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Barriers to seeking care for accidental bowel leakage: a qualitative study

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Abstract

Introduction and hypothesis—Fewer than 50 % of women with urinary incontinence (UI) and 30 % of women with accidental bowel leakage (ABL) seek care. We sought to describe barriers to care seeking for ABL to inform development of an instrument to measure these barriers.

Methods—We recruited women with ABL with varied prior care-seeking experiences to participate in focus groups and cognitive interviews so we could understand factors that may have prevented or delayed care seeking. Focus groups continued until thematic saturation was reached using conventional content analysis. Final themes were established and characterized by comparing within and across the focus groups and with previously described UI and ABL care-seeking barriers. Cognitive interviews were confirmatory.

Results—Thirty-nine women (aged 46–85) participated in six focus groups and ten cognitive interviews; 89 % were white, 8 % African American, and 3 % Latina. We identified 12 barriers to seeking care for ABL: (1) Lack of knowledge about the condition; (2) Lack of knowledge about treatment; (3) Fear of testing/treatment; (4) Normative thinking; (5) Avoidance/ denial; (6) Life impact; (7) Embarrassment/shame; (8) Self-blame; (9) Stigma; (10) Isolation; (11) Provider barriers; (12) Access limitations. These 12 barriers encompassed three overarching themes: the internalized self in relation to ABL; perceptions about ABL and its treatments; and interaction with the healthcare system.

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Compliance with ethical standards

Conflicts of interest Heidi Brown serves as a consultant for Grand Rounds, Inc. Rebecca Rogers is a paid author for UpToDate and receives royalties from McGraw Hill. Meg Wise has nothing to disclose.

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Prior presentations

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Conclusions—ABL care-seeking barriers are similar to those described for UI, with the notable addition of lack of knowledge that ABL is a medical condition experienced by others. Interventions to promote access to effective treatments for ABL should include information about prevalence and treatability.

Keywords

Accidental bowel leakage; Care-seeking; Barriers; Fecal incontinence; Patient perspective; Help-seeking

Introduction

More than 60 % of noninstitutionalized older women in the United States (US) have urinary incontinence (UI) and/or accidental bowel leakage (ABL) [1]. While effective clinical treatments exist for both [2–5], more than 50 % of women with UI and 70 % with ABL do not seek treatment [6]. Further, women with both UI and ABL who seek clinical care are more likely to do so for their urinary symptoms and often do not mention their ABL to a healthcare provider [7, 8].

Condition-specific barriers to care seeking among women with UI have been well described [9–18]. For UI, both lack of knowledge about treatment (KT: thinking nothing can be done or that treatment options are not effective) and fear of treatment (FT: including fear of medication side effects and surgery or its complications) have been described [9, 11, 13, 16–18]. Normative thinking (NT) is the attribution of symptoms to a physiologic process such as aging or childbirth [9, 11, 13, 16, 18]; avoidance/denial (AD) refers to hopes that the issue will resolve itself or go away if ignored; life impact (LI) relates to the perception that incontinence is not as important as other health issues that need to be addressed during the health-care encounter [9–11, 16]. Embarrassment/shame (E) may hinder discussion with a health-care provider and may be associated with stigma (S), isolation (I), and self-blame (SB) [13, 17, 18].

Provider barriers (PB) include prior negative care-seeking experience and lack of comfort with a specific provider due to gender or relationship [9, 16, 17] and are condition-specific external barriers. Access limitations (AL) encompass external barriers that tend not to be condition-specific, such as issues related to cost, transportation, time lost, etc. [17, 19].

In contrast to barriers to care seeking for UI, condition-specific barriers to care seeking among women with ABL have not been extensively studied. Care-seeking for ABL among US women has been associated with greater symptom duration and severity, prior knowledge about the condition and available treatments, higher depression scores, and having a primary care physician [6, 20]. However, ABL remains severely underdiagnosed and treated, even in primary care clinics where 3 % of patients have the diagnosis listed in their chart despite 36 % reporting symptoms [21, 22].

The only large study to date exploring barriers to care seeking for ABL is a qualitative analysis of responses to open-ended survey questions in >600 adults in the UK with inflammatory bowel disease (IBD) and ABL [23]. In this predominantly female sample,

similar barriers to those for UI care seeking were described, including: KT, FT, AD, LI, E, S, PB, and AL [23]. In a 2001 study of multiparous United Arab Emirates women, reasons for not seeking care for ABL included KT, NT, AD, and E [24]. In a 2014 qualitative study of 11 US women with ABL being seen by a urogynecologist, issues related to KT, E, and PB emerged [25].

The relevance and generalizability of these limited findings to women with ABL without IBD and to US women are unknown. Thus, the objectives of our study were to describe and characterize barriers to care seeking for ABL among US women to inform development and revision of an instrument to assess these barriers and to compare our findings with existing knowledge about barriers to care seeking for UI and for ABL.

Materials and methods

After our protocol was deemed exempt by the Health Sciences Minimal Risk Institutional Review Board (#2014-0382), we conducted focus groups and cognitive interviews with community-dwelling women with ABL who had and had not previously sought care to understand factors that may have prevented or delayed care seeking. Flyers were posted in restrooms, clinics, senior centers, and community centers, and short articles were posted online and in local newsletters and newspapers. Interested candidates were screened by senior researchers via phone or email to ensure eligibility (women at least 18 years old who had experienced ABL in the last 3 months and were not currently receiving treatment) and to ascertain care-seeking status. Women at least 18 years old were eligible if they responded affirmatively to this question: “In the last 3 months, since about (date with reference holiday/season), have you had any accidental passage of liquid or solid stool or mucus from your rectum? Here, we are not asking about accidents when you have acute diarrhea or food poisoning. We are asking about accidents that happen during otherwise normal times. Have you had any accidents like this in the last 3 months?” and affirmatively or negatively to the question: “Have you ever discussed this accidental bowel leakage with a health care provider?” Women were excluded if they were currently undergoing treatment for ABL. Focus groups were coordinated based on convenience for eligible participants and included those who had or who had not previously sought care. Between four and eight women were recruited for each focus group, and groups were conducted until thematic saturation was reached.

Each 90-minute focus group was facilitated by a trained moderator who was not part of the research team. Following introductions, participants were asked to take several minutes to imagine what talking with a healthcare provider about their ABL might be like. A paper survey consisting of a list of hypothesized barriers to seeking care for ABL was then distributed and used as a discussion tool. The first discussion tool comprised 14 items addressing each of the nine barriers that had been previously described in the literature regarding care seeking for ABL. Results of the ongoing analyses informed revisions of the discussion tool between groups to reflect women’s lived experience related to their barriers to seeking care for ABL so that some items were revised, some removed, and others added after each group. The moderator followed a semistructured, open-ended interview script to facilitate discussion about each item in the discussion tool. At the conclusion of each focus

group, participants were asked to confirm the moderator's summary of main points and to provide additional insights. The discussion tool was revised following each group to explore new barriers that emerged during groups.

Ten individual cognitive interviews lasting 60–90 minutes were conducted by one of two senior researchers for this study. The semistructured, open-ended, cognitive interviews elicited women's perceptions of clarity, meaning, and relevance of items in the revised discussion tool reflecting barriers identified in focus groups. Each focus group and cognitive interview participant received a folder of information about ABL as well as \$50 cash in exchange for participation. Participants were also invited to stay for an optional 20-minute educational session about ABL following adjournment of the group. All group discussions and cognitive interviews were audiorecorded and transcribed verbatim. We used conventional content analysis—a method of inductive coding used to understand little-understood social phenomena from the perspective of people with the experience of living with the condition—for our iterative analysis of the de-identified transcripts [26]. Throughout the process, two researchers coded independently and then discussed until agreement was reached. The analysis began with line-by-line coding to understand participants' assessment of the relevance and experience behind the items in the paper survey and how they related to the known barriers to care seeking for ABL and UI. Finally, three overarching themes into which barriers could be categorized were identified.

The original focus group size of seven to eight women was decreased to three or four, as 90 minutes did not allow women in larger groups to share to the extent they wished. Saturation was reached after focus group 4, meaning that no new barriers were discovered in focus group 5 or 6, and thus no new informants were needed [27]. Final survey items were categorized into barriers by comparing within and across focus-group data. A similar process was used to analyze the cognitive interviews to confirm relevance, clarity, and meaning of the identified barriers and items in the discussion tool.

Results

Thirty-nine women (aged 46–85) meeting inclusion criteria participated in six focus groups and ten cognitive interviews; 89 % were white, 8 % African American, and 3 % Latina. By the fourth focus group, we had identified 12 barriers to care seeking for ABL; no new barriers emerged. Focus groups 5 and 6 were confirmatory, and saturation was met [27]. Cognitive interviews reinforced these findings and informed additional minor revisions to wording on the list of items on the discussion tool.

Table 1 provides representative quotes and discussion tool items related to each of the 12 barriers identified. Lack of knowledge about the condition (KC) was an unanticipated barrier that emerged in the first focus group and was emphasized in all six groups and many cognitive interviews. Distinct from lack of knowledge about treatment options and efficacy, women were unaware that ABL was a medical condition and reported that it had not even occurred to them to talk with a healthcare provider about this issue. Other barriers expressed were lack of knowledge about the condition (KT) and fear of treatment (FT), which

included fears of the evaluation process itself and that care seeking would lead to an unwanted diagnosis or that treatment would be ineffective or have intolerable side effects.

Normative thinking (NT) about ABL being a normal part of aging was endorsed by women in each focus group. Similar perceptions about ABL being inevitable because of being inherited or a result of childbirth were also placed in this category. Many women expressed sentiments of avoidance/denial (AD), hoping that symptoms were an aberration or that they would resolve without intervention. Life impact (LI) either promoted care seeking or deterred it. When symptoms were episodic or when women had competing medical issues and limited time with a provider, ABL was often not addressed because of its minimal life impact. Conversely, multiple women noted a tipping point when symptoms interfered with life to an extent that they decided to seek care. Often, it was an experience that caused embarrassment (E) that participants described as motivating them to seek care.

Embarrassment was often mentioned in conjunction with time limitations: “You’re only allotted 15 minutes and doctors want to take the first two things, you know. You have to talk about the most important thing... And if you’re embarrassed already, you’re probably going to leave it to the end and say, ‘Well, by the way,’ – and they’re already thinking of something else or on the way out to their next appointment.”

We found that stigma (S) manifested as deeply-felt shame in violating a social taboo to not talk about the bowels and concealing their ABL. Women used vivid terms—bad, smelly, dirty, funky, nasty—to describe how ABL assaulted their sense of self and impacted normal life activities. Popular culture was noted to reinforce taboos around ABL, even as it relaxed old taboos about sex, UI, and erectile dysfunction. “I was at a Paula Poundstone comedy thing. ... She’s hilarious and her first little thing was her doctor recommended the drug. But the warnings said may cause fecal incontinence. And she said, ‘Fecal incontinence. What can be worse than fecal incontinence?’” She said, ‘I wasn’t going to take the drug, I’d rather die.’ And for me it was like, ‘Oh my gosh; I guess I can never say anything about this because this is the most horrible thing anyone could have.’” Concealment was a key dimension of stigma. Women wanted to hide ABL not just from their medical provider and staff and clinical records, but also from their family members. “Who wants their spouse to know that they’re shitting their pants? I don’t—I don’t want him to be grossed out. It happened when we had intercourse—I got up and there it was and I quickly changed the sheet as fast I could. He didn’t know. He didn’t smell it. He didn’t notice it. He didn’t say anything. I would die.” The sentiment of wanting to die rather than have one’s ABL revealed was voiced by multiple women: “The older I get, you see, the more I think 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...”

Women expressed that isolation (I) was both literal and emotional. Women expressed that they felt alone in their experience of ABL and often attributed symptoms to something they had done. Self blame (SB) ranged from the relatively benign mistakes such as: “I wonder what I ate today that I’m in this mess?” to internalizing a sexual experience in their past. Self-blame often manifested as a search for the cause for ABL. Self-blame was also a barrier to care seeking as feeling undeserving of help, or as embarrassment in disclosing to a healthcare provider: “I was raped as a child, and I figured that that’s what it was from. And I

just didn't want to talk about it [to my doctor]. But I didn't know what I had. ... I keep getting worse, I asked her, and she didn't think so. So, you know, that's – that was the most embarrassing question because I don't want to talk about it."

Women expressed provider barriers (PBs) as discomfort discussing ABL with a particular provider due to interpersonal relationship or gender and also having had a prior negative experience that discouraged further care seeking. Some women who had previously sought care described their doctors as seeming uncomfortable, dismissive, or intimidating: "I have had the feeling that doctors either don't know too much about it, or also share with you the embarrassment of talking about it." These experiences imbued a sense of not being heard, failure, and hopelessness: "Since my doctor hadn't reacted I think I thought, in a sense, maybe nothing could be done." Women recounted poignant vignettes about prior negative experiences seeking care, many of which prompted them to abandon further care seeking efforts, and expressed their desire that doctors start the conversation about this condition (Table 2). Some women, even those with health insurance, further expressed access limitations (AL), including transportation, cost, the need to take time off work, and the additional hurdle of seeing a specialist.

Women's experience of these 12 barriers was often interrelated rather than distinct, making generation and revision of items mapping to a single barrier a challenging enterprise. In the final phase of the analysis, we identified three overarching themes for the 12 barriers: the internalized self in relation to ABL; perceptions about ABL and its treatments; interaction with the healthcare system. Figure 1 illustrates how each barrier fits within these overarching themes. Three of the 12 actually encompassed all three themes. Seven barriers encompassed two of the three themes, and only two of the 12 barriers fit within a single theme.

Discussion

The primary objective of this study was to describe and characterize barriers to care seeking for ABL among US women. From focus groups and interviews of women with varied prior care seeking experiences, we identified 12 barriers and categorized them into three broad themes: the internalized self in relation to ABL, perceptions about ABL and its treatments, and interaction with the healthcare system. All but two of the 12 barriers identified encompassed multiple themes, suggesting that the experience of these barriers is overlapping and interrelated.

We compared our findings with existing knowledge about barriers to care seeking for UI and ABL. Many of the barriers identified in this study have been previously described for both ABL and UI. Importantly, KC, which we identified in our study, was also recently described in a North Carolina survey of 36 adults (predominantly female) with ABL who had not sought care. In that study, 36 % of participants reported not thinking ABL was a real medical problem [20]. All other barriers we identified have been previously described, suggesting that similar strategies to promote care seeking may be effective for women with either condition.

KT and FT have been described in reference to both UI [9, 11, 13, 16–18] and ABL [23–25] and can likely be improved through dissemination of information about the existence of safe, effective, minimal-risk therapies for these conditions. Interestingly, women in our study endorsed both NT on the one hand and SB and I on the other; these barriers are likely to be responsive to similar educational efforts. Conversely, AD and LI, also described for both UI [9–11, 16] and ABL [23, 24], relate more to a woman's individual experience and context and thus may not be modifiable through education alone.

In some studies, E and S have been described in relation to care seeking for UI [13, 17, 18]. These barriers dominated most discussions in focus groups and cognitive interviews in our sample and have been described widely in the limited literature describing barriers to care seeking for ABL [23–25]. Not surprisingly, given the associated feelings of embarrassment and stigma, the power of PBs regarding ABL was overwhelming. This barrier has been described regarding UI as well [9, 16, 17], but it is likely that the relative lack of awareness by both physicians and patients alike that ABL is a treatable condition increases the impact of this barrier. In another qualitative study in New Mexico, USA, women identified three concepts that they felt were important but lacking in their treatment, including hope for improvement, that it would take personal effort to improve their symptoms, and that they should be encouraged to live their lives despite having symptoms of ABL [25]. Our current findings and the prior literature support the idea that women with ABL may be responsive to one of the many simple interventions available for treatment if recommendations are given in a safe environment, women are encouraged to participate in their own care, and are given hope by their care provider that their condition will improve. Future studies are necessary to determine whether education targeting both physicians and patients could effectively minimize this barrier.

A recent survey of 36 predominantly female patients in NC, USA, with ABL identified 12 reasons for having not sought care that align with eight barriers identified in our study [20]. These reasons included not thinking ABL is a real medical problem (KC); thinking treatment does not exist or physicians are unable to help with ABL symptoms (KT); wanting a natural solution, or fear of expected medical side effects (FT); not thinking the condition is serious enough, or having other priority issues and limited time to discuss with their physician (LI); thinking ABL is a normal part of aging (NT); being embarrassed or thinking the physician would be embarrassed (E); being uncomfortable with a specific physician/gender or being uncomfortable with any physician (PBs) [20]. The study corroborates our findings and confirms that we did not stop data collection prematurely.

The strengths of our study are its focus on ABL, recruitment of women from outside the healthcare setting, inclusion of women with varied prior care seeking experiences, and robust qualitative methods. ABL is understudied in the urogynecologic literature, and many qualitative studies include only women with ABL recruited from healthcare settings, thus limiting their generalizability. We recruited women who had never sought care as well as those who had to ensure representation of their diverse perspectives in our final list of items for instrument testing. Focus groups provided surprisingly rich data, perhaps because of women's surprise to learn that they were not alone in their experiences, and cognitive interviews allowed for in-depth exploration of individual items within each barrier. The

iterative analysis process enriched our data quality by allowing exploration of new barriers and corresponding items as they emerged, putting items into participants' own words.

Limitations include the inherent limitations of any self-referral recruitment strategy and qualitative study. It is likely that the women who experience the strongest barriers to seeking care for ABL are the least likely to self-refer into a study such as this one. To increase our chances of reaching these women, we recruited for focus groups and cognitive interviews at the same time, allowing those who might not feel comfortable in a group to self-refer for the individual interview. We placed flyers with tearoffs inside bathroom stalls so that interested women could obtain information about the study without being seen by anyone else. As with any qualitative study, the barriers and themes identified are limited by the experiences of our participants. We did reach saturation with all identified barriers to care seeking for ABL, suggesting that our findings might be generalizable to US women with ABL.

Similarities between barriers identified in this study and those identified in other studies regarding care seeking for UI or ABL suggest that similar strategies to promote care seeking may be effective for women with either condition. Dissemination of information about the prevalence, causes, and availability of effective, minimally invasive treatment options should target both patients and providers. Further research should examine which of these barriers can be minimized simply through such dissemination of information and to determine which strategies are most effective to decrease barriers related to normative thinking, self-blame, isolation, embarrassment/shame, stigma, and life impact.

Conclusion

We identified 12 barriers to seeking care for ABL among women with varied prior care-seeking experiences, many of which are interrelated and correlate with previously described barriers to care seeking for UI, suggesting that similar interventions may promote care seeking for both ABL and UI. The discussion tool used in this study will serve as the foundation for development and validation of an instrument to measure Barriers to Care-Seeking for Accidental Bowel Leakage (BCABL). Our next step is a validation study administering this 49-item BCABL questionnaire to a national sample of women. This study will determine, via factor analysis, which items map to which barrier and will identify the most salient barriers to seeking care for ABL. The resulting validated BCABL instrument can then be used to measure the impact of interventions to decrease barriers to care seeking.

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Fig. 1.
 Themes across Barriers to Care-seeking for Accidental Bowel Leakage (ABL)

Table 1

Identified barriers to care-seeking for accidental bowel leakage, representative quotes, and items from discussion tool

Barrier	Representative quotes	Discussion tool items
Knowledge condition (KC)	“How can you talk about something [when] you don’t even know what it is?”	It has not occurred to me to talk with a health care provider about my accidental bowel leakage.
	“I saw a poster [for this study] ... and it was like, ‘Oh my goodness, this is something? It’s not just me, it’s like other people.’ But I didn’t even know there was a name for it. I didn’t even know it was a thing. I thought I just had to live with it.”	I do not think of my accidental bowel leakage as a medical condition.
Knowledge treatment (KT)	“I would have no idea what the treatment even would be if there were one.”	Accidental bowel leakage cannot be treated.
	“I got the hemorrhoids taken care of, so I feel that was pretty much my one shot at an improvement. And so when I see the doctor now, I don’t think to ask because I thought I had done everything I could.”	There really isn’t anything a health care provider can do to help me with my accidental bowel leakage.
Fear of treatment (FT)	“When I have thought about telling my doctor the next place my brain goes is, ‘Oh for God’s sake, what are they going to do next? They’re going to send me to a specialist who’s going to be some guy, probing, who I’ve never met before, and expect me to talk to him...’”	I do not want to talk to a health care provider about my accidental bowel leakage because I do not want to be poked and prodded.
	“When it first started what made a lot of my hesitation to talk about it is I was worried I might have some kind of digestive-related cancer.”	I do not want to talk to a health care provider about my accidental bowel leakage because I am scared it might be related to cancer.
Normative thinking (NT)	“I didn’t want to be put on some pill that would make me more constipated. Sometimes the cure is worse than the disease...”	I am worried about the side effects of treatments for accidental bowel leakage.
	“I thought it was just a part of aging. I didn’t know it was a medical condition or that it could be treated. I started buying adult diapers. I carried a bag with a clean change of clothes, sometimes two, wet wipes and plastics bags.”	Accidental bowel leakage is just another part of aging.
	“We, as women, go through so many changes in our bodies that we succumb to them and figure that’s the way it should be.”	Accidental bowel leakage is a typical bodily change for women.
Avoidance/denial (AD)	“My feeling at first was, ‘Oh, it happened but it will probably never happen again.’”	Accidental bowel leakage runs in some families.
	“So I don’t mention it; they don’t notice it. It’s my little secret. It’s like I don’t want this to be part of my story of who I am.”	I don’t want to talk with a health care provider about my accidental bowel leakage because I hope it will just go away on its own.
	“I just keep thinking maybe it will go away because I’ve lost 15 pounds. I’m like, ‘Okay, so, maybe another 15 and it will stop.’”	My accidental bowel leakage will go away if I get my other health issues under control.
Life impact (LI)	“I just forget about it, because it’s not an every week thing.”	I don’t want to talk to a health care provider about my accidental bowel leakage because it only happens once in a while.
	“When I see the doctor I do try to prioritize the list and ABL would probably be at the bottom of the list.”	I have other, more important concerns than accidental bowel leakage to discuss with a health care provider.
	“I have to see the eye doctor every week. I have high blood pressure, and I have a lot of things that are more important in my daily life.”	I don’t want to talk with a health care provider about my accidental bowel leakage because I have my symptoms under control.
	“I’m just accepting that my body’s changing and as I age, there will be things that I just have to learn to tolerate it and do what you have to. ... I can kind of tell like I’m going to have a problem. So then I,	I worry about having an accident if I leave home.

Barrier	Representative quotes	Discussion tool items
Embarrassment/shame (E)	you know, like I'll take a piece of tissue and stick it in my butt. Well, you're not really taking care of it. You're just accepting it."	
	"I wouldn't care if my doctor was an orangutan. I want it to stop happening."	I am embarrassed to talk with a health care provider about my accidental bowel leakage.
	"I never brought this up to a doctor, male or female. It was too embarrassing, it was too ridiculous. It's like I understand that's silly, but I never wanted to discuss it."	
	"We were in a grocery store... I go to the bathroom ... and I'm just full of stool, liquid stool. I never knew it. I was like, 'Oh my God.' I ... cleaned myself up, tied up all my clothes and threw it in the garbage. I was not carrying that home! ... I was very embarrassed because of the way it happened and I didn't think it happened to anybody else."	I do not want to talk to my health care provider about my accidental bowel leakage because I feel ashamed.
Stigma (S)	"This is more personal than just a regular gynecologist."	I do not want to talk to a health care provider about my accidental bowel leakage because it is a sensitive matter.
	"We live in such a society that's so open about so many things – sexuality and, you know, really odd other behaviors – and yet we have this tradition of being so unable to really discuss our own physiologic problems. And we're taught 'Oh, don't mention that.'"	I don't want to talk with a health care provider about accidental bowel leakage because it is a taboo topic.
	"I don't want to see my doctor about it because they're going to diagnose me and then it's going to be on my problem list... I don't want this documented as one of my diagnoses or something."	I do not want the diagnosis of accidental bowel leakage in my medical record.
	"You wonder what they're going to think about you. I wonder what they would think about me when I left that appointment. Did I make them uncomfortable? What is their impression of me? Do they go, 'Oh, here comes X...' and start thinking about uncomfortable things?"	I don't want accidental bowel leakage to be part of the way a health care provider thinks about me. Talking about my accidental bowel leakage with a health care provider would make me feel bad about myself.
Self-blame (SB)	"When I was younger I took a lot of laxatives, so I did this to myself."	My accidental bowel leakage is my fault.
	"I'm overweight and so I read all the crap on the internet that people say about fat people: 'You're overweight, so it's your fault and because it's your fault, you don't deserve any help.'"	My accidental bowel leakage is related to being overweight.
	"I think it's me, it's something I eat or did that causes it to happen. And then finally I say, 'Oh, probably this is happening because I had anal sex. My gosh, it was just two times in my whole life. Why is this happening? It has to be related to that.'"	My accidental bowel leakage is related to prior use of laxatives.
	"Things happened in my past. I am not a saint. I gave birth to my daughter at home by myself when I was 18 years old. I had sex in my rectum; it really, really hurt and I bled from my butt. All that was many years ago, but I am wondering if all of that could have built up."	My accidental bowel leakage is related to a prior experience with anal sex. My accidental bowel leakage is because of something that happened to me in the past.
Isolation (I)	"My final conclusion is I was probably one of the only people who had this ongoing problem."	I feel like I am the only person who has a problem with accidental bowel leakage.
Provider barriers (PB)	"[ABL] is, just by its nature, very isolating. You could be in a whole room of people with the same problem and not know it," ... "I don't think most of us have ever known anybody with this problem who's talked about it enough to actually sort of show us a path."	
	"And then when I was probably 30 my internist said, 'Ah, you have a very weak sphincter muscle,' and I just said, 'Oh.' I was too embarrassed to say, 'Why? What?' It's embarrassment; male doctor down there in the first place... it was like, 'I'm not going to mention...'"	My health care provider's gender is one reason I have not talked with him about my accidental bowel leakage.

Barrier	Representative quotes	Discussion tool items
Access limitations (AL)	“I went back to the doctor to talk about [a scar]. ... And he was just like really dismissive... So it's like, well, if I can't even talk about my scar, how am I going to talk about this?”	I don't know my health care provider well enough to talk about my accidental bowel leakage symptoms.
	“At the end of my exam, I said, ‘I'm having this problem,’ and it was like I didn't say anything.”	I tried to talk to a healthcare provider about my accidental bowel leakage but s/he didn't listen.
	“I did broach the subject with my doctor once and she wasn't particularly helpful... and each time I have a physical I think about doing it and just haven't done it again because I was unsuccessful the first time.”	I tried to talk to a healthcare provider about my accidental bowel leakage but s/he did not help me.
	“To see a healthcare provider I have to get off work and take three buses.”	It was difficult for me to arrange transportation to see a healthcare provider about accidental bowel leakage.
	“Adding a problem to your problem list in our current healthcare system just starts this whole thing rolling. You get shipped off to do something else. Explain your whole situation all over again, two or three different times.”	
	“I am on SSDI. I am not a rich person so they throw me off to the side.”	It was a hassle to get a referral to a specialist or to have multiple appointments.
	“I have way too many healthcare provider appointments in my life right now, so it's just a giant hassle to get care for anything that a primary care provider can't actually feel like it's in their scope to treat. Going to a specialist means yet another medication. Another story that I have to reiterate – again. Another location I have to go to.”	I could not afford to see a health care provider about my accidental bowel leakage. I was too busy to go see a healthcare provider about accidental bowel leakage.

Table 2

Provider interactions: real and ideal

Actual experiences	Suggestions for better experiences
<p>Frustration: “The first time I got the diverticulitis, I went to Hospital X and they gave me a shot of Dilaudid in my butt and sent me home. The doctor said to take some over-the-counter medicine that plugged me up. The next time I went to Hospital Y; it was so bad that the doctor [referred me to] a colonoscopist. And that’s when they found all these polyps. Just recently, I told the doctor at Clinic Z I have been having diarrhea for 2 months. He didn’t even push my stomach. And they won’t remove the polyps. It’s a nightmare to live with.”</p> <p>Hopelessness: “I’ve had this problem for years, and when I spoke with a GI doctor she said, ‘Oh, there is something they do to the vagina, they put a purse string in it, but they always do it too tight.’ So she was really negative about it, so that was the only person I ever spoke with professionally.”</p> <p>Humiliation and Failure: “Since I’ve had my children I’ve had leakage. I mean I have poop issues—mucus and blood and all that. That’s been constant. My doctor was examining me. I had my ass up in the air. He has an intern, he’s like, ‘Okay, see this.’ He says, ‘Okay, you can sit down.’ I sit on a chair bare ass, nothing on the chair. He says, ‘Well you have stage 4 hemorrhoids. I think you should have this [hemorrhoidectomy] or you’ll have fecal incontinence.’ ... But guess what, the hemorrhoids came back and I still have a problem.”</p>	<p>Increased awareness: “These are just common questions that a woman might not feel comfortable bringing up, [a brochure] is an automatic thing that might help to bring a woman out, ‘Have you heard about something called Accidental Bowel Leakage? And if not we’ve got a pamphlet out here.’”</p> <p>Written inquiry: “The survey opens the door. . . It’s easier to walk through an open door than knock on it yourself.”</p> <p>Starting the conversation: “At my annual GYN exam [I would want] for the provider to ask about any troubles peeing, urinary or anal, or ask about my pelvic floor... They could put it on a form that you fill out. This would be my fantasy doctor. They’d say, ‘Is there something you want to talk to me about your health that you never brought up and you’re too embarrassed or you’d want to make another appointment to talk to me about?’ That would be my fantasy because I never get to do that. I’m a very shy person.”</p> <p>Provider gender: “Female doctors know everything. I mean, male doctors are good; male doctors delivered my three boys, but they don’t know. They can only say things, but they don’t, deep down, know, what a cramp feels like. Females know.”</p> <p>Closing the gap: “I think that it is easier when you’re sitting side by side with a nurse practitioner or even a nurse. It has a different feel to it, like more of a friend feel -- there’s less distance sometimes.”</p>