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Help-Seeking for Fecal Incontinence in People With Inflammatory Bowel Disease

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PURPOSE: The purpose of this study was to enhance our understanding of factors that influence help-seeking in people with inflammatory bowel disease (IBD)–related fecal incontinence (FI), and their needs or desire for continence services.

SUBJECTS AND SETTING: We conducted a survey of FI in community-dwelling people with IBD, all members of a United Kingdom IBD charity, and received 3264 responses. As part of the study, we asked 3 questions about help-seeking for IBD-related FI to which respondents were able to give free-text responses. We analyzed the responses to these help-seeking questions, continuing until data saturation when no new themes emerged (617 free text comments analyzed, 19% of total respondents).

METHODS: For the full survey, a mixed-methods design was used to collect and analyze quantitative and qualitative data. Qualitative (free-text) responses relating to help-seeking behavior reported in this article were analyzed using a pragmatic thematic approach.

RESULTS: Seventy-four percent of the total sample (2415 out of 3264 respondents) reported some degree of FI. Of these, only 38% (n = 927) reported seeking help for FI. In the data reported in this article (n = 617), only 13.5% reported seeking help for FI. Help was described as satisfactory, unsatisfactory, or alternative (acupuncture, counseling, hypnotherapy). Reasons for not seeking help included believing nothing could be done, not knowing who to ask, feeling too embarrassed, ashamed or dirty, and perceived lack of interest, sympathy, or understanding from health care professionals. Although respondents wanted to talk to "someone with specialist knowledge about incontinence" only 6 out of 617 (0.9%) reported awareness of specialist continence services. Standard treatments were rarely mentioned (n = 2). Respondents' focus was on better management of FI rather than on cure.

CONCLUSIONS: Many people with IBD-related FI are not aware of the services or treatments that are available to help them manage this distressing problem, and most do not seek help, often due to embarrassment and lack of knowledge that help might be possible. Clinical staff could communicate their awareness for the potential for FI to occur by proactively asking about symptoms during clinic appointments to provide an opportunity for symptoms to be disclosed and described.

KEY WORDS: fecal incontinence, inflammatory bowel disease, qualitative methodology, treatment seeking

Introduction

Although bowel control is reported as a major concern by people with inflammatory bowel disease (IBD),[1] fecal incontinence (FI) remains a largely unvoiced symptom.[2] The prevalence of FI is 2.2% to 15% in community-dwelling adults without IBD.[3-6] There is evidence regarding help-seeking behavior for specific health problems, such as for irritable bowel syndrome[7] and among men generally,[8] but none was found that specifically addressed IBD-related FI. We conducted a mixed-methods survey that addressed the following aims: (1) to determine the prevalence of continence problems and concerns in people with IBD, (2) to understand the experience of people with IBD and continence-related issues, (3) to understand the help-seeking behaviors of people with IBD-related FI, and their needs or desire for continence services, and (4) to better understand how people with IBD and continence symptoms manage their problem. This article provides a brief description of

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the full study, but its primary focus is on Aim 3, help-seeking for IBD-related FI.

Methods

As part of a larger study that used a postal and Internet survey conducted with members of a national Crohn's and Colitis support group to address the 4 aims described previously, we asked respondents 3 questions to determine help-seeking behaviors for IBD-related FI (Table 1). The full survey, designed specifically for the study by the authors and piloted prior to roll-out, contained 11 sections encompassing 83 individual items, including 6 open-ended questions aimed at understanding the experience, management, and help-seeking behaviors of people with IBD-related FI. Completion required approximately 30 to 60 minutes based on data collected during a pilot study.

We sent the full survey to a random sample of 10,000 support group members. Inclusion criteria were 18 years of age or older, resident anywhere within the United Kingdom, self-reported diagnosis of IBD, and no stoma. Respondents completed the study questionnaire in hard copy, or via a secured online site. Ethical approval was granted by the Research Ethics Committee at King's College London. Participants received a study information leaflet with a detailed explanation of the study processes, participant involvement, and rights. Return of a completed online or paper questionnaire was taken as consent to participate. Data collection took place between June and October 2010.

Quantitative data were entered into Excel. Demographic, diagnosis, IBD and other medical history, and obstetric history data, and completion of validated measures to assess urinary incontinence,[9] bowel symptoms,[10] quality of life[11] and disease activity[12,13] enabled identification of prevalence of FI and associations with factors known to predispose to FI in the non-IBD population.

Using a sample of convenience, surveys were selected from the total responses available (N = 3264). Free-text responses were dictated into digital audio files, continuing until data saturation was reached at 617 surveys (19% of the total responses) with no new themes emerging. The files were professionally transcribed. We also used other data from these 617 respondents, in addition to in-depth interviews with 28 people, to identify and describe the complex experience of FI in IBD, which addressed Aims 2 and 4 (above), and which is reported elsewhere.[14] The current study focuses on the replies to the 3 questions in Table 1.

Data Analysis

Qualitative data were analyzed using a pragmatic thematic analysis approach.[15] Analysis begins with a series of preidentified themes, developed naturally from the original questions (Table 1). For example, responses to question 1 lead the qualitative analyst to look for representations of current or past worry, emotions, and concerns in the data. These points became the initial codes that guided analysis, while new themes arising in the data were assigned to new codes. For instance, while searching the data for text aligning to the *emotions* code, we found frequent descriptions of embarrassment as a barrier to help-seeking, and so *embarrassment* became a new code. The process enabled synthesis, comparison, and analysis of large amounts of qualitative data to capture an understanding of the experience in question. It proved useful when trying to see patterns and connections in the data.[16] The WORD software program (Microsoft Corporation, Seattle, Washington) was used to create a separate table for each question. Extracts from each transcript were cut and pasted into the appropriate table. The tabulated transcripts were then read and coded independently by both authors, who subsequently collaborated to agree on key themes.

Results

Ten thousand surveys were sent out and 3264 adequately complete responses were received from persons who met inclusion criteria, yielding a response rate of 32.64%. The sample is described in Table 2. In response to the question "Do you experience fecal incontinence?" only 26% (n = 857) reported never having FI. Seventy-four percent of respondents (n = 2415) reported some degree of FI. Only 38% of these (n = 927) had sought help for FI, which was often unrelated to disease activity. The details of this and other associations with FI, addressing Aim 1 of the study, are reported elsewhere.[17]

A minority of respondents (84/617; 13.5%) reported actively seeking help for FI. Those who experienced FI rarely,

TABLE 1.

Questions Used to Gather Help-Seeking Data From Study Respondents (N = 617)

Q.1	Have you ever sought professional help for incontinence? Yes ☐ Go to Q.2 No ☐ Go to Q.3
Q.2	Please describe the help you have sought. Try to explain how you felt about asking for help, describe the services you accessed, and how helpful you feel these have been to you.
Q.3	Please describe any factors that stopped you from seeking help. Try to explain how you feel about asking for help, what stops or prevents you, and which services you would access if you were able to.

TABLE 2.

Demographic and Pertinent Clinical Characteristics of Study Sample

	Main Study (N = 3264)	This Study (N = 617)
Female	66.7% (2178)	71% (443)
Age, y		
Mean (range)	50.3 (19-92)	50.4(19-88)
Underlying diagnosis		
Crohn disease	47% (1543)	45% (279)
Ulcerative colitis	49% (1599)	50.5% (310)
Other form of inflammatory bowel disease[a]	4% (126)	4.5% (28)
No diagnosis provided	0.2% (6)	0
Symptom duration, y		
Mean (range)	16 (0.5-71)	13 (0.5-60)
Confirmed diagnosis duration, y		
Mean (range)	13 (0.5-71)	13 (0.5-56)
Experienced fecal incontinence (FI)		
Never	26% (857)	13% (80)
Rarely	34% (1088)	38% (234)
Sometimes	31% (1004)	39% (240)
Regularly	9% (299)	10% (63)
Sought help for FI	38% (927)	14% (87)

[a] Crohn's colitis, indeterminate colitis and proctitis

or only during a flare-up of symptoms, were less likely to seek help. When asked to describe the help that had been sought and received, responses fell into 3 categories.

Thirty-six of the 84 people who had sought assistance for FI from medical (primary care or hospital specialist) and nursing (IBD nurse specialist or community nurse) staff reported receiving beneficial help. "Help" was reported as perceptions that the health care professionals consulted were sympathetic, prescribed stool bulking agents or antidiarrheal medication, referred onward for interventions, provided protective pads, or listened to concerns. Specific interventions for FI as recommended by UK national clinical practice guidelines (2007),[18] such as biofeedback and pelvic floor muscle exercises, were mentioned only twice. Four had seen a physiotherapist for pelvic floor exercises with varying degrees of success. In addition, 6 respondents reported being referred to a specialist continence nurse or clinic.

Twenty-nine of the 84 people reported seeking help for FI but felt that they did not receive a satisfactory response. Some reported that health care professionals were unsympathetic: *I either get more tablets or double the dose or an increase of dosage which does not help long term. Or, I get a condescending "that's the nature of the illness."* Others stated that health care professionals appeared to expect people with IBD to anticipate and live with FI. They stated that health care professionals had not offered any practical advice or support or did not refer them on to potential sources of help. One respondent said *I did ask to be referred to an incontinence specialist nurse but was informed that I did not have sufficient need.* For some, practical assistance had been offered (the use of protection products, meetings with dieticians, for example) but these had been unhelpful.

Ten participants reported trying at least 1 allied health or complementary source of help such as acupuncture, Bowen Therapy, hypnotherapy, kinesiology, or Shiatsu with varying levels of success. Two respondents reported seeking treatment from a herbalist. Four reported seeking care from a psychologist or counselor; they also reported varying degrees of success. Complementary and alternative therapies tended to help respondents to manage stress and anxiety associated with the FI, rather than resolving fecal leakage. One respondent shared, *"Had a course of hypnotherapy, learned how to relax. I've used this method ever since to help with bowel control."*

Decision Not to Seek Help for Incontinence

Thirty-five participants provided 1 or more reasons why they chose not to seek assistance for FI. These reasons included thinking nothing else could be done to help them, not realizing that there were additional specialist services, or not knowing who to ask (n = 94). Embarrassment or feeling ashamed or dirty was cited as a reason for not seeking assistance by 73 respondents, even though many stated that they wished to ask for help. As one respondent stated, *"I find this [FI] to be a very—extremely—embarrassing, distressing and private condition. The nature of the illness does discourage you from asking for any help;"* and *"I hate having to talk about what happens. I'm embarrassed, no matter how much I tell myself it's not my fault or I don't do it on purpose, I am still very, very embarrassed …."*

Sixty-one participants reported that they perceived FI as too insignificant or insufficiently severe to warrant asking for help; one respondent pointed out that FI… *"doesn't happen very often and I feel I can deal with it."* Forty-three people stated that they accepted FI as part of IBD; one respondent stated, *"Any continence issues I have are related to my disease, and controlling the disease relieves the issues. So I get help controlling the disease, expecting eventual resolution of the symptoms."* This acceptance is perhaps more likely when FI is directly related to IBD flare-ups but some respondents reported regular FI regardless of disease activity, an aspect of their illness that may be overlooked by clinicians.

A perceived lack of interest, sympathy, or understanding from medical and nursing staff prevented others from asking for help (n = 20). One participant stated, *"The specialist thinks I should be able to manage, so I don't say much on my checkups;"* another stated *"My hospital consultant … was horrible, unhelpful, uncooperative, uncaring and difficult to contact and talk to"*; and *"I would like to ask for more help, but the [health service] does not have the time and the patience for you."*

Difficulty accessing services was also identified as a factor that deterred participants from seeking help for their FI (n = 11). Transport problems, long delays between requesting and receiving appointments, being unable to attend clinic during working hours, too much time off work for other appointments, seeing a different clinician at every visit, and fears about having to see a clinician of the opposite sex were all discussed as barriers to accessing help. Others identified a wish to avoid invasive, unpleasant, or intrusive tests, or unwanted treatments such as surgery (n = 17). One respondent said, *"I don't want to have surgery, I can live with it. I don't want to have to wear big incontinence pads."* Another reported, *"I hate having to take drugs or steroids, so I sometimes delay making contact to avoid this option"*. Others were hopeful that ignoring the problem might solve it: *"I didn't like asking for help … I thought if I left it long enough, it might go away,"* while others wanted to avoid even more hospital and clinic visits than are already endured: *"I see doctors so many times that I'm loathe to go if I don't have to."* Twenty-nine people reported that they manage their symptoms themselves and seem happy to do so: "I am a very independent person and always manage somehow" and *"I do not seek help as I believe I manage my condition as best as possible."*

Eight respondents stated that they had never been asked about FI by their care providers and they did not think to ask for help themselves. They wished the provider had taken the initiative to ask about incontinence. One respondent noted, *"Perhaps they should automatically ask about incontinence or any accidents where you cannot reach the loo in time, instead of waiting for a patient to tell them."*

Desired Services

When asked about the type of services respondents would like to help them manage IBD-related FI, responses fell broadly into 2 principal categories: public and social issues and access to services. Improved public and employer knowledge about IBD was considered essential; as one participant shared, *"Mostly for everyone to be aware of what this illness is, especially in public places like pubs, office buildings, railway and underground stations. I have a permanent fear of losing my job."* Another respondent advised *"Educate the public so you can go to any shop where they will allow you to use the toilet."* Public understanding of the nature of IBD was desired in order to relieve some of the stress that arises from attempting to make use of such facilities while having an invisible condition: *"I'm often challenged as I can walk in [to toilets for the disabled] … attendants only think you have to be in a wheelchair, along with some of the public thinking the same."*

Participants reported minimal success, using the "Can't Wait" card, a pocket-sized card that can be shown in shops and cafes in the United Kingdom to gain access to toilets that are not usually available to the public. Wider recognition and support of this initiative would be beneficial. References to public toilets covered all aspects from accessibility and quality. One respondent commented on the need for *"more clean public toilets with sinks included in facilities,"* and another stated a desire for increased availability of public toilets. *"There are just not enough public facilities and the Government and councils need to recognize this fact and support us."*

Recognition of IBD as a disability was also considered essential. Respondents noted that legal recognition would make people eligible for financial benefits, and national disability parking schemes: *"the blue badge parking exemption would be helpful."* Holding a blue parking exemption was desired because it would enable rapid and easy access to public toilet facilities. Applications for social benefits payments and disability parking schemes were often unsuccessful and participants noted that the relapsing and remitting nature of IBD proved difficult since disabling symptoms were not consistently present. As one respondent noted, *"The difficulty is that things are not always bad, so it would be up to the patient not to abuse the [blue badge parking] system and only use these things when necessary."* Some participants reported applying for and receiving a

"RADAR" key that enables free access to locked toilet facilities for disabled people across the United Kingdom. The IBD charity, Crohn's & Colitis UK, was described as being helpful by being sympathetic, supportive, providing useful information, and enabling connection with other people with IBD.

Access to Services

Participants also reported a need for access to services designed to cope with or alleviate the emotional impact of IBD-related FI. One participant shared, *"The support I need is … someone to talk to about it."* Sixty-two respondents reported wanting to do this informally through local support groups, or formally via professional counseling services. As one respondent noted, *"I did not access counseling and in retrospect I should have. I settled for solving the medical issue rather than dealing with my own feelings."* Another stated, *"I think my ideal professional support service would be if the person dealing with your illness would be able to give you more time to speak to them, not only about the illness you have, but be able to give you some emotional support as well. I would like them to treat me as a whole person, not just an illness and a set of symptoms."*

Eighteen participants identified a need for access to better designed protection products. One participant pointed out the need for *"…correct products to manage [FI], ideally pads designed for that area of underwear, not great big nappy type pads"* and another shared a need for "Guidance on availability of discreet underwear or pad systems for men—some commercially available systems resemble nappies, [and are] not conducive to dignity!" Many were also unaware that these products are available through the UK National Health Service. Respondents wanted practical guidance on managing FI, and on adjusting diet to help control symptoms. Professional staff were apparently reluctant to accept the role of diet in exacerbating symptoms: *"I try … to control my diet as this seems to me to be of some importance … it is my opinion that sugars and starchy food cause me to have diarrhoea, usually the next day. My consultant however does not seem to accept these statements."* Respondents expressed a desire for more guidance on how to determine which foods trigger their individual symptoms, not just general advice to find this out for themselves.

Finally, 32 participants identified the need for access to well-informed and sympathetic IBD specialists: "It would be good to have access to a physician with good knowledge of Crohn's, and current thinking about treatment." Some participants stated a desire for their health care professional to be proactive and ask if there were any continence issues, and others for health care providers to listen to them more carefully. Access to IBD nurses, in particular, appears patchy, with some respondents (n = 14) reporting an apparent absence of these specialist nurses in their region of the country. One respondent noted the need for *"…more support from a dedicated nurse practitioner at my local hospital and clinic"* and "A nurse who knows about IBD would be a help." Another stated, *"I wish I could ring a specialist nurse, like I do for my diabetes [care]."* Discontinuation of services caused concern: *"We used to have an IBD nurse, but this has been withdrawn. It would be helpful if we could have this facility back."*

The value of access to knowledgeable and supportive IBD nurses was stressed by multiple respondents (n = 14). One respondent opined, *"All hospitals should have IBD [specialty practice] nurses. You cannot over-estimate the value of talking to someone who understands and get tips from other patients."* Some respondents, mindful of the isolating and limiting nature of their FI and concerned about their future, suggested a home nursing service for people with IBD: *"a health visitor … like you get when you have a first child, but for IBD sufferers."*

Discussion

As part of a larger study addressing FI in people with IBD,[14,17] we aimed to understand the experience of help seeking and needs and desires for help and services. Study findings support the observation that talking about IBD-related FI is challenging and stressful and affects people's ability to be proactive in help-seeking. Although some respondents reported receiving effective help, others had not and the majority had not asked for help. The main reasons for not seeking help were a lack of awareness of the services available to them, not knowing who, where, or how to ask for help, embarrassment and avoidance due to a concern that invasive tests or surgery might be offered, or that the time spent at hospital clinics would increase.

Effective help-seeking involves 3 antecedents: recognizing and defining the problem, making a decision to act, and identifying a source of help.[19] This can explain why those who do not see FI as a problem, as was the case with some of our respondents, do not seek help. However, those who do recognize and define their problem struggle to fulfill the remaining antecedents. Deciding to act means addressing social and cultural expectations, and one's own and other's knowledge, expectations, and attitudes.[19]

Most societies disapprove of poor control of natural body functions in adults,[20] often because of the perceived connection with dirt, disease, and perils associated with being unclean.[21-23] In addition, discussing excretory or sexual function is often taboo.[24] Admitting to poor bowel control may bring an expectation in the individual that society (including any potential source of help) will disapprove, and this may deter the person from making a decision to act and seek help. Once the decision to act is made, a source of help must be identified. Without knowing what help is available or how to get it, any potential source of help cannot be identified and help cannot be asked for. People with IBD-related FI face 2 challenges: lack of awareness of where or from whom to get help, and the need to overcome the psychosocial taboos associated with reporting symptoms to an IBD nurse or other care provider. Even if helping sources are available and widely known about, the individual still has to communicate their need. The process can be described as an exchange; the person in need hands over information in exchange for knowledge or other means by which the problem can be addressed.[25]

The potential helper plays a key role; *seeking assistance, consider the type and services they are seeking from the provider before contact is initiated.*[19] With an extremely embarrassing subject such as FI, placing this onus on the patient may mean that they do not ask, especially if they are already doubtful that they will receive effective help. The helper has to be seen to be likely to help, be approachable, sympathetic, and supportive.[26]

People who need to reveal difficult or sensitive information are more likely to be able to do so if they are given an opportunity.[27,28] The first professionals that patients with IBD and FI are likely to contact are a gastroenterologist or IBD nurse specialist. We recommend that these individuals enable patients to seek help by initiating a discussion about bowel control, thereby demonstrating to the patient that they expect FI might be an issue, and are ready to listen. Depending on the therapeutic relationship between patient and health care professional, the question may need to be asked on more than 1 occasion, before the patient feels able to respond. The results of Duncan and colleagues[29] support our findings here that IBD nurses do not ask, and patients are reluctant to volunteer information about their FI.

Few study respondents reported being referred for additional interventions to relieve or resolve FI. Referring patients on to the most appropriate support service requires the professional to have current knowledge of the wide range of services available, to listen to the help the individual desires, and to appreciate that more than 1 type of service may be required to achieve improvement. This may explain the limited success of continence services in helping the few respondents who reported being referred. Patients who are referred to a continence service that does not address their needs, or one with limited experience managing people with IBD-related FI, may be perceived as ineffective. Referral for additional services, such as cognitive-behavioral therapy and counseling, alongside physiological interventions, or simply having more time to talk with the IBD nurse, might enhance perceived effectiveness through a reduction in anxiety associated with the problem, and development of effective coping strategies. Referring patients for these services is recommended because it increases the sense of personal control and improves health-related quality of life, reduces the sense of isolation, and encourages help-seeking.[30-35]

Our findings demonstrate that the most commonly cited reason for not seeking help was not knowing who, how, or where to seek that help. It has been demonstrated that a continence educational brochure can facilitate help-seeking because it lets people know that help is available and increases awareness, which decreases embarrassment.[36] Educational resources, available in hard copy or via an electronic source, may overcome this barrier. Once they know the range of service available, patients may be more likely to then ask an IBD nurse or gastroenterologist for assistance with FI and associated bowel elimination symptoms.

Low expectations of a solution to the problem of IBD-related FI, coupled with minimal awareness of the availability of potentially effective interventions, may have influenced the types of help people desired. Respondents tended to focus on access to toilet facilities or other strategies that enables better management of the problem rather than discussing strategies to resolve FI.

Inflammatory bowel disease remains a poorly understood disease among the general population. Its status as a hidden chronic illness with fluctuating symptom severity compounds the difficulties of convincing the public, and official bodies, of its seriousness and impact on ability.[37] Policymakers who guide disability provisions including financial benefits, care assistance, and practical aids often fail to appreciate the complex difficulties caused by IBD. Official and public acceptance of IBD as a disability would add credibility and make it easier for people to ask for help for related problems, including FI.

Limitations

Limitations of this study are acknowledged: the main study sample was self-selected, not necessarily representative of all people with IBD, and was likely biased in favor of those who experience FI. Of those whose answers were selected for this study, more had FI and fewer had sought help for it, than in the main study population. Those who have received effective help may be less likely to have responded and the proportion of those who have sought and received effective help is unknown. However, our clinical experience indicates that few people with IBD are referred to continence services.

Conclusion

Most people with IBD-related FI had not sought help for their problem either from IBD clinicians or nurses or from specialist continence services. Help, where sought, was described as satisfactory, unsatisfactory, or alternative. Of the latter, the most beneficial appeared to be psychological or counseling interventions that reduced anxiety related to poor bowel control. Few respondents sought referrals for interventions to improve their bowel control, suggesting either a lack of awareness of the availability of such services or lack of conviction that anything could be done to improve their situation.

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