

# Quality of life impact in women with accidental bowel leakage

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## SUMMARY

**Background:** Accidental bowel leakage (ABL) is associated with negative impact on quality of life (QoL) and many women do not seek care. **Objectives:** To assess current perspectives and QoL among women with ABL; to identify factors associated with severe impact on condition-specific QoL; and to describe care-seeking for ABL. **Design, setting and participants:** Sub-analysis of 1096 women with ABL identified through an internet-based, self-administered survey of 5817 US women  $\geq 45$  years old. **Main outcome measure:** Severe impact on QoL was defined as response of 'affects very much' or 'greatly' to any of seven domains within Pelvic Floor Impact Questionnaire. **Results:** QoL data were available for 85.6% (938/1096) of women with ABL. Domains relating to frustration, emotional health and participation in social activities demonstrated the greatest negative impact, with 39.2% (95% CI 36.1–42.4%) having overall severe impact. More frequent ABL, faecal urgency, nocturnal bowel movements, FI without warning, stress FI, weekly urinary incontinence and underlying bowel disorder were associated with severe impact on QoL. Of the 28.6% (268/938) of women who spoke to a physician about their ABL, the majority did so with a general practitioner or family physician (56.0%, 150/268). Only 19.0% (51/268) consulted an internist or gastroenterologist [27.2% (73/268)]. **Conclusions:** Nearly 40% of adult women with ABL have severe negative impact on QoL, but less than one-third seek care. More than half of those who seek care do so with their primary care provider. Improved awareness of the prevalence and impact of FI by these providers may decrease barriers and improve QoL.

## Introduction

Faecal incontinence (FI), defined by the International Continence Society (ICS) as 'the involuntary loss of liquid or solid stool that is a social or hygienic problem,' has a significant negative impact on quality of life (QoL) even if the condition is infrequent (1,2). In our companion manuscript in this journal, we report a prevalence of 18.8% for at least yearly FI among community-dwelling United States (US) women 45 years and older, and a prevalence of 13.9% when including social or hygienic impact (3). We also report that most women with this condition prefer the term accidental bowel leakage (ABL) to describe it (3).

In 2007, the National Institutes of Health (NIH) consensus panel concluded that efforts to raise public awareness about FI or ABL 'should aim to eliminate stigma, promote disclosure and care-seeking, and

reduce suffering' (4). Thus, the goals of the Mature Women's Health Study were to update prevalence rates for ABL and explore current impact on QoL and care-seeking behaviour. While negative impact on QoL has been fairly well established (2,5–13), rates of care-seeking for this condition vary widely and remain low, ranging from 8% to 27% (7,14,15). These low rates may be explained by embarrassment associated with FI, as well as poor understanding by the public of treatment options (16,17).

The objectives of this study were to (i) update the current literature regarding attitudes, perspectives and QoL among women with ABL; (ii) identify factors associated with severe impact on condition-related QoL; and (iii) determine rates of care-seeking in a large sample of community-dwelling, internet-accessible women with ABL. Our hypotheses were that a significant proportion of women with ABL would express distress related to this condition and

### What's known

Nearly one in five mature US women suffers from faecal incontinence or accidental bowel leakage. Although the negative impact of this condition on quality of life has been explored, little is known about emotional well-being, perspectives and coping. Despite its significant negative impact on quality of life, rates of care-seeking for this condition vary widely and remain low, ranging from 8% to 27%.

### What's new

In the largest existing sample of US women with faecal incontinence, nearly 40% report a severe impact on quality of life, and many endorse sentiments of wishing to get one's normal life back or feeling frequently depressed, indicating a negative impact on emotional well-being as well. Still, less than 30% have sought care from a physician. More than half who sought care did so with their primary care provider (PCP).

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### Disclosures

Heidi Brown has nothing to disclose. Steven Wexner is a paid consultant in the field of faecal incontinence for Ethicon, Inc., Oceana, Ventrus, Renew Medical, Inc., and Medtronic. Mark Segall is a paid consultant for Renew Medical, Inc. Kelly L. Brezoczky is a former employee of Renew Medical, Inc. Emily Lukacz is a paid consultant for Pfizer, consultant and recipient of grant funding from Johnson and Johnson, and research and educational grant funding from National Institutes of Health and Renew Medical, Inc. Renew Medical, Inc. markets devices for the treatment of faecal incontinence.

### Prior presentations

Society for General Internal Medicine 34th Annual Meeting May 4–7, 2011; International Urogynecological Association 36th Annual Meeting June 28–July 22, 2011; American Urogynecologic Society 32nd Annual Meeting September 14–17, 2011.

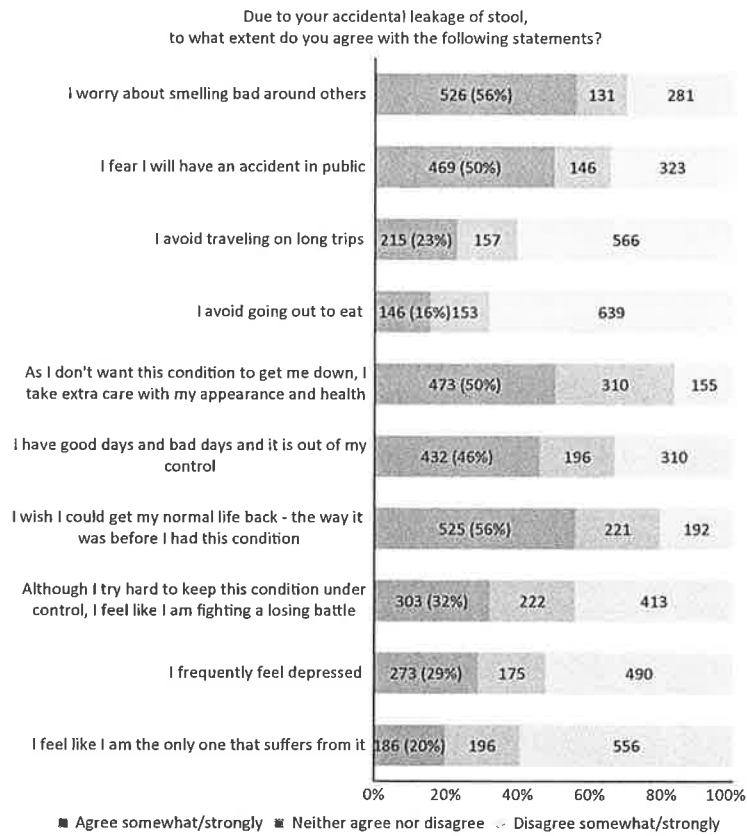


Figure 1 Attitudes & perspectives regarding accidental bowel leakage (ABL) (N = 938).

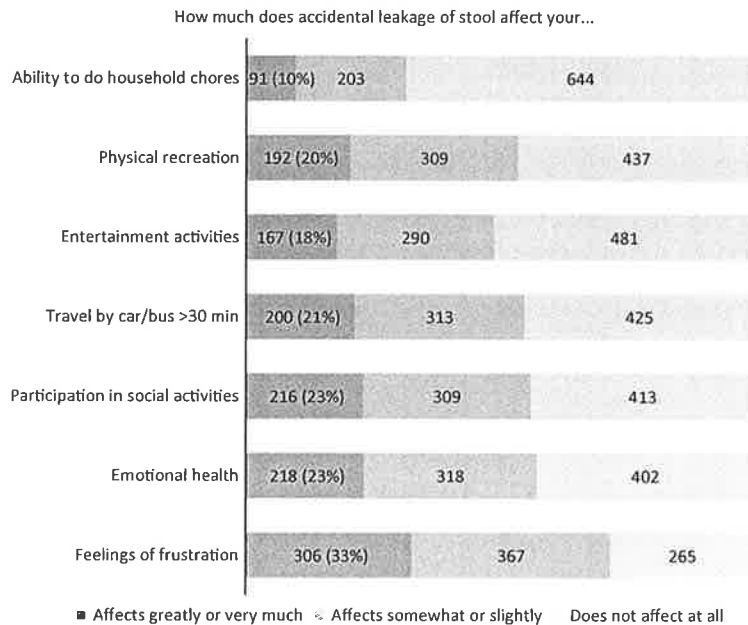


Figure 2 Impact of accidental bowel leakage (ABL) on quality of life (N = 938).

Using a definition of at least one episode of bowel leakage per year, the prevalence of ABL was 18.8% (1096/5817; 95% CI: 17.8–19.9%), and 97% (1064/1096) expressed ‘bother’ related to this condi-

tion. Of women with ABL, 28.8% (316/1096), vs. 14.8% (701/4721) of women who were continent of stool, rated their general health as fair or poor (p < 0.001). Complete data regarding attitudes and

Table 1 Continued

| Characteristic                    | Severe impact on QoL n (%) | Multivariate OR (95% CI) | p-value      |
|-----------------------------------|----------------------------|--------------------------|--------------|
| No ABL without warning            | 74 (22)                    | –                        | –            |
| Has ABL without warning           | 294 (49)                   | <b>1.72 (1.18, 2.50)</b> | <b>0.004</b> |
| No flatal incontinence with ABL   | 83 (23)                    | N/S                      | –            |
| Flatal incontinence with ABL      | 285 (49)                   | –                        | –            |
| Does not have stress ABL          | 174 (29)                   | –                        | –            |
| Has stress ABL (activity-related) | 194 (59)                   | <b>1.56 (1.08, 2.23)</b> | <b>0.017</b> |
| No small amounts of ABL           | 53 (24)                    | N/S                      | –            |
| Has small amounts of ABL          | 315 (44)                   | –                        | –            |

QoL, quality of life; OR, odds ratio; CI, confidence interval; DM, diabetes mellitus; ABL, accidental bowel leakage; UI, urinary incontinence; BM, bowel movement; N/S, non-significant. Bolded odds ratios highlight statistically significant variables that remained in the model.

perspectives, coping, QoL and care seeking were available for 85.6% (938/1096) of women with ABL.

Figure 1 outlines condition-specific attitudes and perspectives among women with ABL as assessed by their agreement or disagreement with ten statements. The most commonly endorsed statements were worry about smelling bad, fear of having an accident in public, taking extra care with one's appearance, and wishing to get one's normal life back (Figure 1). Almost one-third of women with ABL endorsed feeling that they were fighting a losing battle, and 29% reported frequently feeling depressed (Figure 1).

Figure 2 displays perceived impact on QoL in seven domains included in the PFIQ as assessed by responses to statements about how much ABL affects one's life: greatly, very much, somewhat, slightly, or not at all. The greatest impact was seen in domains relating to frustration, emotional health and participation in social activities. A total of 39.2% (95% CI 36.1–42.4%; 368/938) of women with ABL were categorised as having severe impact on QoL in one or more of the seven domains listed in Figure 2. Table 1 presents factors associated with severe impact on condition-specific QoL. The first column displays the proportion of those with severe impact on QoL stratified by various factors. The next column shows the odds ratios of those factors that remained associated on multivariate logistic regression analysis.

On multivariate analysis, more frequent ABL, faecal urgency, nocturnal bowel movements, ABL without warning, stress ABL (leakage of stool with activity), weekly urinary incontinence and underlying bowel disorder (IBS or IBD) were positively associated with severe impact on condition-specific QoL (Table 1). Considering one's general health as 'good' and age category 65–74 were inversely related to

severe impact on condition-specific QoL. While prior stroke, self-reported race/ethnicity, income, insurance status, diabetes mellitus, care-seeking for ABL, flatal incontinence and ABL of small amounts (smudges/stains) were all significant in univariate analyses, these variables did not remain in the multivariate model (Table 1).

When asked about whether they had spoken to anyone about their ABL, 51.0% (478/938) had spoken to a friend, partner or loved one, and only 28.6% (268/938) had spoken to a physician about this condition. Those who had discussed their condition with a physician were asked to specify the type(s) of physician with whom they spoke. Most women who spoke to a physician about their ABL did so with a general practitioner or family physician (56.0%, 150/268); 19.0% (51/268) consulted an internist and 27.2% (73/268) spoke with a gastroenterologist (Figure 3).

## Discussion

As evidenced in our companion paper, ABL is common and has a significant negative impact on QoL. Women with ABL have worse overall perceived health than those without ABL and nearly a third feel defeated or depressed. ABL has severe impact on QoL in nearly 40% of those who suffer leakage at least once a year. Despite these large numbers, still few women seek care. It is important to note that among those in this sample who did seek care, the majority did so with their primary care physician. In keeping with the 2007 NIH consensus conference recommendations, we hope that these data stimulate discussion among patients and providers with the ultimate goal to relieve suffering through accurate

because most women see a PCP, or because they feel most comfortable with their PCP, or because PCPs are more likely to screen for this condition. Interestingly, the practitioners who specialise in evaluating problems such as IBS, IBD and anal sphincter defects subsequent to vaginal delivery are the physicians least likely to be consulted by these women. Specifically, only 19/268 patients (7.1% of those who sought care) were evaluated by colorectal surgeons and only 73/268 patients (27.2% of those who sought care) were seen by gastroenterologists.

The strengths of this study include its large sample size, high response rate, and the incorporation of questions from validated questionnaires whenever possible. The internet-based administration may have facilitated more honest responses given the sensitive nature of many of the questions asked. Limitations include the inherent limitations of survey research: possible reporting, response, and recall bias, as well as limitations of an internet survey specifically, including selection bias, which can limit generalisability to the overall population, and risk of incomplete data as respondents self-administer the survey privately and anonymously. We did not have data on obesity, prior hysterectomy, hormonal status or comprehensive medical history. Despite its limitations, the Mature Women's Health Study is the largest internet community-based assessment of ABL conducted in the US to date. The subsample used for this analysis comprises the largest sample of women with ABL studied thus far, and is almost twice the size of the next largest study of 503 Olmstead County, Minnesota residents with ABL (7).

In this sample of women with ABL, almost 40% of women had a severe impact on QoL, but less than 30% sought care for their condition. This finding highlights the fact that a campaign of public awareness as well as awareness amongst general practitioners and family physicians is sorely needed, and may prove fundamental to the improvement of QoL of these women. The dramatic under-reporting of the

problem to PCPs, colorectal surgeons and gastroenterologists is even more significant when a prevalence of ABL of 20% is considered. These data provide clear testimony to our need to increase public and healthcare provider awareness about this condition, which should be referred to as 'accidental bowel leakage,' or ABL when communicating with patients and the public. Special efforts should be made to target women with more severe ABL, concomitant UI and underlying bowel disorders, as they appear to be at increased risk for severe negative impact on QoL.

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## Author contributions

Heidi Brown participated directly in the literature search, figures, data analysis and interpretation, and manuscript writing. Steven Wexner and Mark Segall participated directly in the study design, data interpretation and manuscript writing. Kelly Brezoczky participated directly in the literature search, figures, study design, data collection, data interpretation and manuscript writing. Emily Lukacz participated directly in the literature search, figures, study design, data analysis and interpretation, and manuscript writing.

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