

## **DEVELOPMENT 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 20% of older United States women and, like urinary incontinence (UI), significantly negatively impacts mental health and quality of life (1). Effective clinical treatments exist for both UI and ABL, yet more than 50% of women with UI and 70% of women with ABL do not seek treatment (1). A quantitative instrument has been validated to assess barriers to care-seeking for UI but does not include condition-specific domains (2). Previous qualitative work has identified multiple barriers to care-seeking for UI, many of which are condition-specific: 1) fear of treatment; 2) lack of knowledge about treatment; 3) communication issues; 4) provider barriers; 5) avoidance/ denial; 6) normative thinking; 7) other priority health issues; and 8) limitations to access (3). In contrast to care-seeking for UI, little is known about care-seeking barriers for ABL. Thus our aims were to:

- 1) Develop and revise an instrument to identify barriers to care-seeking for ABL; and
- 2) Compare care-seeking barriers for UI and ABL

### Study design, materials and methods

We developed a preliminary instrument, the Barriers to Care-seeking for Accidental Bowel Leakage (BCABL), based on the existing validated instrument to assess UI care-seeking barriers (2) and incorporating items to assess condition-specific domains previously identified for UI (3). We then conducted six focus groups of women with ABL to gain feedback about this instrument. For this IRB-exempt study, recruitment was by self-referral from flyers, online posts and newspapers. Eligibility screening was by phone or email; women were included who were >18, had experienced ABL in the past three months, and were not currently receiving treatment for ABL. Focus groups consisted of introductions followed by a semi-structured, open-ended discussion of the survey instrument, item by item, facilitated by a trained moderator. Participants received ABL education and \$US 50 cash reimbursement. Groups were audio-recorded and transcribed verbatim. Two researchers conducted thematic analysis independently and discussed together until consensus was reached. Analyses informed revisions to the survey instrument between groups 1-2-3-4 based on data obtained. Saturation was reached after group 4; groups 5-6 were confirmatory and only minimal revisions were made to the survey instrument between those groups. Final ABL care-seeking themes were established and characterized by constantly comparing within and across the focus groups and with previously identified UI care-seeking barriers.

### Results

Twenty-nine women participated in six focus groups. Ages ranged from 46-85 (75% were >60); 86% were White, 10% African-American, and 4% Latina. The initial BCABL instrument included six introductory yes/no questions followed by two multi-item questions that assessed various potential barriers, both general and condition-specific. These questions contained seven to ten items with the stem, "Below is a list of reasons that a person may avoid or delay talking to a doctor about accidental bowel leakage. Please indicate how important each of these reasons is or has been to you," with possible responses on a 5-point Likert scale from "not at all important" to "extremely important". During the first three focus groups, proposed barriers were revised based on data provided by participants, and response options were varied from a 5-point Likert scale to a 3-point Likert scale and then to yes/no/not applicable options. Based on participant confusion, question stems were simplified to read, "To what extent do you agree or disagree with the following statements?" with no more than five items to a given stem and with response options on a 5-point Likert scale from "agree strongly" to "disagree strongly". The final instrument contains a total of 27 items and includes yes/no questions, multiple choice questions, Likert scale options, and open-ended questions based on data obtained from focus groups. This instrument is now being tested in cognitive interviews with individuals in preparation for a quantitative validation study.

We identified a total of twelve domains for ABL care-seeking barriers. Barriers 1-8 were identical to the previously identified UI care-seeking barriers (see hypothesis). Four interrelated barriers, 9-12, were unique to ABL. 9) Isolation was expressed as being alone and not having role models: "Most of us have never known anybody with this problem who's talked about it enough to actually, like, sort of show us a path. So you feel very isolated." Isolation was related to 10) Stigma, expressed generally as shame and guilt: "I'm the only one in this room that has this problem coming to the doctor and everybody's looking at me and I'm ashamed to talk about it. So I'm going to keep my mouth shut." This shame led to keeping ABL a secret: "Maybe I don't ever have to tell [my children]. I could have a stroke or a heart attack, they'll never know, you know? Just quietly die..." and "...I don't mention it, they don't notice it, it's my little secret...I don't want this to be part of my story of who I am." Stigma was also related to 11) Self-blame, or "There's something I did that made it happen..." including socially stigmatizing events, "Probably this is because I had anal sex...Oh my gosh, it was just two times in my whole life," or "I was raped as a child, and I figured that's what it was from." Other activities entailed, "I took a lot of laxatives, and that's bad, you know, so I did this to myself," or "I ate something wrong. I did some off-the-grid socializing in the Bahamas and got amoebic dysentery." Isolation, stigma and self-blame were all associated with 12) Not knowing that ABL is a common, treatable condition: "I didn't really know that it was a condition that I should go to the doctor about," or "How would you know whether you have it if it doesn't have a name? How can you talk about something you don't even know what it is?"

### Interpretation of results

Simplified question stems were more effective than complex question stems to assess ABL care-seeking barriers. Smaller item groupings (3-5) were preferable to larger item groupings (7-10). It was important to participants that the instrument include at least one open-ended item so that those who wanted to could share additional information.

ABL care-seeking barriers included and expanded upon those identified for UI. Notable differences between UI and ABL include isolation, ABL-specific stigma, self-blame, and not knowing about the prevalence, causes and treatments for ABL. While normative thinking is a barrier to care-seeking for both conditions, isolation and stigma play a larger role for women with ABL. In prior quantitative work fewer than half of women with ABL had heard of "faecal incontinence" or "bowel incontinence" (1) and in this qualitative study respondents provided context: perception that it does not have a name and is not a condition appropriate for medical attention.

### Concluding message:

Given the low rates of care-seeking for both UI and ABL, validated instruments that assess condition-specific barriers to care-seeking are imperative. Development and validation of an instrument to assess barriers to care-seeking for ABL is underway. Many of the barriers to care-seeking for ABL could be addressed through dissemination of information about the prevalence, causes, and treatments available for this condition. Whereas many US women receive information about the prevalence and treatability of UI through direct-to-consumer advertising of medical therapies, there is limited advertising of ABL treatments, so public health campaigns need to promote this information. The National Institutes of Health has launched a Bowel Control Awareness campaign (<http://bowelcontrol.nih.gov/>) and the Healthy Mature Living Foundation has developed an informative website, "Living Well with ABL" ([www.ABLinfo.org](http://www.ABLinfo.org)), but additional efforts are needed to promote awareness of the prevalence, causes, and treatments for ABL.

### References

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