

Development of the Adaptations Index for women with pelvic floor disorders: The value of the patient's voice

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Purpose: Women with pelvic floor dysfunction often engage in adaptive behaviors to minimize their symptom experience. An adaptation index was initially developed by clinical experts and researchers. This study describes the additional benefit of conducting focus groups to capture patient's own experiences.

Methods: The NICHD-sponsored Pelvic Floor Disorders Network (PFDN) developed an Adaptation Index with 24-items generated by: (a) literature review; (b) PFDN clinical experts; (c) anecdotal patient reports; and then conducted a pilot study by telephone interview. Subsequently, six focus groups involving 35 women were conducted. Participants engaged in discussions about adaptations and reviewed the measure. Focus group themes using observation notes were generated by three independent research team members.

Results: Focus group participants confirmed several major adaptive behaviors including use of sanitary napkins or pads, and limiting food and beverage consumption. The women did not endorse items related to keeping a jar or commode nearby. Discussions yielded important modifications to items about restroom use, clothing preferences, keeping a "survival kit," and informal pessary use. The focus groups described adaptations involving social isolation and preparations for sexual relations that led to the creation of new items.

Conclusion: New measures intended to capture the impact of disease and treatment on a patient's quality of life are often developed primarily by clinical experts or researchers. This study confirmed the value of incorporating women's voices through in-depth focus groups. The process revealed important patient experiences and led to significant refinements of the measure. The revised Adaptation Index will undergo further psychometric evaluation.

1. Apply qualitative and quantitative methods to the development of psychosocial measures for use in clinical care and research.
2. Characterize the extent to which women with pelvic floor disorders (i.e., pelvic prolapse, urinary incontinence, and fecal incontinence) engage in self-initiated adaptations .
3. Describe the significant additions, deletions, and modifications made to the PFDN Adaptations Index as a result of the pilot study and focus groups.