

Towards a more scientific approach to measuring barriers to seeking health care in women with fecal incontinence: the BCABL questionnaire

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Although barriers to seeking care in women with fecal incontinence (FI) have been identified consistently in the literature [1–4], research on this topic is inadequate for methodological reasons. Most importantly, there is currently no validated technique for reproducible measurement of these barriers. Furthermore, barriers to seeking incontinence care, whether urinary or fecal, are influenced by confounding anthropological and societal variables including ethnicity, culture, geopolitical orientation, indigenous psychology, personality and the individual's understanding of health, experience of health and illness, and health services utilization [5, 6]. Hence, most of the available qualitative research data on care seeking, that is primarily based on thematic or deductive analysis of patient narratives, is not able to demonstrate the full impact of each care barrier with a significant overlap between barriers [4]. Another major problem is the assumption that care seeking is primarily dependent on the severity of FI without further critical evaluation of this observation or factor analysis to determine the contribution of other condition-specific quality of life measures [2]. In fact, mild FI is sometimes a greater problem for affected women than severe incontinence [7]. Finally, survey instruments to assess the epidemiology of FI are limited by differences in definition (incontinence to feces versus incontinence to feces and flatus, or incontinence only versus incontinence and fecal soiling), onset (over the last month or last year), severity (whether or not a social or hygienic problem) and frequency (daily or episodic) [2, 7].

It is obvious that we lack a validated and structured method to measure factors interfering with care seeking in women with FI and that we need a robust scientific approach to the development of a new research tool. Brown et al. elegantly review the subject in this issue of the *International Urogynecology Journal* [8]. The authors discuss the strengths and weaknesses of current methods evaluating barriers to seeking care in women with FI or “accidental bowel leakage”. They test the validity of a questionnaire designed to measure 12 barriers to seeking care for FI identified by the group through previous focus group discussions with 29 women and cognitive interviews with 10 women with FI. A final questionnaire was constructed comprising 42 potential items about condition severity, patient activation (knowledge level, skills and coping), prior care seeking and demographics, and was administered via an electronic survey to a cohort of women with FI who were already enrolled as consumers in a health industry database. Based on an a priori calculation of the study power, a convenience sample of 427 women completed the questionnaire at baseline, and 182 of these women repeated the test after 2 weeks. The psychometric properties were examined using rigorous statistical methodology. Test–retest reliability and criterion validity were excellent for all items with a final questionnaire structure of 16 barrier items in six domains. Acknowledging the selection bias and the low response rate (only 40% for test–retest reliability) in their study, Brown et al. propose a novel validated questionnaire for measuring barriers to seeking care in women with accidental bowel leakage – the BCABL instrument.

The BCABL questionnaire is an important milestone in health research in women for measuring the community impact of FI. For the first time, a structured and validated instrument is available to identify and analyze, both separately and collectively, the barriers to seeking care in women with FI. The ability to calculate a final score is another great advantage

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that provides a simple numerical estimate of the extent to which the barriers interfere with care and in turn a quantitative impression of the magnitude of the problem. The most significant value of the BCABL questionnaire, however, is that it combines in one instrument barriers to seeking care with condition-specific, patient action and care experience factors. This allows the health-care provider to gauge care-seeking patterns in women with FI in relation to disease severity as well as other important variables [8]. Prospective evaluation of respondents over time can assess the effectiveness of public health endeavors to influence health behavior, promote care seeking and enhance health services utilization [5]. The 16 final barrier items of the BCABL questionnaire include almost all known barriers to seeking care for FI and clearly outline the action plan agenda for improving patient access to care. This information can thus be used to support health policy initiatives and fiscal programs to expand incontinence care delivery in primary care, decrease incontinence service costs and develop patient-centered knowledge translation toolkits [2, 4, 6].

Further testing of the BCABL questionnaire in a representative community sample of women with FI recruited randomly from a population-based resource that includes sufficient numbers of ethnically diverse women and that captures high response rates will provide more data on the reproducibility of the instrument in different settings. To increase responsiveness in low resource areas and among less privileged women, a hard copy of the BCABL questionnaire should have the same validity and reliability when self-administered as when administered by electronic interview. Studying the demographic differences between responders and nonresponders to the BCABL questionnaire, that was not possible in the survey by Brown et al., will further our understanding of the relationship between patient characteristics and their attitude to health

and illness, health engagement behavior and perception of health care. It remains to be seen whether improving the health literacy of women who develop FI will overcome the knowledge barrier domain of the BCABL questionnaire and increase patient access to care in the long term.

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