

FAECAL INCONTINENCE IN INFLAMMATORY BOWEL DISEASE (IBD): EFFECT ON QUALITY OF LIFE

Hypothesis / aims of study

1. To understand the experience and concerns of people with IBD and continence-related issues
2. 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

Faecal incontinence and the location of toilets are known to be a major concern of people with IBD (1). However, we know that most do not present for help with symptoms. As part of a larger postal and internet survey to determine the prevalence of faecal incontinence among members of Crohn's and Colitis UK we purposively selected participants who indicated that they were willing to be interviewed about their faecal incontinence. We deliberately selected people to represent a range of ages, both genders, who had either Crohn's disease or ulcerative colitis, from newly diagnosed to many years since diagnosis, and who lived in a variety of geographical locations throughout the UK. Potential participants were contacted by telephone and then sent a participant information sheet if willing to be interviewed. A convenient time was arranged to interview participants in their own home. All participants gave written informed consent. Semi-structured interviews were conducted by an experienced qualitative researcher. The interview schedule was developed following a systematic review of the literature; interviews were individualised by drawing on and following up on responses by interviewees to the earlier prevalence questionnaire, where space had been allowed for qualitative comments. Interviews were recorded digitally and transcribed verbatim by a professional transcriber. Data were analysed using a pragmatic thematic analysis approach (2), a recognised approach for enabling synthesis, comparison and analysis of large amounts of qualitative data to capture an understanding of the experience in question. Two researchers undertook transcript reading and theme identification independently, before collaborating to agree on central themes and related sub-themes.

Results

We conducted interviews with 28 participants. There were 13 males and 15 females. 14 had a diagnosis of Crohn's disease, 2 Crohn's Colitis, and 12 Ulcerative Colitis. Mean age was 48.9 years (range 31 – 77 years). All reported that they experienced regular FI and were willing to be interviewed. Interviews were between 35 – 90 minutes duration. Four central themes emerged, each with several sub-themes (Table 1).

Symptoms were described in various ways. For example, unpredictability ... *'And it scares you because you know you're going to have to get out of the car and get somewhere, and it (incontinence) might happen where people are there.'* Odour was also frequently mentioned ... *'and sometimes the smell is horrendous'* as was noise associated with explosive bowel actions ... *'... it's not always just silent, it can be mucous and very noisy and it's ... the embarrassment of it.'*

Lives were described as having been restricted in financial and practical ways: *'I tried my best to go back to work and I just couldn't do it. And I miss, I've missed that part of me life, thinking ... what do the children think that you're not working?' and 'I feel ... annoyed, angry, upset, depressed even, because my wife is in a job which she doesn't particularly like doing ... we'd always had thoughts of once the children had left, we would downsize and move somewhere nice, you know. But I feel as if I've trapped her into continuing to work because I've taken an ill-health early pension which isn't enough to actually live on.'*

Practical Issues included reducing food to reduce risk of needing the toilet ... *'It sounds ridiculous now, but that's how I managed it, by not eating until I was somewhere that if I knew I needed to get to the loo straightaway, I could.'* There was frequent mention of access to and standards of cleanliness in public toilets ... *'You need not just toilet facilities ... you need the whole thing to be able to wash yourself' 'I've had to take my trousers off, and with the floor being wet, and no paper towels, you have to do the best you can but, then you're damp, you've got no pants on, so you get chaffed and this just leads to another fistula.'* Everyone described an emergency clean up kit that they took with them when away from the house, but the difficulty was in finding somewhere appropriate to get cleaned up.

Central theme	Symptoms	Restricted Lives	Practical Issues	Emotional & Social Impact
Sub-themes	Unpredictability Urgency Passive loss stool Triggers: food, stress, exercise, activity Bad odours Passing blood and mucous Pain Sore skin	Housebound Toilet mapping Cannot: eat out, work, travel Limits on partner & family Toilet focus to everything	Limit eating Limit food types Clean up kit & change of clothes Hiding / avoiding Having to go home Access to toilets—public work, disabled, que flushing Sleep disruption Little or no professional help / support Patchy specialist IBD nurse service	Partner attitude important Embarrassment a major concern Shame, humiliation Fear over future coping When / who / how to tell? Depression, anxiety, frustration, anger Makes some people stronger Brings strong couples closer Acceptance, resignation get on with it Regrets - life that could have been different? Parenting Relationships

Table 1: themes and sub-themes emerging from the data

There was also a clear emotional and social impact: “ ... *it makes me terribly embarrassed if it happens when I’m with ... friends and loved ones. And frustrated as well because you know you can’t do anything about it*. There were also examples of direct affects on relationships, whilst this respondent describes how her incontinence affects her sense of femininity and desirability ...’ *Horrible, disgusting, dirty.... He’s excellent with me but I feel embarrassed all the time. Sex life has gone out the window*”. People often described a sense of social isolation ... *‘I feel as if I’ve receded into the background.’*

Interpretation of results

The themes and sub-themes revealed in this data reflect what is already known about the impact of faecal incontinence in the non-IBD population. The themes which set these findings apart, and demonstrate the uniqueness of IBD-related faecal incontinence, are those referring to symptoms and bowel behaviour. In adults without an underlying relapsing-remitting disease such as IBD, the additional aspects of pain and blood and mucous usually do not arise. Whilst urgency is reported elsewhere as a concern, there is little detail as to the immediacy of that urgency. Respondents in this study describe clearly that the urgency can be immediate, giving them perhaps only a few seconds warning of the need to defecate. Another issue is that of unpredictability. Participants reported that there is often no discernible pattern to bowel activity, and people are constantly anxious about if and when incontinence might occur. This unpredictability - and the consequent loss of control this forces upon people - appears to be the catalyst that generates other problems which lead to social, emotional, work-related and financial restrictions. These findings support earlier work identifying the main concerns of people with IBD.

Concluding message

Faecal incontinence associated with IBD can have a devastating impact on the patient, affecting all aspects of their lives. Feelings of shame and embarrassment, not knowing how to tell another person about the problem, and a consequent reluctance to seek help confirm what is already known. The evidence presented here of the complex ways in which faecal incontinence impacts on people’s lives, and the lives of those in their immediate social world, demonstrates how important it is that professionals begin to address these issues. It may not always be possible to stop people with IBD from being incontinent, although intervention studies are lacking and clinical experience suggests that many symptoms can be improved with interventions used for other patients with faecal incontinence. It should also be possible to develop emotional and practical support strategies which enable people with IBD to cope better with their faecal incontinence, and so reduce the overall negative effect that faecal incontinence has on their wellbeing and quality of life.

References

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2. 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* 5:1. Accessed 28/02/2011 from http://www.ualberta.ca/~iiqm/backissues/5_1/pdf/fereday.pdf

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<i>Was this study approved by an ethics committee?</i>	Yes
<i>Specify Name of Ethics Committee</i>	Buckinghamshire New University Ethical Committee.
<i>Was the Declaration of Helsinki followed?</i>	Yes
<i>Was informed consent obtained from the patients?</i>	Yes