

## HELP-SEEKING FOR FAECAL INCONTINENCE IN PEOPLE WITH INFLAMMATORY BOWEL DISEASE

### Hypothesis / aims of study:

Faecal incontinence is reported as a major issue by people with inflammatory bowel disease (IBD) (1), but remains a largely unvoiced symptom (2). It is unclear what influences help-seeking behaviours in people with IBD-related faecal incontinence, or what type of help would be both acceptable and useful. We aimed to understand how people with IBD and continence symptoms manage their problem, and their needs or desire for continence services.

### Study design, materials and methods

As part of a larger postal and internet survey to determine the prevalence of faecal incontinence (FI) among members of a national Crohn's and Colitis support group, we asked respondents three questions to determine their help-seeking behaviours for IBD-related faecal incontinence. We sent the questionnaire to a random sample of 10,000 members of the support group and received 3,264 replies (32.64% response rate) from people who met the study criteria (aged over 18, resident anywhere within the UK, self-reported diagnosis of IBD, no current stoma). Respondents completed the bespoke study questionnaire either in hard copy, or via a secure online facility. Quantitative data were handled with SPSS v18. 74% reported some FI, detailed findings are reported elsewhere. Qualitative (free-text) responses from 636 (20% of the total) were dictated into digital audio files, continuing until no new themes emerged. Audio files were transcribed verbatim by a professional transcriber.

Data were analysed using a pragmatic thematic analysis approach (3), enabling synthesis, comparison and analysis of the large amounts of qualitative data to capture an understanding of the experience in question. Both authors undertook transcript reading and theme identification independently, before collaborating to agree on central themes and related sub-themes.

### Results

Of the 636 sets of responses analysed, 89% reported FI. 205 people (32.23%) responded to the open question: *Have you ever sought professional help?* Only 75 of these stated that they had specifically sought help for FI. Of these, 35% reported not receiving satisfactory help, 12% reported accessing sources of help other than regular health services, and 53% reported receiving satisfactory help. **Unsatisfactory help** included health professionals being unsympathetic, failing to offer practical advice or to refer on to specialist continence services. **Alternative sources of help** included complementary therapies (such as acupuncture, counselling, hypnotherapy), and accessing disabled toilets. **Satisfactory help** included receiving sympathetic responses and practical help (bulking agents, anti-diarrhoeals, referral for interventions, protective products, listening) from medical and nursing staff, and from lay support services.

332 people (52%) responded to the open question: *Please describe the factors which stopped you from seeking help.* 35 people identified that nothing stopped them from asking for help, whilst 297 respondents (89% of those answering this question) provided one or more reasons for not seeking help, including:

- Believing nothing else can be done, not aware of additional services (other than medication, surgery, diet and protection advice), not knowing who to ask (n=94; 35%)
- Feeling too embarrassed, ashamed or dirty to ask for help (n=73; 24.5%)
- FI an infrequent or mild problem that didn't warrant seeking help (n=61; 20.5%); FI accepted as part of condition [when linked to flare up] (n=43; 14.5%)
- Apparent lack of interest, sympathy or understanding from GP, medical consultant or nurse (n=20; 6.7%)
- Difficulties in accessing services: transport, appointment scheduling, seeing a different clinician at each visit, seeing a clinician of the opposite sex, too much time off work for appointments.

267 people (42%) responded to the open question: *'Thinking about faecal incontinence, what type of help do you need the most? If the type of support you need is not available, please describe what your ideal professional support service would be.'* Almost nobody reported having accessed the specialist continence services available throughout the UK and there was little mention of standard treatments for FI such as pelvic floor muscle training, bowel retraining or biofeedback. IBD specialist nurses, where accessed, gave reassurance but apparently did not employ techniques known to work for FI in other patient groups. Responses fell broadly into two categories of what respondents felt would help:

### *Public and social issues*

Better public and employer knowledge of IBD; better public knowledge of the Can't Wait Card (a pocket-sized card which can be shown in shops & cafés to gain access to toilets which are not usually available to the public); better public toilets (accessibility, availability, quality, cleanliness); wanting IBD to be recognised as a disability.

### *Access to Health Services*

Lay talking (non-professional formal and / or social informal support forums); professional counselling support; clinical staff asking about incontinence; help and advice e.g. dietary; easier access to, and better designed, protection products; financial help with products, prescriptions for medicines, laundry and clothing costs; ability to access well-informed, sympathetic specialists, and consistent access to IBD treatments throughout the country; home care / nursing services.

Embarrassment is a key feature: *'I find this to be a very - extremely – embarrassing, distressing and private condition. The nature of the illness does discourage you from asking for any help'*. Respondents did not expect clinicians to be interested, and they report that the subject is rarely if ever raised in clinical encounters: *'Specialist thinks I should be able to manage, so I don't say much on my check ups'*; *'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.'* Others, who have had negative experiences, perhaps with unsympathetic responses from those they did ask to help, are put off: *'My hospital consultant ... was horrible, unhelpful, uncooperative, uncaring and difficult to contact and talk to'*; *'I have asked for help but real help is not forthcoming, so one stops asking.'* Those who experience incontinence only in relation to flare-up often accept this as part of the disease: *'Any continence issues I have are related to my disease, and controlling the disease relieves the issues'*. Many respondents reported regular FI unrelated to disease activity, an aspect of their illness which is often overlooked during symptom management. IBD places intense energy demands on people. Those who endure a round of clinic and hospital appointments, tests, treatments and interventions, cannot face the thought of exposing themselves to more intrusion. Unaware of the services which are available to them, they avoid finding out in case doing so will place further unwanted physical and emotional demands on them: *'I don't want to have surgery, I can live with it. I don't want to have to wear big incontinence pads'*; *'I see doctors so many times - I'm loathe to go if I don't have to.'*

Desired services to manage faecal incontinence focussed around raising awareness amongst public, employers, and policymakers which would enhance access to existing services (for example, disabled toilet and parking facilities, welfare benefits, and hospital and IBD nurse services), making management of their bowel activity easier ...*'all IBD sufferers should have access to disabled toilets with keys'*. Few seemed to think that it might be feasible to resolve FI.

#### Interpretation of results

Accessing help for IBD-related FI is challenging and stressful for people. Almost nobody mentioned accessing proven (in non-IBD FI) interventions such as biofeedback therapy, nor the nationally-available specialist continence services. Although the connection between stress and anxiety and worsening bowel symptoms is well known, the potential for counselling / behaviour-change therapies to have a positive impact on FI was rarely considered possible by respondents.

#### Concluding message

These findings demonstrate that many people with IBD-related FI avoid seeking help, or are not aware of the services that they could access to help them manage this distressing problem. Whilst FI during flare up is routinely accepted as part of the disease by medical and nursing staff, as well as by the patient, embarrassment and the taboo nature of the topic prevents people revealing the extent of their FI when unrelated to disease activity. Clinical staff could communicate that they are aware of the potential for FI to occur by proactively asking about symptoms during clinic appointments, or by using an assessment tool to provide a non-verbal opportunity for symptoms to be described.

#### References

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2. Leigh RJ, & Turnberg LA (1982) Faecal incontinence: the unvoiced symptom. *The Lancet* 319; 8258:1349-1351
3. Fereday J & Muir-Cochrane E (2006) Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*

#### Disclosures

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