationships between ABI domains and baseline symptom severity for UI, FI, and/or POP stage ranged from 0.43 – 0.79 (Table 2). Over time, PFDN trials used different questionnaires based on their individual study objectives. Consequently, actual numbers reported in these analyses are less than the overall study sample. All correlations were statistically significant (p values <0.0001).

Responsiveness to change—Findings illustrated in Figure 1 show a reduction in mean ABI scores for both the Avoidance and Hygiene domains evident by three months post-treatment and maintained at 12 months. At 12 months, we observed significant correlations between changes in ABI domain scores and changes in UI and FI severity, but no such significant correlation between the ABI and changes in POP stage (Table 3).

Variance between symptoms and impact

The two regression models revealed that the ABI domains explained additional variances of 26%, 8%, and 10%, for UI, FI, and/or POP, respectively (Table 4).

Discussion

According to Wilson and Cleary[17], biologic disturbances result in symptoms that lead to organic dysfunction that, in turn, impacts health-related quality of life. Conceptually, their model allows non-biological individual factors such as symptom amplification, personality motivation, and values to impact quality of life. Environmental and personal factors may modify the effect of symptoms on HRQOL through either a direct or indirect impact on

perception of dysfunction. For example, depression and anxiety have been associated with UI.[18; 19] As symptoms of UI, FI, and POP become more severe, quality of life decreases. [20–22] In addition, adaptive behaviors as an individual characteristic can also alter the continuum between biology and HRQOL.

This study extends our prior work by refining the original measure of adaptive behaviors (MAPS)[7] into the current ABI, which incorporates quantitative scoring and explicit domains evaluating Avoidance and Hygiene behaviors. Our analyses provide empiric evidence that women reporting greater pelvic floor symptom severity are more likely to utilize adaptive behaviors. However, while the ABI was moderately responsive to changes in UI and FI, it did not appear responsive to changes in the POP Q score. This may reflect the limited power of using a categorical measure where changes in POPQ were fairly consistent. What is yet undetermined is how much change in the ABI domains constitutes a minimally important clinical difference. Nevertheless, the finding that women appear to reduce their use of adaptive behaviors with changes in their symptoms and condition specific impact is novel and consistent with our concept of adaptive behaviors.

The ABI quantifies adaptive self-management behaviors and provides a measure to better understand how self-management can affect health-related quality of life. Specifically, we can apply the ABI to statistically examine the effect adaptive behaviors have on the continuum between symptom severity and quality of life. This not only helps to explore how women self-manage these conditions, but also enables researchers to examine the gap between symptom severity, symptom bother, and quality of life. For example, the significant quality of life impact reported by a woman who leaks drops of urine once per week may be explained by the many life-altering restrictions she has placed on herself to avoid urine leakage.

In earlier focus groups, we elicited a number of themes describing a host of adaptations and coping strategies employed by women with pelvic floor disorders. Among these, seclusion, being prepared, planning, and clothing considerations were incorporated into the ABI. Other themes, including two items related to disclosure, failed to yield sufficient reliability to stand as an independent domain. Similarly, adaptive behaviors related to sexuality, while very important, could not be advanced in our quantitative measure due to the fact that approximately 50% of women were not currently sexually active. While we have focused on the most highly endorsed adaptive behaviors reported in our prior work, we understand that other adaptive behaviors not included in the ABI are likely utilized by certain women. Nonetheless, this refined version of the instrument allows us to better understand the magnitude of impact that self-management can have on quality of life.

Many women do not seek medical care for their pelvic floor symptoms.[23–25] This has been attributed to access issues or lack of appreciation for treatment options. Clinicians are aware that fear, impact on relationships, and cost also play a role. Using the ABI, researchers can now also examine the degree to which adaptive behaviors impact a woman's decision to defer medical attention or recommended treatment. Moreover, trade-offs in the form of cost and convenience to an individual woman, relative to adaptive behaviors, have yet to be examined. If the findings from our analyses are typical, there is a substantial societal benefit

from adaptive behaviors that, heretofore, has gone unmeasured. Whether this self-management is helpful and translates into individual benefit to the woman will require further exploration.

Several limitations of this work should be considered. Our study included only women, limiting the validity of the ABI for men, although they also report UI and FI, albeit at much lower rates. The study population, drawn from participants in clinical studies were fairly homogeneous. While the ABI's two domains (Avoidance and Hygiene) incorporate the majority of behaviors endorsed by women with pelvic floor disorders, they are not inclusive. Lastly, we failed to meaningfully advance our understanding of the role of adaptive behaviors relating to sexuality and coping. While clearly these are important areas that emerged in focus group sessions, the lack of uniform endorsement limited our ability to move these themes into the quantitative realm. Further research would be necessary to verify our findings in other populations.

Conclusions

The Adaptive Behavior Index is a valid and reliable two-domain, self-administered measure with established reliability and validity that captures commonly endorsed adaptations by women affected with pelvic floor disorders, including UI, FI, and/or POP. The use of adaptive behaviors accounted for a significant proportion of the previously unexplained variance between symptom severity and impact on daily activities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Changes in Adaptive Behavior Index domain scores over time following intervention for pelvic floor disorders

Among the subset of participants who underwent an intervention for pelvic floor disorders, a decrease in use of both hygiene and avoidance behaviors are noted when compared to baseline. This effect is noted at three months and sustained at one year.

Table 1

Baseline participant characteristics at time of enrollment into one of six PFDN registered clinical trials examining pelvic floor disorders

Characteristic	Category	N (%)
Age		Mean – 59.1 Range 21–88
Race	White	744 (85.2%)
	Black	80 (9.2%)
	Other	49 (5.6%)
Marital status	Married/living with partner	563 (64.6%)
	Widowed/separated/never married/divorced	301 (34.5%)
	Other	9 (0.9%)
Urinary incontinence randomized trials	OPUS *	458 (52.5%)
	RUBI *	22 (2.5%)
	ATLAS *	170 (19.5%)
	ABC *	44 (5.0%)
Fecal incontinence cohort study	ABBI *	115 (13.2%)
Pelvic organ prolapse randomized trial	OPTIMAL *	64 (7.3%)

* Description of trials:

OPUS: Randomized controlled trial (RCT) comparing anti-incontinence procedure vs. sham incisions in women with pelvic organ prolapse without stress urinary incontinence planning vaginal surgery

RUBI: RCT comparing intradetrusor injections of botulinum toxin vs. placebo in women with urgency urinary incontinence

ATLAS: RCT comparing behavioral therapy, vaginal pessary, or combination therapy in women with stress urinary incontinence

ABC: RCT comparing intradetrusor injections of botulinum toxin vs. oral anticholinergic therapy in women with urgency urinary incontinence

ABBI: Cohort study describing fecal incontinence after standard of care therapies

OPTIMAL: RCT comparing 2 surgical techniques in women with pelvic organ prolapse with stress urinary incontinence planning vaginal surgery for both prolapse and stress urinary incontinence

Table 2

Relationship between disease specific health-related quality of life and Adaptive Behavior Index domains (Pearson correlation)[§]

PFDI/PFIQ	N	Hygiene (p value)	Avoidance (p value)
Urinary Distress Inventory [*]	94	0.43 (<.0001)	0.51 (<.0001)
Urinary Impact Questionnaire [#]	94	0.61 (<.0001)	0.73 (<.0001)
Pelvic Organ Prolapse Distress Inventory [*]	362	0.32 (<.0001)	0.52 (<.0001)
Pelvic Organ Prolapse Impact Questionnaire [#]	355	0.35 (<.0001)	0.67 (<.0001)
Colo-rectal-anal Distress Inventory [*]	66	0.55 (<.0001)	0.64 (<.0001)
Colo-rectal-anal Impact Questionnaire [#]	65	0.68 (<.0001)	0.79 (<.0001)

^{*} Pelvic Floor Distress Inventory domains

[#] Pelvic Floor Impact Questionnaire domains

[§] Observed significant correlations below 0.3 are generally considered low, between 0.3 and 0.5 moderate and 0.5 or above high. (Cohen J, Statistical power analysis for the behavioral sciences. Mahwah, NJ: Lawrence Erlbaum Associates, 1988.)

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Responsiveness of ABI. Pearson correlation between changes in ABI domain scores and changes in symptom severity measures for urinary incontinence, fecal incontinence, and pelvic organ prolapse at 12 months following disease specific intervention.

Table 3

	n	Hygiene	P value	Avoidance	P value
Change in Incontinence Severity Index	44	0.26	0.09	0.41	0.007
Change in Fecal Incontinence Severity Index	42	0.45	0.002	0.34	0.02
Change in Pelvic Organ Prolapse Quantification (ordinal stage 0–4)	248	0.08	0.20	0.06	0.3

Table 4

Additional variance explained by adaptive behaviors. Coefficient of determinations from Model I (PFDI domains regressed on PFIQ domains) and Model II (PFDI and ABI domains regressed on PFIQ domains).

Pelvic Floor Impact Questionnaire Domains	Model I (PFDI only)	Model II (PFDI+ABI)
Urinary Impact	0.27	0.53
Colo-rectal-anal Impact	0.46	0.54
Pelvic Organ Prolapse Impact	0.21	0.31

PFDI: Pelvic Floor Distress Inventory

PFIQ: Pelvic Floor Impact Questionnaire

ABI: Adaptive Behavior Index